MENTAL HEALTH AND HUMAN RIGHTS: REPORT OF THE TASK PANEL ON LEGAL AND ETHICAL ISSUES

Submitted to
The President's Commission on Mental Health
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The Arizona Law Review *is pleased to publish the report,* Mental Health and Human Rights, *which was submitted to the President's Commission on Mental Health by the Commission's Task Panel on Legal and Ethical Issues. The study, which also appears in an Appendix to the Commission's Report, is printed here in the exact form in which it was submitted to the Commission, with the exception of renumbering all footnotes. Because this report represents a valuable contribution to the literature in the mental health law field, the* Arizona Law Review *hopes to increase the report's accessibility to those involved in that field. The editors believe it to be particularily appropriate to publish the report in the* Review *because Dr. Allan Beigel, of the University's Department of Psychiatry, served as a member of the Commission, and Professor David B. Wexler, of the University's Law College, served as a member of the Task Panel on Legal and Ethical Issues.*

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I. INTRODUCTION AND SUMMARY

The Task Panel on Legal and Ethical Issues represents the full diversity of perspectives and expertise among professionals, policymakers and mentally handicapped persons.[1] Its members include social workers, psychologists, psychiatrists, lawyers, educators, a mental health commissioner, civil servants and recipients of mental health services. Our recommendations and analysis, here presented, are the outcome of an intensive process—from early exploration of the issues through individual position papers and proposals by small working groups—culminating in five days of comprehensive discussion by the full Panel.

The report encompasses legal and ethical issues in education; employment; housing; Federal benefits; confidentiality; guardianship; experimentation; treatment (including the right to treatment and to protection from harm, the right to treatment in the least restrictive setting, the right to refuse treatment and to the regulation of treatment); civil commitment; and the criminal justice system. Other sections discuss the need for advocacy and suggest structures for a patient's or consumer's bill of rights and the resolution of ethical dilemmas.[2]

Given the complexities of these issues and the variety of Panel members' perspectives, we were pleasantly surprised by the extent of consensus as to the directions for action and reform. There is much talk these days of polarization between different disciplines within the professions and of competing philosophies or value preferences even within the advocacy movement itself. Even so, the individual members of the Panel on Legal and Ethical Issues, working closely together and with respect for each other's views, were able to reach agreement on significant reforms in many areas.

In the three sections of this report which follow this introduction and summary, 42 recommendations, some containing many parts, are set forth and each is followed by a discussion and justification. Where consensus was not achieved, alternative approaches and/or simple discussion of the relevant issues are set forth.[3] Appendix A lists all our recommendations in one place, for the reader's convenience. Appendix

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[1] In this report, the term "mentally handicapped person" is used to include the mentally ill and mentally retarded and other developmentally disabled persons, along with those perceived to have such conditions. The term is used interchangeably with "mentally disabled."

[2] Each of the areas covered in this report has both legal and ethical dimensions. Because the initial discussions in Section III are basically rights-oriented, however, an attempt is made in Section V to organize the important ethical issues in basic categories and to provide a preliminary structure for clarifying and resolving ethical conflicts.

[3] In the process of reaching consensus, there was much give and take, including compromise by particular Panel members on initial positions. Where consensus was eventually achieved, however, this report sets forth the recommendations agreed upon and gives the rationale for the recommendation without attempting to describe and rationalize other possible positions.

B lists those recommendations relating to research and training initiatives.

The Panel's recommendations cover both specific initiatives that could be taken at the Federal executive or legislative level and others that would have to be taken by State legislators or administrators. While a Federal commission obviously cannot dictate State initiatives affecting civil commitment or guardianship, nevertheless the Panel believes it can make a valuable contribution by providing models of progressive reform for use by the States.

Our discussion suggests both specific actions which could be taken immediately and more general approaches to long-term goals.

Our discussions speak generally to the problems of all mentally ill persons and mentally retarded and other developmentally disabled persons, as well as to the problems of children, the elderly and other racial or cultural "special populations." The reader should bear in mind that there will be a need to adapt particular recommendations to reflect both age-specific differences and the unique needs of particular subgroups.

While many of the recommendations we suggest would cost little if any new money, some do indeed have cost implications. But we believe that our national values and priorities must reflect a commitment to mentally handicapped persons, who are a disadvantaged, vulnerable and often-forgotten group. It would be both self-deceptive and a disservice to the Commission and the President to assume that to fully protect the constitutionally-mandated and other rights of mentally handicapped persons will not require the expenditure of additional funds.

Perhaps the most important point that the Panel wishes to convey to the Commission is the importance of building a strong "patients'-rights" and consumers' perspective into any reforms in the services system. All Panel members recognize the importance of increasing the quality and quantity of mental health services available to the public, especially on a voluntary basis. But the Panel is also keenly aware that even the best-intentioned efforts to deliver services to mentally handicapped persons have historically resulted in well-documented circumstances of exploitation and abuse. As Mr. Justice Brandeis put this perspective so eloquently in his dissenting opinion in *Olmstead v. United States*:

> Experience should teach us to be most on our guard to protect liberty when the government's purposes are beneficent. Men born to freedom are naturally alert to repel invasion of their liberty by evil-minded rulers. The greatest dangers to liberty lurk in insidious en-

> croachment by men of zeal, well-meaning, but without understanding.[4]

While there is understandable concern about balance and the danger of excesses, the "patients'-rights" or advocacy movement is widely credited with producing the most significant reforms in the mental health system during the past ten years. The Panel hopes that the Commission, in writing its report and making its recommendations, will keep in mind the importance of the advocacy perspective, recognizing that the most well-intentioned efforts to provide services without checks and balances to protect human rights can lead to unfortunate results. In this connection, the Panel anticipates that, as our country moves increasingly from institutional to community-based care, it will be important for advocacy efforts to shift from exposing abuses and deficiencies in institutions to protecting mentally handicapped persons from a wide range of deprivations of basic civil rights and privileges that they too often experience in the community.

In keeping with the Panel's priorities, a discussion of particular initiatives which might be taken to promote legal advocacy on behalf of mentally handicapped persons immediately follows this introduction and summary. It might seem to be putting the cart before the horse to discuss advocacy in Section II before discussing in Section III the substantive content of what should be advocated. However, this organizational framework reflects the Panel's view that legal and ethical claims by the consumers of mental health services will be of little significance unless an advocacy process or structure has been established to ensure that serious, ongoing attention is paid to these important issues.

Quite apart from the specific recommendations and supporting justifications which we have made, the Panel members have become convinced that there is an acute need for continuing discussion among mental health professionals, legal professionals, concerned lay persons and the "consumers" themselves. Our own recent experience demonstrates that such discussion is both possible and productive—that it can lead to better understanding and constructive recommendations among all of the various people concerned with improving the mental health system.

While legal and ethical issues are the focus of this report, our deliberations have clearly shown that there are crucial legal and ethical dimensions to the work of every other task panel established by the President's Commission on Mental Health. For example, the concept of deinstitutionalization cannot be discussed meaningfully apart from a review of the legal and ethical claims for a right to treatment and the

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[4] 277 U.S. 438, 479 (1928).

principle of "less drastic means" or the "least restrictive alternative." Or, to give another example, it would be irresponsible indeed to consider the subject of prevention without giving due consideration to related legal and ethical issues of due process in testing and placement decisions, of the confidentiality of mental health records or of the ethics of allocating resources between preventive efforts and the delivery of services to those most immediately in need. Therefore, we believe it is important for the Commission, and for those implementing the Commission's final report in the future, to consider the legal and ethical issues which we discuss in relation to the broader themes of prevention, service delivery, research and training, rather than as an isolated subject.

It is the earnest hope of all members of the Panel on Legal and Ethical Issues that our work, as embodied in the recommendations and discussion which follow, will be of value to the Commission in its own deliberations and in the formulation of its final recommendations and be of value as well in the public debate about legal and ethical issues.[5]

II. ADVOCACY

Recommendation 1.

> *The President's Commission should support legislation which would establish and adequately finance a system of comprehensive advocacy services for mentally handicapped persons.*

Commentary:

Advocacy is a broad concept that covers many different kinds of efforts to secure better services for and to protect the rights of (in this instance) mentally handicapped persons. Many mental health professionals and citizen volunteers see themselves quite appropriately as the primary advocates for patients. While all advocacy efforts are valuable, the Panel on Legal and Ethical Issues has focused upon one kind—legal advocacy—which is directed toward establishing and enforcing the legal rights of mentally handicapped persons. Legal advocacy includes both consumer-oriented efforts to improve the quantity and quality of services and civil rights-oriented efforts to protect the liberty and other fundamental rights of mentally handicapped persons.

The need for and significance of legal counsel as a means of ensur-

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[5] Because of the nature of the topic and the material presented, and because many of the citations are to an extensive variety of cases and other articles, footnotes and references in this report do not conform to the traditional journal style used in other reports of the President's Commission on Mental Health and are placed as notes at the end of each section or subsection of this report for the convenience of the reader.

ing "equal access to justice"[6] is the cornerstone of the American judicial system, extending to matters involving a potential "substantial loss" or "serious legal consequence."[7] Such a need for counsel is, of course, magnified in cases involving mentally handicapped persons, in matters involving both institutionalization and its potential consequences, as well as noninstitutional problems which relate in any way to the person's "deviant status."[8]

In recognition of this need for legal services, several States have established systems to provide counsel to mentally handicapped persons as a means of ensuring that there is "someone on the 'outside' who is concerned about [a patient's] . . . fate".[9] Additionally, Congress had enacted Federal legislation—the Developmentally Disabled Assistance and Bill of Rights Act[10]—requiring that, in order to be eligible to receive funds under the Act, a State must provide "a system to protect and advocate the rights of persons with developmental disabilities," with the specific "authority to pursue legal, administrative and other appropriate remedies to insure the protection of the rights of such persons" and a mechanism specifically established so that a developmentally disabled person "has the means to reach outside of the established delivery system for examinations of situations in which his rights as an individual citizen may have been violated."[11]

Also, Congressional legislation has been introduced to create a National Mental Health and Disability Advocacy Services Office.[12] The bill, modeled after the New Jersey advocacy program, would mandate the provision of legal counsel and professionally trained advocates in individual and class matters for indigent patients as well as residents

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[6] Herr, *Advocacy Under the Developmental Disabilities Act* 88 (1976).

[7] See, for example, *Powell v. Alabama*, 287 *U.S.* 45 (1932); *Gideon v. Wainwright*, 372 *U.S.* 335 (1963); *Argersinger v. Hamlin*, 407 *U.S.* 25 (1972); *Cleaver v. Wilcox*, 499 *F.* 2d 940, 945 (9 Cir. 1974); *Crist v. N.J. Div. Youth and Family Services*, 128 *N.J. Super.* 402, 414, 320 *A.* 2d 203 (Law Div. 1974), aff'd in part, rev'd in part on other grounds, 135 *N.J. Super.* 573, 576, 343 *A.* 2d 815 (App. Div. 1975).

[8] See, respectively, *Dale v. Hahn*, 440 *F.* 2d 663, 668 (2 Cir. 1971) and Friedman, *The Rights of Mentally Retarded Persons* 150 (1976); *Lynch v. Baxley*, 386 *F. Supp.* 378, 389 n.5 (M.D. Ala. 1974); and Cohen, "Advocacy," in Kindred *et als*, eds., *The Mentally Retarded Citizen and the Law*, 592, 614 (1976), and Herr, above, at 5.

[9] Ellis, "Volunteering Children: Parental Commitment of Minors to Mental Institutions," 62 *Calif. L. Rev.* 840, 890 (1974).

See also *N.J.S.A.* 52:27E-21 *et seq.* (the Division of Mental Health Advocacy within the New Jersey Department of the Public Advocate) (discussed at length in Perlin and Siggers, "The Role of the Lawyer in Mental Health Advocacy," 4 *Bull. Am. Acad. Psych. & L.* 204 (1976); *N.Y. Mental Hygiene Law* § 29.09 *et seq.* (the New York Mental Health Information Service); and *O.R.C.A.* § 5119.85 *et seq.* (the Ohio Legal Rights Service for the Mentally Retarded).

[10] 42 *U.S.C.* § 6001 *et seq.*, and, especially, 42 *U.S.C.* § 6012.

[11] Herr, above, at 11, quoting Sen. Rept. 94-160, at p. 38 (describing the system created by 42 *U.S.C.* § 6012).

[12] H.R. 10827, 94th Cong., 1st Sess. The bill has not been reintroduced in the 95th Congress because its sponsor, Rep. James J. Florio (D.-N.J.), intends to offer it as an amendment to the bill which would extend the authorization for the Community Mental Health Centers program (H.R. 10553, 95th Congress, 2d Session).

of facilities for the retarded, participants in community mental health programs and persons in geriatric facilities, in matters involving admission to and release from such facilities as well as in matters relating to residents' treatment and conditions while institutionalized.

Finally, legal services offices in States such as Minnesota, Washington and Vermont have established high-quality special advocacy projects with outside sources of Federal money. This legal services-delivery model might be expanded.

The Panel suggests that the Commission endorse a Federal mechanism or, in the alternative, urge States to develop advocacy systems which are (1) able to respond to the legal needs of mentally disabled persons and (2) independent of providers of mental health and developmental disability services. An essential feature of such advocacy systems should be their effort to provide a continuity of legal services to such persons at all stages of their contact with the mental disability system. Such advocacy systems should provide services at involuntary-commitment proceedings and to institutionalized persons of all ages as well as to community residents in matters involving institutionalization (commitment, release, treatment issues) and the fact of present or former institutionalization (availability of economic benefits, aftercare, denial of civil rights, employment, education issues) and in other matters related to the existence—or perceived existence—of a handicap (domestic relations, contracts, wills, tenancy issues). In addition to attorneys (an "indispensable element in seeking and securing many types of remedies"),[13] the advocacy system should be staffed by persons trained as "mental health professionals" *(e.g.*, social workers and psychologists who provide advocacy services), lay advocates, present and former recipients of mental health services, so as to provide a full-time staff with the necessary academic training and practical experience to provide full advocacy services for its clientele.[14]

The effect of an organized, specialized counsel system is clear. Counsel plays a critical and, in some cases, nearly dispositive role in involuntary commitment proceedings—where active attorneys are employed, fewer persons are committed.[15]

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[13] Herr, above, at 12.

[14] See, for example, Nat'l. Ass'n. for Retarded Children, *Citizen Advocacy for Mentally Retarded Children: An Introduction* (1974); Chamberlin, Testimony Prepared for the President's Commission on Mental Health (Nashville, Tenn., May 25, 1977), at 4; Perlin and Siggers, 4 *Bull. Am. Acad. Psych. & L.*, above, at 206-207; Note, "The Department of the Public Advocate—Public Interest Representation and Administrative Oversight," 30 *Rutgers L. Rev.* 386, 416-417 (1977).

[15] "Developments in the Law—Civil Commitment of the Mentally Ill," 87 *Harv. L. Rev.* 1190, 1285 (1974).

Two clear conclusions may be drawn from statistical surveys: a large percentage of State hospital patients can be safely treated elsewhere (the number varying from 43 percent to 68 percent to 75 percent), and, where counsel is operative, the number of committed persons plummets, especially when compared with persons not represented by counsel.[16]

Advocacy services should be available on both an individual and class-action basis. Although the impact of class representation is often profound, concentration *solely* on class aspects of a matter runs the danger of "sacrific[ing] the good of the individual to the welfare of the group."[17] Furthermore, the vast majority of cases involving commitment or release from institutions will involve individual fact-determinations. The ability to handle both types of cases will give the advocacy system the ability to deal with the "forest" as well as the "trees."

Provision of legal advocacy services cannot be limited to court appearances; it must extend to the full panoply of legal activities, including counseling, drafting, lobbying and negotiating, in a manner which takes into basic consideration at every step the *actual* views and wishes of the patient/client, which may not always coincide with recommendations made by others. The Panel supports expanded legal advocacy services which would be available to all mentally handicapped persons (from children to the elderly), including free legal advocacy services for indigent persons, but does not express an opinion on whether a means test should be invoked.

Rights cannot be enforced if patients or clients do not know of their existence. The Panel therefore believes that there must be mechanisms to inform patients or clients about their rights, about the availability of advocacy and about how to use it—for example, by requiring that the names and telephone numbers of available advocates be posted in locations frequented by clients. For further discussion of this issue, see Section IV.1., "Bills of Rights," Recommendation 2, page 138, below.

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[16] See, for example, Scheff, *Being Mentally Ill* 168 (7th ed. 1973) (the presence of 43 percent of patients in hospitals studied could not be explained in terms of their psychiatric condition); Abraham and Bueker, "Preliminary Findings from the Psychiatric Inventory" 3 (1971) (68 percent of patient population at St. Elizabeths Hospital in Washington not considered dangerous to themselves or others), and Mendel, "Brief Hospitalization Techniques," 6 *Current Psychiatric Therapies* 310 (1966) (75 percent of patients with diagnosis of schizophrenia studied could be suitably discharged), as cited in Ferleger, "A Patients' Rights Organization: Advocacy and Collective Action by and for Inmates of Mental Institutions," 8 *Clearinghouse Rev.* 587, n.1 (1975).

[17] Boggs, "Collective Advocacy (Systems Advocacy) vs. Individual Advocacy," (paper prepared for presentation at the Conference on Developmental Disabilities, Advocacy and Protective Services, Washington, D.C., October 13, 1976), at 2.

Recommendation 2.

> *The protection and advocacy (P&A) systems established in each State under the Developmentally Disabled Assistance and Bill of Rights Act as of October 1977 should be carefully evaluated and this approach to advocacy services should be supported if it proves effective. If it does, mentally ill persons should either be brought within the jurisdiction of the "P&A" systems or else a parallel system which will represent mentally ill persons should be established.*

Commentary:

The Developmentally Disabled Assistance and Bill of Rights Act has established a protection and advocacy system, not limited to legal advocacy and independent of service providers, in each State. Given the newness of this system, the Panel is unable to make any specific recommendations concerning continuation or modifications of this program, except to recommend careful evaluation and follow-up. However, one striking fact was of concern to the Panel: At present we have a nationwide system of advocacy for developmentally disabled persons, supported with Federal funds, but no similar provision has been made for advocacy on behalf of mentally ill persons. This deficiency is unfortunate and should be remedied as promptly as possible.

This recommendation is made not as an alternate but as a complement to our first advocacy recommendation. Given the small amount of money allocated and the limitations of the system, the "P&A" system should in no sense be viewed as a panacea.

Recommendation 3.

> *The President's Commission should support efforts by which currently existing legal aid, legal services and public defender programs and the private bar at large can more adequately represent mentally handicapped persons at every stage at which such persons have contact with the mental disability system. These efforts should be directed at providing a continuity of legal care and should include, but not be limited to, the following:*
>
> > *(a) Recommending to the Legal Services Corporation that it establish a national support center to assist local offices in representation of mentally handicapped persons, and that it run special training programs so that members of local offices can effectively and adequately represent mentally handicapped persons.*
> >
> > *(b) Endorsing legislation which would give the United States Department of Justice standing to litigate on behalf*

of mentally handicapped persons whose civil and/or constitutional rights have been violated.

(c) Endorsing legislation which would mandate the Law Enforcement Assistance Administration of the Department of Justice to provide economic, staff and training support to state and local public defender and prisoners' rights programs so as to provide more effective and adequate representation for mentally handicapped persons who have been criminally charged and/or who are incarcerated in jail or prison facilities.

(d) Endorsing state legislation which would ensure that the jurisdiction of public defender programs established pursuant to state statute specifically includes representation of persons in matters involving determinations of competency to stand trial and of criminal responsibility, as well as matters involving transfers of persons from criminal detention and incarceration facilities to psychiatric hospitals or similar facilities.

(e) Recommending to local and state bar associations that they train members of the private bar and establish lawyer-referral panels so as to more effectively and adequately represent mentally handicapped persons.

Commentary:

Although it is clear that the creation of a unified, specialized, trained advocacy-service mechanism in all states and communities must be a top priority, there are other steps that can and should be taken before such a program is created. Expanding the capabilities of existing legal aid and defender programs (as well as the private bar) in representation of handicapped clients would at least partially fill current gaps in service delivery, would sensitize thousands of practicing lawyers to problems faced regularly by handicapped persons and would create specialist advocates who could effectively represent a handicapped clientele.

a. Legal Services Corporation:

As noted above, special Legal Services offices, with outside sources of funding, have provided top-quality legal representation to mentally handicapped persons in a few states. Such projects should be recognized and encouraged. Other Legal Services systems, however, have done little to represent mentally handicapped persons, not only because of their limited funding in the face of competing demands upon lawyers' time but also because the lawyers lack special expertise in mental health law issues and in how to communicate and work comfortably with mentally disabled persons. Existing legal services support centers provide special skills, technical assistance, training and legal expertise in subject matters such as welfare, employment, senior citizens' rights, health law and juvenile law. Attorneys from these centers have been instrumental both in winning landmark cases affecting thousands of citizens and in heightening understanding by the courts, by other legal services lawyers and by the general public of the particular problems facing their discrete client constituencies.

The problems of the mentally handicapped, like the problems of the unemployed, the elderly, welfare recipients, and the young, need the additional resources of a national-level support center. The Legal Services Corporation should build such a national center into its own network, perhaps by contracting with an existing project which already has an experienced and qualified staff. The President's Commission should make such a recommendation to the Legal Services Corporation.

While the mentally handicapped are faced with special problems, some of their problems are parallel to or even the same as those for which legal services offices already provide services to other groups—e.g., access to social-welfare programs and entitlements. Lawyers need to see the mentally handicapped as part of their regular clientele, and also to learn how to handle the special legal problems they have and the special problems they may present as clients. A national support center would help sensitize Legal Services lawyers to these special problems and train them to provide solutions.

It is clear, however, that such nationally based centers are not a palliative for all the problems faced by an underrepresented group; they are simply necessary so that lawyers in local legal aid and legal services offices may be trained in both the substance of "mental health law" and in the process and techniques of representing and counseling mentally handicapped persons on the whole range of legal issues which affect them.

b. Justice Department Standing to Sue:

Proposed Federal legislation[18] supported by the Administration would authorize the United States Department of Justice to intervene in or initiate civil actions when there is a pattern or practice of violations of the Federal constitutional and/or statutory rights of individu-

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[18] H.R. 9400, 95th Congress, introduced by Rep. Robert W. Kastenmeier (D.-Wis.) and S. 1393, 95th Congress, introduced by Sen. Birch Bayh, (D.-Ind.).

als incarcerated or institutionalized in State facilities. This bill would greatly increase the likelihood of ameliorating unconstitutional and illegal practices and conditions in State institutions by providing to those persons who are least able to represent themselves a mechanism whereby their fundamental grievances can be addressed. The continuity of expertise and resources provided by the Department of Justice is an essential underpinning for the maintenance of responsible and high quality litigation.

c. LEAA Support:

As underserved and underrepresented as most mentally handicapped persons are, it is likely that those charged with criminal activity and those either detained awaiting trial or incarcerated following conviction are even more underserved and underrepresented than other mentally handicapped persons.[19] One corollary of this underrepresentation is that mentally handicapped persons accused or convicted of crime are often processed with little consideration for the specific legal and ethical issues which may have an impact upon their status.[20] The rights and special-service needs of mentally handicapped juveniles who come before the courts as status offenders or juvenile delinquents are often equally ignored. These youths are either shunted back and forth from juvenile correctional facilities to facilities for the mentally retarded or mentally ill, or are dumped with all the other juvenile offenders. Neither advocates nor funds have been available to define their rights or to seek appropriate services for them.

The Law Enforcement Assistance Administration (LEAA) has the capability of providing staff and training support to local public defender offices and to legal aid programs representing convicted and detained persons on matters of prisoners' rights.[21] The President's Commission should support legislation which would require the LEAA to devote a percentage of its time and resources to the training of local defender programs so as to enable attorneys working for such programs to represent mentally handicapped persons effectively and adequately. Further, the President's Commission should recommend that the Office of Juvenile Justice and Delinquency Prevention in LEAA target a proportion of its funds and resources toward the problem of the mentally handicapped juvenile offender.

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[19] See for example, Note, "The Accused Retardate," 4 *Colum. Human Rts. L. Rev.* 239 (1972).

[20] See, for example, *United States v. Masthers*, 539 *F.*2d 721 (D.C. Cir. 1976); Perlin, "Psychiatric Testimony in a Criminal Setting," 3 *Bull. Am. Acad. Psych. & L.* 143 (1975).

[21] See, for example, 42 *U.S.C.* § 3731(b)(10); 42 U.S.C. § 3737.

d. Public Defender Jurisdiction:

Although most States have established some sort of public defender programs in the wake of *Gideon v. Wainwright*,[22] few appear to make provision for the special problems endemic to representation of persons charged with criminal offenses when there are questions raised as to a defendant's competence to stand trial or as to his responsibility for the criminal act in question.[23] Although clients are represented, there does not appear to be any law-reform office, legal services office or public defender office created especially to provide expertise in these areas.

A problem perhaps even more pressing is the ultimate fate of persons found "not guilty by reason of insanity," of whom it has been accurately said, "No [other] group has been more deprived of treatment, discriminated against, or mistreated."[24] Once persons in this category are transferred to hospitals for the "criminally insane," it is most likely that any representation has long ceased.

The President's Commission should endorse legislation on a state level which would amend those statutes establishing jurisdiction of public defender offices to specify that such offices should represent persons in all matters involving determinations of competency to stand trial, criminal responsibility and transfer of such persons to and from psychiatric facilities, whether such transfers be pursuant to court order or to administrative directive.

e. Private Bar Initiatives:

Whether or not any or all of the above recommendations are enacted, it is still an inescapable fact that members of the private bar will continue to come into contact with mentally handicapped persons with whom they often have great trouble in dealing. The private practitioner will still—on an occasional basis—represent (or file suit against or defend against) handicapped persons in actions involving estates, negligence, contracts, divorces, custody and zoning, to skim the surface; it is likely that s/he will similarly require training in the specialized process of representing (or opposing) handicapped persons in litigation.

While bar activation efforts of the American Bar Association's Commission on the Mentally Disabled have begun to address this problem, more and greater resources and efforts are necessary. There-

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[22] 372 *U.S.* 335 (1963).

[23] See, respectively, *Drope v. Missouri*, 420 *U.S.* 162 (1975) and American Law Institute, *Model Penal Code*, § 4.01.

[24] German and Singer, "Punishing the Not Guilty: Hospitalization of Persons Acquitted by Reason of Insanity," 29 *Rutgers L. Rev.* 1011, 1074 (1976).

fore the President's Commission should recommend, through the American Bar Association, to local and state bar associations that they train and establish referral panels of their member lawyers to more adequately and effectively represent mentally handicapped persons.

III. RECOMMENDATIONS IN SPECIFIC RIGHTS AREAS

1. *Education*

Recommendation 1.

> *The Department of Health, Education, and Welfare should vigorously implement and enforce the requirements of the Education of All Handicapped Children Act, P.L. 94-142, (20 U.S.C. §1401 et seq.) and the new regulations implementing section 504 of the Rehabilitation Act (45 C.F.R. Part 84). A program of financial assistance, similar to the Emergency School Aid Act, should be initiated to help school districts with the costs of compliance. The funds for such a program could be drawn from other education programs that have outlived their usefulness such as Emergency School Aid and the Impact Aid program.*

Commentary:

As recognized in the historic Supreme Court decision of *Brown v. Board of Education*,[25] educational opportunity is the primary vehicle for social and economic advancement in our society. Without access to education, other rights—such as freedom of speech and the right peaceably to assemble and to petition the government—are diminished, perhaps entirely nullified. Historically, however, mentally handicapped children have been excluded from receiving a free appropriate public education either on the grounds that the school system lacks the capacity to deliver needed educational services or because the mentally handicapped child is labeled as a disciplinary problem and expelled.

Leading court cases such as *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania*,[26] and *Mills v. Board of Education*[27] have established that systematic exclusion of mentally handicapped children from schools violates the equal protection and due process clauses of the Constitution and have prescribed procedural protections to ensure appropriate classification and placement of mentally handicapped children. The best features of these court cases have

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[25] 347 *U.S.* 483 (1954).

[26] 334 *F. Supp.* 1257 (E.D. Pa. 1971); 343 *F. Supp.* 279 (E.D. Pa. 1972).

[27] 348 *F. Supp.* 866 (D.D.C. 1972). See also *Frederick L. v. Thomas*, 408 *F. Supp.* 832 (E.D. Pa. 1976); *Fialkowski v. Shapp*, 405 *F. Supp.* 946 (E.D. Pa. 1975); but see *Cuyahoga County Assoc. for Retarded Children and Adults v. Essex*, 411 *F. Supp.* 46 (N.D. Ohio 1976).

been incorporated into the Education of All Handicapped Children Act[28] and the new regulations[29] implementing section 504 of the Rehabilitation Act.[30] In the Panel's view, these laws represent a major step forward in vindication of the rights of mentally handicapped children, and all possible emphasis and assistance should be given to implementation of this new Federal legislation. A concrete suggestion is that a program of financial assistance similar to the Emergency School Aid Act[31] be initiated to help school districts with the cost of complying with these important requirements. Such assistance, which would be awarded to districts that demonstrate their intention to comply with Federal standards, could be used to meet the cost of additional staff (e.g., teachers, physical therapists, psychologists) and expenses of eliminating architectural barriers and installing needed special equipment. The Education of All Handicapped Children Act already authorizes grants for this latter purpose,[32] and other bills are currently pending in Congress which would help to one degree or another in financing section 504 compliance.[33]

Recommendation 2.

> *As part of their right to education, mentally handicapped individuals should be provided with compensatory education services beyond ordinary age limits, where past deprivation of education makes this necessary.*

Commentary:

Experts agree that early identification and treatment of handicapped children is vital to such children's educational success and that many mentally disabled individuals can continue to benefit from education after the age of 21. Indeed, the argument can be made that some mentally handicapped persons are entitled to *extra* years of education if their learning opportunity is to be equalized with that of "normal students." Every effort should therefore be made to expand the education of handicapped students beyond the ages (typically 6 to 21) for which it is now legally mandated. At a minimum, mentally handicapped adults who were denied their right to education as children should be provided with compensatory educational services beyond the ordinary upper age limits for public education, under the same principle which has supported compensatory education for minority students

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[28] 20 *U.S.C.* 1401 *et seq.*, as amended by Public Law 94-142.
[29] 45 C.F.R. Part 84, 42 F.R. 22675 (May 4, 1977).
[30] 29 *U.S.C.* 794.
[31] 20 *U.S.C.* 1601 *et seq.*
[32] 20 *U.S.C.* 1406.
[33] S. 2302, H.R. 7626, H.R. 10071, H.R. 10010.

who have been forced to attend inferior, segregated school systems.[34]

Recommendation 3.

> *Institutionalized mentally disabled children must also be provided with an appropriate education, in a community setting wherever possible, as the Education for All Handicapped Children Act of 1974 requires. Surrogate parents, not drawn from institutional staff, must be appointed to protect the rights of such children when the natural parents are unavailable.*

Commentary:

The Panel recommends that, whenever possible, mentally handicapped children now residing in institutions be provided with appropriate education in the community, in order to normalize their lives and to reduce stigma. This recommendation includes not only children in mental hospitals and State schools for the mentally retarded, but also mentally handicapped children who may be placed—properly or not—in various correctional or juvenile facilities. The considerations—legitimate or not—which lead to institutionalization of children—often have nothing to do with educational needs, and should not be allowed to interfere with such children's right to an appropriate education in the least restrictive and most normal setting feasible.[35]

Particular attention must be paid to ensuring that children in State custody have access to appropriate representation and that they and their advocates are fully informed of their education rights and of procedures for protecting these rights.[36] It is estimated that as many as 750,000 children live in foster homes or in group residential settings at State expense and under State auspices.[37] Without special efforts, it is likely that little attention will be directed to ensuring these children—many of whom are mentally handicapped—the appropriate education to which they are legally entitled.

Recommendation 4.

> *Colleges and universities must be encouraged and assisted to train teachers and other education personnel in methodologies appropriate for instruction of severely handicapped individuals and for management of handicapped students in a regular classroom setting.*

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[34] See *Milliken v. Bradley*, 97 S. Ct. 2749 (1977).

[35] 20 *U.S.C.* 1412(5)(B); 45 C.F.R. § 121a.550 *et seq.*, 42 C.F.R. 42473, 42497-42498 (August 23, 1977); 45 C.F.R. § 84.34.

[36] 20 *U.S.C.* 1415(b)(1)(B), 45 C.F.R. § 121a.514.

[37] Children's Defense Fund, *Children Without Homes: An Examination of Public Responsibility to Children in Out of Home Care (An Overview)*, at 3 (Washington, D.C. 1977).

Commentary:

New Federal and State legislation, with its emphasis on "mainstreaming" and on provision of services to severely disabled children,[38] requires increased emphasis by teacher-training institutions on preparation in techniques for education of handicapped students. "Mainstreaming" does not mean that all children, regardless of the nature or severity of their handicaps, must immediately be assigned to regular classroom situations; it does require that all teachers—not just those certified or concentrating in special education—be prepared to deal in a normal classroom setting with children who exhibit various types and degrees of handicapping conditions. Moreover, the mandate to educate *all* handicapped children requires a revision of traditional notions of what constitutes a program of education, or even of special education. For the most disabled individuals, education may consist of inculcation of basic self-help, social or behavioral skills, or remediation of severe emotional problems, before academic or pre-academic instruction in the usual sense can be considered. Because many teachers now certified in "special education" are not equipped to provide this type of service, they themselves must receive necessary training.

Recommendation 5.

> *States must be encouraged, assisted and required, if necessary, to provide training for parents, guardians, surrogate parents and lay advocates in the use of special education due process procedures, as well as for the hearing officers designated to conduct due process hearings. HEW should collect and analyze the transcripts and records of a representative sample of such hearings and take appropriate action to ensure that educational placement decisions are made after full and fair consideration of all relevant factors, including the views of those representing the interests of the student.*

Commentary:

The due process in educational placement guaranteed by the Education of All Handicapped Children Act[39] and the section 504 regulations[40] can be a cruel illusion unless parents and advocates are trained to utilize the prescribed procedures and unless State or local hearing officers are equipped to conduct due process proceedings in a judicious

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[38] 20 *U.S.C.* 1412(3), 1412(5)(B); 45 C.F.R. §§ 121a.320 *et seq.*, 121a.550 *et seq.*, 45 C.F.R. § 84.34.

[39] 20 *U.S.C.* 1415, 45 C.F.R. § 121a.500 *et seq.*

[40] 45 C.F.R. § 84.36.

and compassionate manner and to render truly impartial decisions based on an understanding of both legal and educational requirements.

Training of parents and advocates is particularly important because experienced and concerned lawyers are simply not likely to be available in sufficient number to represent all the children whose placements come into question. There is no apparent reason why lay persons—with proper advocacy training—cannot function as effectively as lawyers, at least in the administrative stages of due process proceedings which do not present novel legal issues, and any State statutory or regulatory impediments to such participation should be removed. (The effectiveness of lay representation and the need, if any, for increased legal assistance should also be carefully monitored.)

Additionally, early experience under recent Federal[41] and State special-education laws indicates that prescribed procedures may not be consistently observed and that hearing officers, lacking a clear definition of their role or of the standards they must apply, may be inclined to give undue deference to or resolve all doubts in favor of the views of State and local school officials. At least in connection with its review of annual State plans under the Education for All Handicapped Children Act, HEW should closely monitor the hearing process in order to determine whether proper procedures are being followed and plenary review afforded and whether the views of parents, advocates and students themselves are fully and fairly considered.

2. *Employment*

Recommendation 1.

> *The Task Panel endorses the efforts of the Department of Labor to enforce section 503 of the Rehabilitation Act and encourages voluntary compliance with both 503 and 504 by private employers who are not regulated by these sections.*

Commentary:

Because of the stigma which attaches once someone is labeled mentally ill it is commonly difficult if not impossible for patients and former patients to find employment. Sections 503 and 504,[42] Title V of the Rehabilitation Act of 1973, were designed to protect individuals with mental and physical handicaps from this discrimination. Section 504, enforced by program or funding agencies, prohibits discrimination against handicapped persons in any federally funded program or activity. Section 503, administered by the Department of Labor, requires all

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[41] See, e.g., the "Education Amendments of 1974," Pub. L. 93-380, 88 Stat. 484 *et seq.*

[42] 29 *U.S.C.* 793 and 794, respectively.

Federal contractors with government contracts over $2,500 to take affirmative action to hire and advance qualified handicapped individuals.

Section 503 requires outreach, positive recruitment measures and a good-faith effort on the part of employers with job vacancies to notify handicapped individuals and give them a fair opportunity to fill any vacancy. While section 504 does not require the same affirmative efforts, it does require a self-evaluation to be conducted by employers in consultation with interested persons, including handicapped individuals and the groups that represent them. Recipient employers are required to take appropriate steps to eliminate the effects of any discrimination; if HEW finds that any employer has discriminated, it may order remedial action to be taken. Both sections explicitly provide for notice to handicapped people of nondiscrimination.

Sections 503 and 504 also provide protections in the area of preemployment inquiries. Because of the effects of stigma on employers' preconceived notions, section 504 prohibits questions concerning the nature and severity of a handicap (see also dicussion of confidentiality); employers may only inquire as to specific abilities and talents. Section 503 requires employers to review all physical and mental job requirements; those requirements which tend to screen out handicapped individuals must be proven by the employer to be "job related" and consistent with "business necessity and the safe performance of the job." Each section mandates that any medical information received be kept confidential, with some limited exceptions. Finally, both sections prohibit discrimination in terms of rights, benefits and privileges such as leave time and rate of pay, and require that reasonable accommodations be made for handicapped individuals.

These sections govern only those programs and activities receiving Federal funds, in the case of section 504, and, in the case of section 503, Federal contractors with contracts over $2,500. While compliance by such employers represents an obvious advance for mentally handicapped individuals, the Panel believes that it is essential that *all* employers comply with these laws on a voluntary basis.

Moreover, because a law without effective enforcement may not cause fundamental changes for the mentally handicapped person seeking employment, enforcement procedures with "teeth" should be given to the Office of Civil Rights to insure that appropriate leverage is accessible to carry out Congress' intent.

Recommendation 2.

> *Title VII of the Civil Rights Act of 1964 should be amended to prohibit discrimination on the basis of handicap.*

Commentary:

Title VII[43] now prohibits employment discrimination on the basis of race, color, sex, religion and national origin. This statute should be amended to cover, in addition, discrimination on the basis of mental handicaps and physical handicaps, which are often associated with some type of mental disability. Such amendments would eliminate the often troublesome constitutional arguments which now must be made on behalf of handicapped individuals in litigation against public employers. They would also provide a generally applicable legal basis for eliminating discrimination against handicapped persons in the private sector. The legal protections thus created would be especially beneficial as the locus of treatment and services for mentally disabled persons shifts from large institutions to the community.

At least two pending bills[44] would amend Title VII as recommended above. The Administration should support these or similar proposals.

Recommendation 3.

> *State minimum wage and civil rights laws should be amended to prohibit discrimination against the handicapped.*

Commentary:

Amendment of State laws would clarify the rights of handicapped individuals and provide them with further protections against discrimination in the private sector.

Recommendation 4.

> *Congress should be requested to condition revenue sharing upon an agreement by State governments that mentally handicapped persons who, as employees, perform work of consequential economic benefit to the States shall be paid either the minimum wage or else wages which are commensurate with those paid nonhandicapped workers in the same vicinity for essentially the same type, quality and quantity of work, whichever is higher. States should be required, as a condition of revenue sharing, to agree to the same principles as are currently embodied in 29 CFR Part 529.*
>
> *In the alternative, the provisions of 29 CFR Part 529 should be incorporated in their entirety into HEW regulations 45 CFR Part 84, subpart B (employment practices) implementing Section 504 of the Rehabilitation Act of 1973.*

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[43] 42 *U.S.C.* 2000e *et seq.*

[44] H.R. 3504, S. 1346.

Commentary:

"Institutional peonage" describes the formerly widespread practice of employing residents in institutions for the mentally handicapped to perform productive labor associated with the maintenance of the institutions, without adequate compensation.[45] A 1972 study of 154 institutions in 47 States, which represented 76 percent of existing public facilities for the mentally handicapped, found that 32,180 of 150,000 residents were participating in work programs. Thirty percent were receiving no payment at all and an additional 50 percent were receiving less than $10 per week.[46]

In many State institutions, cleaning, laundering, kitchen work, waiting tables and preparing food, maintenance housekeeping and care of other residents have traditionally been performed in large measure by working residents. In exchange for this labor, working residents may be given open-ward privileges or some other "symbolic" reward; they are virtually never paid the prevailing wage. Institutional peonage exists in part because, given their understaffing and underfinancing, our public institutions cannot afford to pay regular employees for the work which is necessary to run them.

Exploitative motives aside, such nonremunerated work has traditionally been allowed because of difficulties in distinguishing between work which is primarily for the benefit of the institution and work which is chiefly for the benefit of the resident. Uncompensated labor injures resident-workers in a number of ways beyond the obvious loss of income. They are denied work-related benefits such as workmen's compensation and State retirement plans. They are denied the therapeutic benefits of appropriate monetary rewards. Perhaps most significantly, working residents who are not paid for their labor often perceive themselves to be exploited or enslaved and thereby lose a basic sense of self-respect and dignity which is both their right as human beings and a vital element of any meaningful habilitation or rehabilitation program.

Most institutions for the mentally handicapped would maintain that they do not force their residents to work. But, as is widely recognized, there are many pressures in institutions which coerce residents to perform institution-maintaining work and to conform to other institu-

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[45] See generally Friedman, "The Mentally Handicapped Citizen and Institutional Labor," 87 *Harv. L. Rev.* 567 (1975). "Institutional peonage" is to be distinguished from vocational-training tasks not involving the operation or maintenance of the institution and from personal-housekeeping tasks, such as the making of one's own bed.

[46] J. Richardson, *A Survey of the Present Status of Vocational Training in State-Supported Institutions for the Mentally Retarded* 4, 11-12, July 18, 1974 (written for Dr. I. Ignacy Goldberg, Columbia University Teachers College).

tional norms. A resident's refusal to work often results in staff antagonism, restriction of ground privileges or increased medication. It is common for the resident to be labeled uncooperative—with bad effects on his efforts to be released—when he fails to participate in a "voluntary" work program.

A major step in the abolition of institutional peonage was the decision of the United States District Court for the District of Columbia in *Souder* v. *Brennan*.[47] This ruling stated that the 1966 Amendments to the Fair Labor Standards Act extending the minimum wage and overtime provisions to all employees of "hospitals, institutions, and schools for the mentally handicapped" applied to resident workers. The *Souder* court also held that the United States Department of Labor must undertake reasonable enforcement activity on behalf of resident-workers. Addressing the Department of Labor's defense that it is very difficult to distinguish between work and vocational training, the court in *Souder* v. *Brennan* noted,

> 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. So long as the institution derives any consequential economic benefit the economic reality test would indicate an employment relationship rather than mere therapeutic exercise.[48]

Final regulations concerning "employment of patient-workers in hospitals and institutions at sub-minimum wages" were published on February 7, 1975.[49] These regulations, covering employment of patients whose earning or productive capacity is impaired, allow employers to pay such workers a pro rata share of the full minimum wage adjusted to the actual productivity of the handicapped worker relative to that of a "regular" employee.

The United States Supreme Court's decision in *National League of Cities* v. *Usery*[50] appears to limit significantly the reach of the *Souder* decision. In *National League of Cities*, a consortium of States successfully argued that the Federal government's attempt to regulate the minimum wage in State-operated facilities was an unconstitutional intrusion upon State sovereignty. Therefore mentally handicapped workers in State-run facilities, just like their nonhandicapped co-workers, are arguably no longer guaranteed a Federal minimum wage, although they are still entitled to the State minimum wage. However, because *National League of Cities* pertains only to State employees, the Fair

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[47] 367 *F. Supp.* 808 (D.D.C. 1973).

[48] *Id.* at 813 (footnotes omitted).

[49] 29 C.F.R. §§ 529.1-17.

[50] 426 U.S. 833, 44 U.S.L.W. 4974 (June 24, 1976).

Labor Standards Act and the *Souder* decision still apply to mentally handicapped residents working in private facilities.[51]

The incorporation of the regulations currently codified at 29 CFR section 529 either into revenue sharing agreements with the States or into the employment discrimination regulations under the Rehabilitation Act of 1973 would restore the protection of the minimum wage and the principle of commensurate pay for commensurate work to the full class of mentally handicapped workers.

3. *Housing Within the Community*

Recommendation 1.

(a) *State zoning laws should be enacted which preempt local zoning ordinances and permit small group homes for the mentally handicapped to be considered as permitted "single family residential uses of property."*

(b) *States revising their zoning laws to avoid discrimination against mentally handicapped persons should be alert to the problem of restrictive building codes and/or mutual private restrictive covenants which would undermine the goal of reform.*

(c) *State zoning laws should also prohibit the excessive concentration of group homes in any single neighborhood or municipality within a State.*

Commentary:

Various factors—including the use of psychoactive medication, cost-saving concerns, legal challenges to conditions in institutions and a philosophy of community treatment and "normalization"—have caused increasing numbers of mentally handicapped persons to be released from State hospitals to live in the community. While many of these individuals are capable of independent living, some others need the mutual support and assistance of group living arrangements.

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[51] The Decision in *National League* only clearly applies to "integral functions . . . in such areas as fire prevention, police protection, sanitation, public health, and parks and recreation." 96 Sup. Ct. at 4479. The court specifically noted that its holding left intact two earlier cases *Pardon v. Terminal R. Co.*, 377 U.S. 184 (1964) and *California v. Taylor*, 353 U.S. 553 (1957) both of which held that State employees performing nongovernmental functions, such as operating a State-owned railroad, are covered by the FLSA. Consequently, mentally handicapped residents in State institutions have argued that they are still within the minimum wage coverage of the FLSA. See, *e.g., Schindenwolf v. Klein*, Docket No. L-41293-75 P.W. (N.J. Sup. Ct. Law Div., Mercer Cty. 1976) reported at 10 Clearinghouse Rev. 393 (1976); 11 Clearinghouse Rev. 505 (1977). Moreover, the *Souder* Court's ruling that patient-workers in State institutions should be considered "employees" within the Federal act arguably should be given binding effect in determining applicability of State minimum wage laws. See generally Perlin, "The Right of Voluntary Compensated, Therapeutic Work as Part of the Right to Treatment: A New Theory in the Aftermath of *Souder*," 7 *Seton Hall L. Rev.* 298 (1976).

Experience within the past five years indicates that the development of group residences for the mentally handicapped is often vigorously opposed by members of the communities in which the group homes are to be located. These opponents frequently rely on local zoning ordinances as the principal method for preventing the opening of a group home.

Because there are few standardized zoning laws or models that encourage or even countenance the development of appropriate kinds of community residential facilities for mentally handicapped persons, zoning ordinances tend to be exploited by those opposed to the establishment of community facilities, and in many cases this tactic has proven successful in blocking their development.

Zoning litigation has been employed by both opponents and proponents of group homes, with mixed results.[52] However, as a means of overcoming zoning restrictions against group homes, litigation is particularly unsatisfactory. Unlike lawsuits challenging State statutes or Statewide practices, zoning disputes require almost constant litigation against each new group of opponents and each municipal ordinance that unfairly discriminates against group-living arrangements. Given the expense and duration of lawsuits, legislative solutions are essential in this area.

Although some municipalities have rewritten their zoning codes to deal more rationally and consistently with community residences, the incremental approach to revising zoning ordinances is also an inefficient way to achieve realistic and appropriate regulation of community residences. As changes are made in local regulations, there may develop serious inequities in policies and programs from one locality to another within the same State.

Preemptive State legislation presents the most encouraging way of coping with the impact of restrictive zoning ordinances which discriminate against group-living arrangements by mentally handicapped persons. Such legislation treats a small group of handicapped persons who reside together as the "family" which they functionally are. As a family, the group need not obtain zoning approval prior to moving into their home in "single family residential" zones. Such legislation has no fiscal impact and in fact eliminates the possibility of expensive and time-consuming litigation. Legislation of the type recommended has now been enacted in a growing number of States, now numbering ten.[53]

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[52] Compare *City of White Plains v. Ferraioli*, 34 N.Y.2d 300 (1974) with *Browndale Int'l. v. Board of Adjustment*, 208 N.W.2d 121 (Wisc. 1973).

[53] California, Colorado, Michigan, Minnesota, Montana, New Jersey, New Mexico, Ohio, Rhode Island and Virginia. See, for example, California Welfare and Inst. Code § 5116; Minn.

The experience of some States which have recently passed preemptive zoning statutes has been that both building codes and mutual private restrictive covenants can undermine the attempt at reform. Building codes can make distinctions in terms of the number of unrelated persons in a dwelling and can require prior local zoning approval before issuance of a building (or renovation) permit, which may bring local zoning ordinances into play. The private covenants are also a serious problem, already existing on many plots and being written to "protect" neighborhoods.

Enactment and implementation of preemptive State zoning laws could be facilitated by limiting Federal assistance to communities with zoning laws allowing for group homes.

Closely related to the problem of restrictive zoning is the tendency of some municipalities to encourage or allow group homes to locate only in certain less desirable sections of a city. In some instances, group homes have followed a line of least resistance, locating in such areas rather than going through the delay and expense of zoning disputes. As a result, some of our cities have developed "social service ghettos." These "ghettos" destroy the residential character of the affected neighborhoods and subvert the right of handicapped persons to live in normal residential surroundings. A prohibition on excessive concentration would protect municipalities against the creation of such ghettos by assuring the dispersal of group homes and would assure handicapped persons that they will be able to reside in normal residential areas.

State laws can achieve these results by establishing reasonable criteria for the location of new group homes. For example, the Minnesota law which governs the licensure of group homes[54] prohibits the granting of a new license to a group home when the effect of granting such a license would be the excessive concentration of community residential facilities within any town, municipality or county in the State. In making this determination, the statute requires the licensing agency to consider the population, size, land-use plan, availability of community services and the number and size of existing public and private community residential facilities in the town, municipality or county in which a licensee seeks to operate a residence. The statute further requires the agency to establish regulations to implement its provisions.

Legislation to control the concentration of group homes should be included as a necessary part of a comprehensive and balanced solution

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Stats, § 462.367. Note that five of those 10 State statutes were enacted during the last State legislative session.

[54] Minn. Stats. § 252.28.

to the issue of zoning for group homes for mentally handicapped persons.

Recommendation 2.

(a) *Title VIII, Fair Housing, of the Civil Rights Act of 1968 should be amended to prohibit discrimination in housing on the basis of mental handicap.*

(b) *The Department of Housing and Urban Development should (1) encourage States and localities to allocate additional community development block grant funds to develop more group care facilities and (2) make additional rental assistance funds available to mentally disabled persons living in group homes.*

Commentary:

Congress has recognized and acted upon both the critical importance of housing for all segments of the population and, in section 504 of the Rehabilitation Act of 1973, the fact of widespread discrimination against handicapped persons. Unfortunately, it has not yet acted to protect handicapped persons against private acts of discrimination in housing. (Note that section 504 only prohibits discrimination by recipients of Federal financial assistance.) If community alternatives to institutional care are to be achieved, legislative action is required to protect mentally handicapped persons against housing discrimination.

The Federal government has already in place extensive legislation and enforcement mechanisms to protect members of racial minorities against discrimination in housing. A simple amendment to include mentally handicapped persons in Title VIII, Fair Housing, of the Civil Rights Act of 1968[55] would constitute a major legal protection for this group of citizens. The inclusion of such an amendment would in no way usurp the authority of those States that have taken initiatives to resolve this problem, because the Civil Rights Act requires the Federal government to defer to State and local fair housing acts which provide rights and remedies that are equivalent to those set forth in the Federal act.[56]

The second part of this recommendation is made by the President's Commission on Mental Health in its preliminary report.[57] The availability of adequate and affordable housing for many low-income persons, including mentally disabled persons who have low incomes,[58]

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[55] 42 *U.S.C.* § 3601 *et seq.*

[56] 42 *U.S.C.* §§ 3610(c), 3616.

[57] *Preliminary Report to the President*, the President's Commission on Mental Health, September 1, 1977, page 13.

[58] See 42 *U.S.C.* 5303 (block grants) and 42 *U.S.C.* 1437f (rental assistance).

can be enhanced if such actions are taken.

4. *Guardianship*

Recommendation 1.

(a) *State guardianship laws should be revised to provide: (1) increased procedural protections including, but not limited to, written and oral notice, the right to be present at proceedings, appointment of counsel and a clear and convincing evidence standard as the burden of proof; a comprehensive evaluation of functional abilities conducted by trained personnel; and a judicial hearing which employs those procedural standards used in civil actions in the courts of general jurisdiction of any given State; (2) a definition of incompetency which is understandable, specific and relates to functional abilities of people; (3) the exercise of guardians' powers within the constraints of the right to least restrictive setting, with no change made in a person's physical environment without a very specific showing of need to remove a person to a more restrictive setting; and (4) a system of limited guardianships in which rights are removed and supervision provided only for those activities in which the person has demonstrated an incapacity to act independently.*

(b) *Public guardianship statutes should be reviewed for their effect in providing services to persons in need of but without guardianship.*

Commentary:

State guardianship proceedings have been the traditional means of providing supervision and protection to mentally handicapped persons who are residing in the community. As a result, large numbers of mentally handicapped individuals are subject to guardianship laws and to the profound legal consequences which accompany the guardianship process.

All 50 States have some form of incompetency proceedings. Current guardianship statutes generally authorize the appointment of a guardian upon a finding that a person is mentally incapable of caring for him/herself or his or her property. Following such a finding, a court typically authorizes a guardian to care for the "ward" in all matters connected with the ward's personal welfare and/or property. With this legally authorized transfer of decision-making authority to the guardian, the ward is deprived of his or her fundamental civil rights,[59] including the right to choose a residence, the right to sue in his or her own behalf, the right to enter into contracts and, in some States, the right to vote, to hold a license and freely to marry. In addition, determination of incompetency may also result in the loss of other less obvious but equally fundamental rights. Among the recognized rights to citizenship which an adjudged incompetent may be denied are the right to go from place to place as s/he pleases,[60] to meet with persons in public places,[61] to enjoy the privacy of family life[62] and to determine appropriate medical care.[63]

While loss of physical freedom is not a necessary result of incompetency determinations, a determination of incompetency does often result in some form of institutionalization, particularly for the elderly. Sudden changes in environment have proved traumatic to elderly persons. When such changes in environment result in more restrictive personal control, in a nursing home or in an institution, for example, they can have serious physical effects on an elderly person and can even result in death.[64]

The deprivation of legal rights inherent in guardianship requires that guardianship laws must be scrupulous in their adherence to due process and must be carefully tailored to avoid any unnecessary restrictions. Unfortunately, many guardianship laws contain few, if any, procedural protections, and only a handful of State laws make provisions for limiting the power of guardianship to reflect actual abilities and disabilities of persons under guardianship.

According to the American Bar Association's Commission on the Mentally Disabled's recently completed 50-State survey of guardianship laws,[65] only 25 of the States require any sort of medical or psychological evaluation in connection with a guardianship proceeding, despite the requirement for guardianship of a finding of incompetency. And, while virtually all States make provision for a hearing to review the need for guardianship, laws in 37 States make no specific provision for the fundamental right to present or cross-examine witnesses. Many provide only for the appointment of counsel at the discretion of the court and few require counsel to be compensated by the State if the

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[59] See, generally, J. Regan and G. Springer, "Protective Services for the Elderly," a working paper prepared for the Special Commission on Aging, U.S. Senate, July, 1977.

[60] *Papachristou v. City of Jacksonville*, 405 U.S. 156 (1972).

[61] *Coates v. City of Cincinnati*, 402 U.S. 611 (1971).

[62] *Roe v. Wade*, 410 U.S. 113 (1973); *Griswold v. Connecticut*, 381 U.S. 479 (1965).

[63] *Roe v. Wade*, supra.

[64] See *Klein v. Mathews*, 430 *F. Supp.* 1005 (D. N.J. 1977).

[65] American Bar Association Commission on the Mentally Disabled, draft unpublished document pertaining to rights of institutionalized developmentally disabled persons, in progress.

person is indigent. Numerous commentators have suggested that the procedural protections now established for involuntary commitment laws should also be statutorily required in guardianships.[66] In fact, the need for due process protection in guardianship determinations has been recognized by Chief Justice Burger in his concurring opinion in *O'Connor v. Donaldson*.[67]

Most States' definitions of incompetency are equally in need of revision. Incompetency definitions usually are vague and over-broad. It is often impossible to know whether a person is incompetent under the State's definition without reviewing thousands of individual cases to see what issues courts have found relevant. Just as with the standards for involuntary commitment it is crucial that definitions of incompetency be made specific, clear and understandable, so that rational and fair decisions concerning guardianship can be made. Guardianship proceedings can play an important role for persons who are not able to perform certain basic functions such as obtaining food, clothing and shelter. Specific definitions of incompetency along these functional lines can be written and, as with commitment laws, they should specify that the facts used to justify guardianship must be recent and relevant.

Statutory failure to provide for "limited" guardianship poses very serious legal problems. Because many mentally handicapped persons need only a limited degree of supervision, laws which treat guardianship as an "all or nothing" proposition tend to restrict important legal rights without justification. Such statutes cannot be considered a rational or reasonable exercise of governmental power and are of dubious constitutional validity. Consequently States which do not now require that guardianships be fashioned by courts to meet only the functional inabilities of a ward should amend their laws to permit guardianships only to the extent of and only as supported by proven functional needs.

Use of a functional definition of incompetency also requires consistent and periodic review, to permit lifting of the guardianship when the functional inability ceases. And a functional definition necessarily limits the guardianship to providing for care and assistance only in the context of the individual's particular functional problem.

The right to treatment in the least restrictive setting is discussed elsewhere in this report.[68] It is extremely important to include this par-

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[66] See Regan and Springer, *supra*, and Kindred, "Guardianship and Limitations upon Capacity," *The Mentally Retarded Citizen and the Law* (1976), pp. 63-87, at 75.

[67] 422 U.S. 575, 583 (1975).

[68] Numerous courts have held that government action which infringes on personal liberty must be limited to the extent necessary to achieve the governmental objective. This principle, known as the doctrine of the least restrictive alternative, was first enumerated by the Supreme Court in *Shelton v. Tucker*, 364 U.S. 479 (1960) and has been repeatedly applied in the mental health field. See, e.g., *Welsch v. Likins*, 373 *F. Supp*. 487, 502 (D. Minn. 1974); *Davis v. Watkins*,

ticular right specifically in all incompetency statutes. A guardian usually has the power to determine a ward's environment—an environment which can be unduly restrictive, such as a State institution or a locked nursing home. Concrete provisions to maintain a ward in a setting least restrictive of his or her civil liberties are necessary and are consistent with a policy encouraging keeping people in their own homes to the extent possible.[69]

The demand for the "public-guardian" concept usually comes from individuals or groups who seek to provide services to persons who everyone agrees are incompetent but who have no friends or relatives appropriate to serve as guardians. The number of persons in such need is unknown, but the problem seems to rest most heavily with elderly persons. About a dozen States have provided for public guardians who may be appointed to protect persons and their property.[70] These laws, however, differ in approach and extent. Delaware's public guardian, for example, deals primarily with financial matters and is not really a full-scale guardian. The California law, on the other hand, does provide for full guardianship through the public guardian's office, optionally on a county-by-county basis. The Minnesota law provides for guardianship of the person for mentally retarded individuals. Many States' guardianship statutes allow not only individuals but also organizations or governmental entities to serve as guardians. These statutes do not provide any specific controls over the State or the organization that serves as guardian, because those group guardians would be subject to the same controls as individual private guardians.

While it is tempting to espouse a system of public guardians because of the admitted need of some persons for this service, it is too early to proffer such a recommendation. Very little research has been undertaken so far on the need for or effectiveness of a public guardian. So that rational decisions can be made as to the advisability of a public guardian, a full examination is necessary. Simultaneously, other mechanisms such as private nonprofit corporations and public trusts should be explored.[71]

It is apparent that reform of State guardianship laws is long overdue. The Panel's recommendations are designed to ensure that State

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384 *F. Supp.* 1196, 1206 (N.D. Ohio 1974). A strong argument can be made that use of plenary guardianship when limited guardianship suffices violates the least restrictive alternative doctrine. See also our discussion in III.8, *infra.*

[69] Moreover, any placement in a restrictive setting should be preceded by a judicial hearing which determines the need for institutional care.

[70] These include Arizona, California, Colorado, Delaware, Georgia, Illinois, Maine, Minnesota, North Carolina, Ohio, Oregon and South Dakota. See American Bar Association Commission on the Mentally Disabled draft unpublished document, above.

[71] See Kindred, above, at 72-75.

guardianship laws conform to the basic requirements of due process. The recommended procedural standards represent those protections which are essential for a fair hearing. The recommendations for limiting guardianship to specified activities may be accomplished by providing the court both with testimony and a professional evaluation of the abilities and disabilities of the person being considered for guardianship.

Reforms similar to those recommended here have already been enacted in a number of States,[72] although no particular State's laws are a model for all of the suggestions of the Panel.

Reform of State guardianship laws should be neither controversial nor fiscally burdensome to the States. If achieved, such reform will constitute a major step in promoting the legal rights of mentally handicaped citizens.[73]

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[72] See, for example, Cal. Probate Code 1460 § 1400 *et seq., Idaho Code* § 15-5-101 *et seq.* and § 56-239, *Mich. Stat. Ann.* § 330.1600 *et seq., Minn. Stat. Ann.* § 252A.01 *et seq.* and § 525.54 *et seq., Montana Rev. Codes Ann.* § 91A-5-101 *et seq., N.C. Gen. Stat.* § 35-1.6 *et seq.,* Texas Probate Code Ann. Title 5, § 130 *et seq.,* and *Wash. Rev. Code Ann.* § 11.88-005 *et seq.*

[73] Two broad areas related to guardianship laws that are of special importance to the mentally handicapped were not fully studied by the Panel: protective services and the practice of appointing substitute payees for persons entitled to Federal benefits.

(a) "Protective services" usually refer to services offered a physically or mentally infirm older person or an abused, neglected, or deserted child or an adult mentally retarded person to assist him or her in carrying out activities of normal living or to protect him or her from further harm. These services can include health, medical, psychiatric, social or legal services. When provision of services is accepted voluntarily, and the intervention is slight, these are seen as "supportive" services. When the intervention is significant, or is resisted, there may be a need for legal intervention to authorize the necessary services. It is in situations where legal sanction is involved that the assistance offered is truly "protective services."

Unfortunately, many State protective services laws provide for involuntary protective services without the same due process procedural protections which are required by State guardianship or involuntary commitment laws. These proceedings should not be used as a method of avoiding the constitutionally required procedures.

Additionally, a State's involuntary commitment, guardianship and protective service laws should interrelate to each other in a rational manner and definitions should be consistent. For a full discussion of protective services for the elderly and for a model adult protective services act, see Regan and Springer, above.

(b) Federal laws provide for appointment of a substitute payee for a person entitled to receive Federal funds when that beneficiary is incapable of managing his or her funds. Social security payments, veterans' benefits, and other Federal benefits are affected.

These programs affect the mentally handicapped of all ages. Agency procedures and practices, however, vary as to supervision and review of how the substitute payee handles funds or when the substitute is appointed. The Social Security Administration, for example, without regard to the beneficiary's legal competence, asks merely whether the interest of the beneficiary would be served by the appointment of a substitute. (See, for example, 42 *U.S.C.* 405 (j), permitting payment of Federal old-age, survivors, and disability insurance benefits to "a relative or some other person.") Criteria and standards are vague, and there are many constitutional questions related to the entire system of substitute payees (see Regan and Springer, above, p. 44). The system does appear to serve a useful purpose, however, and might usefully be reviewed for reforms. Moreover, consideration should be given to whether the system might serve more effectively if it were part of or related to guardianship arrangements.

5. *Confidentiality*

The Task Panel agrees with the Congressionally-authorized Privacy Protection Study Commission that "the medical-care relationship in America today is becoming dangerously fragile as the basis for the expectation of confidentiality with respect to medical records generated in that relationship is undermined more and more. A legitimate, enforceable expectation of confidentiality that will hold up under the revolutionary changes now taking place in medical care and medical recordkeeping needs to be created."[74] Confidentiality, however, cannot be an absolute and unbending requirement, because it must be reconciled with legitimate needs for access to mental health records. With these recommendations the Panel attempts to balance the needs for confidentiality and access.

Recommendation 1.

> *Federal and State laws should recognize the principle that patients must have access to their mental health records and the opportunity to correct errors therein.*

Commentary:

It is ironic and unacceptable that at present in many jurisdictions patients cannot see their own mental health records even though these records are available to others. Personal access to an individual's records is essential. Aside from patients' right to know about the information compiled on them, such knowledge is essential if the patient is to give truly informed consent to release of such records. A person cannot consent to disclosure of information s/he knows nothing about.

Most Panel members agreed on the necessity for limited exceptions where the revelation of information could cause concrete harm or would violate a confidential relationship between the mental health professional and third parties who supplied the information. Such circumstances will be exceptional; several studies have shown that rather than causing harm, access to records has in fact increased patient cooperation and lessened anxiety.[75] Parents should have access to the records of their children except where children have sought therapy on their own. In such cases, children should have access to their own records.

Access to records is in itself insufficient without procedures for correcting information. Procedures set forth in the Privacy Act of

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[74] Privacy Protection Study Commission, *Personal Privacy in an Information Society*, 1977, p. 306.

[75] Roth, L., Wolford, J., and Meisel, A., *Patient Access to Records—"Tonic" or "Toxin,"* paper presented to the American Psychiatric Association at its annual meeting, May 1977.

1974[76] and the Buckley Amendments[77] could be used as models. Records should be copied with minimal reproduction fees and professionals should be available when necessary to aid in interpretation of information in the files. Where the patient disagrees with information in the file, the patient's own version should become a permanent part of the files, and mediation should be provided where professional and patient cannot agree on changes, with ultimate recourse to the courts when necessary. Education is essential, both for the public, so that patients know and can take advantage of their right of access, and for professionals, so that they can prepare records in an appropriate manner.

Recommendation 2.

> *Except where otherwise required by law, confidentiality of mental health information must be strictly maintained by all persons who have contact with such information. Mental health professionals must alert their patients at the outset of therapy about special conditions under which complete confidentiality cannot be maintained. States should also enact strong penalties for the inappropriate release of confidential materials by mental health professionals without the patients' consent.*

Commentary:

The Task Panel recognizes the importance of protecting the confidentiality of mental health treatment records from disclosure to others.[78] All mental health information must be so protected, even that in the files of general medical practitioners. While the primary caregiver has the most obvious responsibility to preserve confidentiality, State laws should include penalties against anyone who discloses confidential information without consent. The Privacy Commission has recommended criminal fines and penalties for disclosure[79] and the Department of Health, Education, and Welfare, in a response to the Privacy Commission report, recommended injunctive relief and damages, to include actual damages, punitive damages in cases of willful disclosure, attorney's fees and general damages of not less than $1,000 nor more than $10,000.[80] The Panel endorses those recommendations. Uni-

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[76] 4 *U.S.C.* 552a.

[77] The Family Education Rights and Privacy Act, 20 *U.S.C.* 1232g.

[78] See, in this regard, "Model Law on Confidentiality of Health and Social Service Records," prepared by the American Psychiatric Association (APA) Task Force on Confidentiality of Children's and Adolescents' Clinical Records and the APA Committee on Confidentiality and approved by the APA Executive Committee of the Board of Trustees, September 1977 and the APA Executive Committee of the Assembly, Feb. 4, 1978.

[79] See *Personal Privacy in an Information Society*, above, pages 294-295.

[80] "Report and Recommendations on Statutory Protection for Health Records," Department of Health, Education, and Welfare staff study, October 12, 1977, pp. 26-27. Transmitted to the

form State laws on testimonial privilege should also be developed, emphasizing that the privilege belongs to the patient or client. Those performing an evaluative function not protected by privilege (*e.g.*, competency evaluators) should be required to so inform the subject at the outset of their relationship.

The areas in which disclosure can be made without consent are very controversial, but Panel members agree that these exceptions must be carefully limited. For example, where a therapist knows that a patient is about to do serious harm to a third party, revealing that information to the police should not subject the therapist to legal penalties.[81] Many therapists believe, however, that if they are compelled to break a confidence for reasons of overriding social policy, they should inform the patient and terminate the therapy, if the patient so requests. In any event, it is the obligation of the therapist to inform the patient at the outset of therapy of the specific situations in which an exception to the principle of confidentiality will be made. To give another example, therapists should inform patients in advance that they will have to supply information when served with a subpoena. In this regard, the Panel condemns the frivolous use of subpoena power and strongly recommends that therapists be fully informed of their right to contest, and that patients be informed whenever any information concerning them is released.

The Panel further recommends that release of information for purposes of auditing mental health service programs be limited, and that laws be amended to allow information to be gathered without patient identifiers. Disclosure of information for research purposes is discussed more fully in another section of this report. It should, however, be noted that any confidential information utilized for mental health research purposes should be coded so as not to reveal the individual subject's identity, and information which identifies the subject should never be passed on to other researchers without express written consent of the subject.

Hon. Paul G. Rogers, Chairman, Subcommittee on Health and the Environment, House Committee on Interstate and Foreign Commerce, October 31, 1977.

[81] The reader should note, however, that (without our attempting to formulate guidelines) there is a significant distinction between knowing with some degree of certainty that a patient is about to commit a crime and guessing or predicting. In a recent controversial decision the California Supreme Court has held psychotherapists responsible in damages for failure to warn an intended victim about their patient's threatened dangerous acts. *Tarasoff v. Regents of University of California*, 13 *Cal. 3d* 177, 118 *Cal. Rptr.* 129 (1974), reaffirmed 17 *Cal. 3d* 425, 131 *Cal. Rptr.* 14 (1976). While the Panel did not have the opportunity to explore the issues posed by *Tarasoff* in any detail, there was consensus that holding a therapist responsible for predicting dangerousness and requiring the therapist to play the role of "policeman," without extremely clear guidelines, would be unfair both because psychotherapists lack the expertise to predict future dangerous conduct accurately and because of the inherent conflicts in the roles of therapist and law enforcer. See our discussions of dangerousness and of the doubt agent, Sections III. 12 (pp. 146, 150-152) and Section V (pp. 176-179), respectively.

Recommendation 3.

> *Consent forms for release of information concerning patients' histories should be limited to particular items of information in their records relevant to the specific inquiry posed by third parties who have a legitimate need for such information. Blanket release forms should be prohibited, and nonspecific requests for information should not receive response. Consent to release information should be of limited duration and should be revocable by the patient at any time. A record should be maintained in each patient's file describing what information has been released, when, to whom and for what purposes.*

Commentary:

Panel members are alarmed by the extent to which requirements of informed consent for release of mental health records are ignored or abused. Patients are often asked to sign away all rights to confidentiality. Blanket consent-to-release forms should be abolished and replaced by easy-to-understand, specific forms which make clear to whom distribution of information may be made. Patients should be informed that refusal to give consent will not jeopardize their right to present or future services except where disclosure is necessary for the specific service or claim in question. See, for example, the recommendation and discussion on appropriate employment questions which follows. The duration of consent should be limited and individuals should have the right to revoke it at any time. For example, in order for insurance companies to perform legitimate cost-and quality-control functions they must occasionally have access to mental health information. Because of the individual's right to privacy and because information about the individual's mental health will change over time, insurance companies should not be permitted to obtain information freely at any time or to store information over long periods of time.

A disclosure log must be included in each file which will show the date and content of the disclosure and the recipient of the information. Disclosure logs are required under the Privacy Act, the Buckley Amendments and several State fair information practices laws and they have been put into effect without undue administrative burden. Consent for release of information from the files of children should be given jointly by the child and the parents, and alternatives, such as the sealing of children's mental health files when they reach a determined age, should be explored.

Recommendation 4.

> *Employers' questions to job applicants and employees must be related to objective functioning skills directly relevant to the specific job for which the applicant or employee is being considered.*

Commentary:

Employers should not be permitted to ask job applicants and employees general questions concerning the nature or severity of any psychiatric or treatment disorders. In a recent case, a social worker was turned down for a county job after refusing to answer questions about such matters as "depression or excessive worry" and "trouble sleeping". The consent order filed in the case halted use by the county government of an employee medical history form which requested intimate details about mental health treatment and which required general release of job applicants' medical records. Such broad questions must be abolished. The burden should be on the employer to justify any inquiry. To avoid stigma or discrimination based upon past mental status, emphasis should be placed upon probationary evaluation periods for new employees. Any mental health information gained from the job applicant or through medical examinations must be held in strict confidentiality. The employer should have no access to the files of employees receiving mental health care as a benefit of employment.

This recommendation adopts and expands the approach of section 504 of the Rehabilitation Act of 1973.

Recommendation 5.

> *Third-party insurers should be encouraged to utilize peer review or other similar mechanisms which allow an evaluation of the necessity and appropriateness of treatment to be conducted while the patient's identity remains anonymous. Centralization and sharing of personal information without the express, written consent of the patient or client should be prohibited.*

Commentary:

Insurers need information to process claims. The burden should be on the insurance company, however, to seek only that information which can be shown to be relevant to determine the appropriateness of a claim and to protect personal information from further dissemination or release. Background data on a patient's mental health history should not be maintained and information should not be gathered from sources other than the patient and the care-giver. Insurance companies should be liable for any release of information. The public should be notified of the existence of data banks, of their rights to have access to and to change personal information and of their right to refuse to consent to centralization and sharing of this mental health information.[82]

Recommendation 6.

> *The Task Panel has reviewed and generally supports the report of the Privacy Protection Study Commission, Personal Privacy in an Information Society, concerning confidentiality of medical records. Implementation of that Commission's recommendations should be required not just in Medicare/Medicaid institutions as the report suggests but by all facilities maintaining mental health records.*

Commentary:

Task Panel members agreed on general support of the thorough and thoughtful report of the Privacy Commission. We recommend, however, that implementation of its recommendations on medical records not be limited solely to institutions covered under Titles XVIII and XIX of the Social Security Act. Rather, all recipients of Federal funds that provide mental health services should be required to implement the Privacy Commission's recommendations, and private institutions should be encouraged by the States to follow these recommendations.

6. *Federal Benefits*

Recommendation 1.

> *Existing Federal statutes, regulations and programs should be reviewed for instances of discrimination against mentally handicapped individuals. Appropriate legislative or administrative action should be taken to eliminate barriers and other restrictive provisions or practices.*

Commentary:

Supplemental Security Income (SSI), Medicare, Medicaid, Social Services; Old Age and Survivors and Disability Insurance; food stamps; CHAMPUS and Veterans' Administration entitlements; specialized services such as vocational rehabilitation, maternal and child

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[82] An alternative which the Panel thinks worthy of consideration is requiring third-party payors to use statements of the general "level of functional impairment" rather than diagnosis in evaluating the necessity and appropriateness of treatment. Such statements would numerically record the patient's level of functional impairment at the time of the treatment in question without saddling the patient with a diagnostic label which could impart lasting stigma. Such an approach has undergone a preliminary test and has been termed "an outstanding success." See "APA Insurance Code System Said Success," Psychiatric News, December 16, 1977, p. 21. See also *Confidentiality and Third Parties*, Task Force Report 9, American Psychiatric Association, 1975, pp. 14-20.

health services, family planning services, and nutritional programs for the elderly—the list of Federal benefits potentially available to mentally handicapped persons is somewhat staggering. Sadly, this list is not an accurate measure of governmental concern for mentally handicapped persons or of the resources actually available to such individuals. To the contrary, mentally handicapped persons often do not receive the full benefits of these Federal programs and are sometimes excluded from eligibility because of their handicap or the locale where the service is provided. These types of discrimination are compounded by restrictive interpretations of "disability" or "illness," by failure to disseminate information about existence of resources or eligibility for benefits and by jurisdictional confusions. Indeed, the experience of many potential beneficiaries of Federal programs is that administrators adopt a negative attitude: "What can I do to keep you from getting this assistance"?

The various Federal benefit programs share only one feature: None views the mentally handicapped individual as a whole person; rather, each, by its nature, attempts to compartmentalize applicants and forces them to fit themselves into arbitrary and conflicting pigeonholes. Each program has its own economic and programmatic eligibility requirements, provides its own level of care and/or offers its own level of benefits. It is difficult enough for a person who is not mentally handicapped to traverse this quagmire, but it can be nearly impossible for many mentally disabled beneficiaries who are expected to "go it alone" at a time when they have no resources, financial or otherwise, and no one to help them along. These legal and administrative barriers to assistance for mentally disabled persons, particularly those attempting to survive in the community and return to society's mainstream, must be identified and eliminated.

Identification and modification of discriminatory or unreasonable Federal practices or requirements should be accomplished, at least in part, in connection with the President's proposed reform of Federal welfare programs and in any proposed program of national health insurance. The welfare reform bill already proposed by the Administration,[83] for example, could usefully be modified in several respects. Under this proposal, reduced benefits would be paid to a mentally handicapped person who has worked in the past but is now able to work only episodically. The automatic assumption that such a person is able but is unwilling to work (which is the cause of the reduction of benefits) is discriminatory. The bill would also mandate review for ability to work every three months. Such frequent reviews may in fact

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[83] See H.R. 9030 and S. 2084, 95th Congress, 1st Session.

constitute harassment for many mentally handicapped individuals. And the Administration proposal would retain the provision for reduction in benefits for an adult "living in the household of another" which is found in the present welfare legislation. Such a provision constitutes a disincentive to keeping families together.

Moreover, the Department of Justice has already announced its intention to conduct a survey, in conjunction with the operating agencies, of existing Federal laws and programs with a view to eliminating or revising provisions which discriminate on the basis of sex. The Panel urges the Department to expand its announced survey to identify instances of discrimination against, or unfair treatment of, mentally disabled individuals, in connection with income maintenance and medical assistance programs and other areas of Federal law.

The primary examples of discrimination in Federal assistance programs are the limitations on coverage of mental health treatment under the Medicare and Medicaid programs.[84] Medicare limits payment for inpatient psychiatric services in psychiatric institutions to 190 days per lifetime[85] and for outpatient physicians' services to $250 per year;[86] persons between the ages of 21 and 65 are excluded altogether from the Medicaid reimbursement for treatment in a psychiatric facility.[87] These provisions are made even more irrational by such provisions as those allowing reimbursement for services in a general hospital but not for the same services in a mental hospital[88] and the "50 percent rule," which deems facilities to be psychiatric in nature—and thus subject to benefit restrictions and limitations—because more than half the residents are mentally ill.[89] Most of these limitations have been upheld by

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[84] See generally 42 *U.S.C.* 1395 *et seq.* and 42 *U.S.C.* 1396 *et seq.*, respectively.

[85] 42 *U.S.C.* 1395d(3) and 1395d(c).

[86] 42 *U.S.C.* 1395l(c).

[87] See 42 *U.S.C.* 1396d(a)(4), (a)(14), (a)(16), and (a)(17), and 1396d(h). These sections define the Medicaid limitations on payments for skilled nursing (facility) services to patients in institutions for mental diseases who are 21 years of age or older, on payment for inpatient hospital services, skilled nursing home services or ICF services for individuals 65 years of age or over in an institution for mental diseases, and on treatment in mental hospitals for individuals under age 21; exclude care or services for any individual who is an inmate of a public institution (except as a patient in a medical institution) or who has not attained 65 years of age and who is a patient in an institution for tuberculosis or mental disease, and limit the receipt of inpatient psychiatric hospital services by those under 21.

Note that the exclusion for inmates of public institutions applies to inmates of jails and prisons. See our discussion of criminal justice system issues in section III. 12, below.

[88] Definitions of "inpatient hospital services" (42 *U.S.C.* 1395x(b)) and "hospital" (42 *U.S.C.* 1395x(e)) do *not* place any limitations on the diagnostic categories of "mental, psychoneurotic and personality disorders" as are stated in 42 *U.S.C.* 1395l(c); but all patients who receive "inpatient psychiatric hospital services" (42 *U.S.C.* 1395x(c)) in "psychiatric hospitals" (42 *U.S.C.* 1395x(f)) are subject to the 190 day lifetime limitation in 42 *U.S.C.* 1395d(b)(3).

[89] The excluded institutions are those 'primarily' providing care for patients with 'mental diseases.' An institution is characterized as 'primarily' one for mental diseases if it is licensed as such, if it advertises as such or if more than 50 percent of the patients are in fact patients with mental disease. In some instances a facility may be 'primarily' concerned with such individuals because they concentrate on managing patients with behav-

the courts against constitutional attack,[90] but they are nonetheless logically and programmatically indefensible. The distinctions between mental health and other kinds of health care should be eliminated; the cost of doing so can be minimized by reducing the emphasis on and need for institutional confinement (see below).

In this connection, the Task Panel agrees with the recommendation in the President's Commission's preliminary report that the current Medicaid ICF (intermediate care facility) provisions be expanded to include such facilities for mentally ill persons, in addition to those for mentally retarded individuals and others already authorized under the law (see below). The Panel would limit this class of providers, however, to facilities serving 15 or fewer patients. Additionally, provider requirements for "generic" skilled nursing facilities and intermediate care facilities should be directed toward their role in caring for mentally handicapped persons. Both staffing and structural standards should reflect the therapeutic needs of the mentally handicapped and the importance of a nonrestrictive environment.

Another area of irrationality and arbitrariness is in the definitions of mental disability for purposes of SSI (Supplemental Security Income) eligibility.[91] The current definitions should be reviewed for equity and for consistency with current concepts in psychiatry and other disciplines. Indeed, the entire administration of the SSI program (if it is continued) needs to be improved in order to make eligibility and recertification procedures more humane, to enhance information, referral and outreach efforts and to foster communication with and understanding of mentally handicapped individuals. For example, it should be possible at least to keep a client's SSI file open when he returns to a mental hospital and/or to consider persons released from mental institutions "presumptively disabled,"[92] in order to avoid repeated and frustrating delays in receipt of desperately needed payments by persons returning to the community.

Handicapped children face special difficulties in receiving Federal benefits under Medicaid and SSI. Under the Medicaid program, both

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> ior or functional disorders and are used largely as an alternative care facility for mental hospitals, even if less than 50 percent of the patients have actually been diagnosed as having a mental disease.

—Social and Rehabilitation Service, Field Staff Information and Instruction Series: FY 76-44, *Federal Financial Participation in Payments for Care in Institutions for Mental Disease*. November 1975.

See also 42 *U.S.C.* 1396d(a)(4) and (15) and (a)(14) and pertinent regulations contained in 45 C.F.R. 248.60 and 45 C.F.R. 249.10(c)(1).

[90] See *Legion v. Richardson*, 354 *F. Supp.* 456 (S.D.N.Y. 1973); *Kantrowitz v. Weinberger*, 388 *F. Supp.* 1127 (D.D.C. 1974), affirmed 530 *F.*2d 1034 (1976).

[91] 42 *U.S.C.* 1382c(a)(1).

[92] 42 *U.S.C.* 1382(e)(1)(B).

maintenance and services are reimbursed for children in institutions, while the program pays only for medical care for children in less restrictive settings. Home health care, while a mandatory service for adults, is not required for those under 21. This amounts to a disincentive for deinstitutionalization. The SSI program has reached only a small fraction of eligible children as a result of inadequate outreach and follow-through procedures and restrictive definitions of disability.

Recommendation 2.

(a) *Federal assistance programs should be administered and governing legal provisions modified, where necessary, to implement the principle of placement or treatment in the "least restrictive alternative" and to foster deinstitutionalization of mentally handicapped individuals. Appropriate measures might include the following steps:*

   (1) *A class of intermediate care facilities for mentally ill persons, comparable to those for mentally retarded individuals and others but limited to a maximum of 15 beds, should be created under the Medicaid program.*

   (2) *"Clinic services" should be a required rather than an optional service in Medicaid; the limitations on outpatient physician services in Medicare should be eliminated; and both Medicare and Medicaid benefits should be made available for inpatient and outpatient services in community mental health centers for the mentally handicapped of all ages.*

   (3) *The thrust of the current Medicaid intermediate care program for mentally retarded persons should be directed toward community-based, rather than institutional, facilities for mentally retarded persons, and appropriate changes should be made in the ICF/MR regulations where necessary to facilitate use of Medicaid funds for community-based programs. Medicaid should also be amended to require health services for children under 21.*

   (4) *The Department of Health, Education, and Welfare should strictly enforce the Medicaid standards for residential institutions for mentally retarded persons set forth in 45 C.F.R. §§249.12 and 249.13 and should ensure prompt decertification of those large institutions which do not meet the standards.*

(5) *Preadmission or admission certification, peer review and utilization review and relevant PSRO activities requirements should be enforced in all inpatient facilities under Medicare and Medicaid to ensure that hospital, skilled nursing (SNF) or intermediate (ICF) care is provided only on the basis of individual need and that alternative, less restrictive placements are considered and provided when appropriate.*

(6) *HEW should require State plans submitted pursuant to Title XX of the Social Security Act (42 U.S.C. 1397 et seq.) to address specifically the problems and needs of mentally handicapped persons who live in the community or who could live in the community if financial or other assistance were available.*

(7) *HEW should require State Developmental Disabilities Councils and other agencies funded under the Developmentally Disabled Assistance and Bill of Rights Act (42 U.S.C. 6001 et seq.) to focus their activities on deinstitutionalization of developmentally disabled individuals and on creation of community-based living arrangements, day programming and support services for such individuals. HEW should specifically prohibit use of D.D. Act funds for construction, renovation or expansion of large institutional facilities.*

(8) *HEW should develop regulations which require State mental health plans mandated under Pub. L. 94-63 (42 U.S.C. 2689t) and State health plans required under Pub. L. 93-641 (42 U.S.C. 300m-2(a)(2); 42 U.S.C. 300k-1 et seq.) to evaluate resources for community programs for the mentally handicapped and to plan for the development of community resources that will ensure that mentally handicapped persons are enabled to live in the least restrictive setting consistent with their individual needs.*

(9) *Federal guidelines for State regulation of group homes (board and care homes) where SSI recipients are living should emphasize the need to encourage personal independence and to provide access to necessary health care and social services. The Department of Health, Education, and Welfare should*

ensure rapid compliance with the interim regulations requiring counseling, and social and other services for children under 7 as well as for those children unable to attend school.

(10) *Federal AFDC foster care funds*[93] *for children should only be available if out of home placement is in the least restrictive setting and in as close proximity to the child's home as is consistent with the child's special needs.*

(11) *The Department of Health, Education, and Welfare should, within the Office of the Secretary, examine the impact of Supplemental Security Income, Medicaid and other Federal programs on the deinstitutionalization of mentally handicapped children, and develop specific proposals for reducing inconsistent fiscal incentives and regulations.*

(b) *As a direct, initial, positive step, the Federal government should develop within 180 days of the Commission's report a coordinated response to and plan for implementation of the recommendations contained in the GAO report of January 7, 1977, "Returning the Mentally Disabled to the Community—Government Needs to Do More".*

Commentary:

In recent years, a substantial number of courts have concluded that mentally handicapped persons have a right to live and receive treatment, if necessary, in the least restrictive environment consistent with their needs.[94] At the same time, a growing number of States have endorsed the concept of deinstitutionalization for those mentally handicapped persons who are capable of living in the community. Despite these positive trends, practical steps have yet to be taken to ensure that mentally handicapped persons can live and work in environments which maximize their opportunities for independence. There is a great need for the development of adequate community based mental health and mental retardation services and support systems.

Funding restrictions have profound implications for most of the desirable community living arrangements. Supplemental Security Income (SSI) restrictions on recipients and Medicare and Medicaid limi-

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[93] 42 *U.S.C.* 608.

[94] See, for example, *O'Connor v. Donaldson*, 422 U.S. 563 (1975); *Lake v. Cameron*, 364 *F.*2d 657 (1966); *Dixon v. Weinberger*, 405 *F. Supp.* 974 (D.D.C. 1975); and *Wyatt v. Stickney*, 344 *F. Supp.* 373 and 387 (M.D. Ala. 1972), aff'd. sub. nom. *Wyatt v. Aderholt*, 503 *F.*2d 1305 (5 Cir. 1974).

tations on providers as well as recipients negatively affect the accessibility and availability of services to the mentally handicapped. Current funding patterns do not readily lend themselves to initiating and maintaining community support systems; transferring institutional resources to the community, if at all possible, has proved difficult; start-up funds for new community programs are scarce and funding sources are fragmented; fiscal incentives often work against service goals. In fact, the Federal government is often placed in the unfortunate position of officially supporting financial disincentives to small congregate living arrangements.

Therefore the Task Panel, as noted above, would agree with the President's Commission's preliminary recommendation with respect to creation of a class of "ICF/MH" providers under Medicaid, governed by a separate set of staffing, programmatic and physical plant requirements which would be tailored to the special needs of mentally ill persons but would not be unduly burdensome and restrictive and would facilitate movement into the community. The Panel supports the provision of Medicare and Medicaid reimbursement for services provided by community mental health centers, so that persons needing such help can obtain it in a convenient and unrestrictive setting. Other changes in Medicare and Medicaid provisions also may be necessary to ensure availability of other types of community services such as home health and day care services.

Modifications in ICF and SNF standards and provider requirements are needed because for many persons with both physical and mental handicaps these facilities may represent the most appropriate care facility. While Federal regulations cover many aspects of the physical structure and staffing of these facilities, there are no specific provisions which require the facility to be able to identify and meet the unique needs of the mentally handicapped.

Similarly, some of the institution-oriented physical standards and medically-based staffing requirements in the current Medicaid (ICF/MR) regulations governing mental retardation facilities ought to be amended, with due regard for the health and safety of beneficiaries, to allow for reasonable application to community residential facilities. The current HEW regulations provide an elaborate set of requirements, tailored to large, traditional mental retardation facilities, which must be met in order to allow Federal reimbursement for services provided to mentally retarded clients. Originally, such standards were to be met no later than March 18, 1977. However, on June 3, 1977, HEW amended the regulations, primarily to allow large State facilities until July 18, 1978 for correction of staffing deficiencies and to give them until July 18, 1980—and in some cases, until July 18, 1982—for correction of fire safety and other physical plant deficiencies. Such an extended period for correction of basic institutional shortcomings has the double drawback of permitting mentally retarded individuals to be maintained in substandard and even dangerous facilities for up to five more years and encouraging States to continue to invest huge sums of money in facilities which should more appropriately be phased out or greatly reduced in size.

HEW would be better advised to begin now to withdraw reimbursement from inadequate and unneeded institutions and to enforce existing admission and review requirements,[95] thus requiring States to plan for and implement movement of clients to less restrictive settings. States must not continue to be encouraged in the belief that the simplest—perhaps the only—way to qualify for Medicaid reimbursement for mental retardation services is to build "bigger and better" institutions.

The same kind of action is required with respect to other Federal programs, in order to ensure the availability of community resources and services for mentally handicapped individuals. For example, HEW should require (1) that States allocate a portion of their Title XX expenditures for the deinstitutionalization efforts of their mental health and mental retardation agencies and to prevention of future institutionalization of handicapped persons, and (2) that social support services necessary for comprehensive community care be a component of all State plans under Title XX. (If such a requirement cannot be imposed by regulation, the Administration should seek the necessary legislation.) Similarly, the regulations issued by HEW under the Developmentally Disabled Assistance and Bill of Rights Act,[96] which now merely parrot the general language of the statute, should be amended where appropriate,[97] to require emphasis on deinstitutionalization and prevention of future institutionalization and to prohibit expenditure of scarce Federal or other public funds on renovation or construction of inappropriate institutional facilities.

Just as the Federal government should take specific steps to facilitate deinstitutionalization for adults, so too it must assume more leadership on behalf of the deinstitutionalization of children. A major step in this direction would be to ensure that all federally funded out-of-home placements for children are in the least restrictive setting. In addition, there is a pressing need for an inter-agency examination of the

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[95] These requirements should be enforced in all programs for mentally handicapped persons which are financed by Medicare or Medicaid payments.

[96] 45 *C.F.R.* Parts 1385-1387.

[97] For example, 45 *C.F.R.* §§ 1386.17(b), 1386.42, 1386.43, 1386.47, 1386.48.

Federal role both within the Department of Health, Education, and Welfare (e.g., the National Institute of Mental Health and the Administration for Children, Youth and Families) and outside of it (e.g., the Law Enforcement Assistance Administration and the the Office of Juvenile Justice and Delinquency Prevention in the Department of Justice). The present lack of Federal leadership in this area should be corrected.

Finally, while the Panel does not possess the factual information necessary to evaluate every recommendation of the above-mentioned GAO report, we approve of the thrust of the GAO recommendations and believe the Federal government should proceed with a plan for their implementation. We acknowledge the establishment of a Task Force on Deinstitutionalization by the Secretary of Health, Education, and Welfare in October 1977 and urge cooperation by all other Federal departments in the efforts begun by this Task Force.

Recommendation 3.

> *Necessary steps should be taken to adapt and, where necessary, expand "generic" Federal programs so that they meet the needs of mentally handicapped individuals. Provision in the laws creating such programs which are designed to assist the mentally handicapped should be fully and promptly implemented.*

Commentary:

Existing Federal programs in such diverse areas as housing, vocational rehabilitation and aid for veterans and the elderly can, with proper emphasis, be a valuable source of assistance for mentally handicapped individuals. In many instances, they can mean the difference between institutionalization and life in the community for such individuals. The recommendation in the President's Commission's preliminary report (pp. 12-13) with regard to housing programs is an excellent example of how Federal funds and leadership could enhance the lives of mentally disabled persons.

Additionally, consideration should be given to steps to help prepare mentally disabled individuals for a vocational goal. For example, a longer period of training and a more structured learning situation may be necessary for the mentally disabled to acquire vocational skills and a longer period of post-employment services for such individuals may be necessary to assure that they maintain employment. The Panel feels that vocational rehabilitation programs, in general, have not been particularly responsive to mentally handicapped persons' needs and, like other generic programs, must be adapted to meet the needs of more severely disabled clients than they are accustomed to serving. We do applaud the recent amendments to the vocational rehabilitation legislation which mandate that if a State agency cannot serve all eligible individuals it must select first those individuals with the most severe handicaps.[98] But this provision is not in practice effectuated by the States. We believe that consideration must also be given to services oriented toward increasing the capacity for independent living of severely mentally handicapped persons who cannot be employed.

The Federal government should also require that State and area agencies funded under the Older Americans Act amendments[99] provide for an assessment of the needs of the mentally handicapped elderly and include services for this group in their development of community-based resources for the elderly. With regard to veterans, the Panel feels that the role of the Veterans' Administration in providing psychiatric services—particularly in administering psychiatric hospitals—should be carefully studied. VA institutions have already been criticized because of their remote locations and because of the artificiality of an environment made up almost exclusively of male, chronic patients.[100] In any event, the current practice of involuntary transfer or commitment of veterans in one State to a VA hospital in another State should be ended, by Federal and State statutory revision if necessary or by administrative action to the extent possible. The VA should use its resources to provide or pay for psychiatric services to veterans in locations as close as possible to their home communities or at least within their State of residence.

Recommendation 4.

> *Federal program and funding agencies should promptly promulgate and enforce regulations implementing section 504 of the Rehabilitation Act of 1973, which specifically prohibits discrimination against handicapped persons by any recipient of Federal funds.*

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[98] 29 *U.S.C.* 721 (a)(5)(A).

[99] See the Older Americans Act of 1965, as amended, Pub. L. 89-73, as amended. Under the amendments, the Administration on Aging within the Department of Health, Education, and Welfare is required to "develop plans, conduct and arrange for research in the field of aging, and assist in the establishment of and carry out programs designed to meet the needs of older persons for social services, including nutrition, hospitalization, pre-retirement training, continuing education, low-cost transportation and housing, and health services" (42 *U.S.C.* 3012(a)(4)). The Act also provides for grants or contracts for model projects to promote the well-being of older persons, with special consideration to programs that will "provide services to assist in meeting the particular needs of the physically and mentally impaired older persons including special transportation and escort services, homemaker, home health and shopping services, reader services, letter writing services, and other services designed to assist such individuals in leading a more independent life" (42 *U.S.C.* 3028(a)(4)). There is, however, no requirement that the State agency include an assessment of the needs of mentally ill older persons in the State plan (42 *U.S.C.* 3025).

[100] See "Health Care for American Veterans," Report of the Committee on Health-Care Resources in the Veterans' Administration, National Research Council, National Academy of Sciences. Washington, National Academy of Sciences, 1977.

Commentary:

Discrimination practices in education, employment, housing, transportation and other public and private services could be significantly curtailed if Federal agencies other than the Department of Health, Education, and Welfare (HEW) would promptly issue program-specific regulations, as HEW has already done, implementing section 504 with respect to the programs funded or supported by each such agency. Section 504, which prohibits discrimination in federally assisted programs on the basis of mental or physical handicap, was enacted more than four years ago; now that HEW has done the groundwork with its extensive 504 regulations, there is no reason why all other affected agencies should not be instructed to follow suit within 180 days.

Moreover, so that the full impact of section 504 can be realized, enforcement procedures should be specified and funds made available for their effectuation. We understand, for example, that until very recently the Office of Civil Rights (OCR) in HEW spent less than one percent of its time on section 504 enforcement and that there at present exists a three year backlog of complaints. More staff and fiscal resources are obviously necessary if OCR is to handle and address issues of systematic discrimination.

Recommendation 5.

> *There should be periodic program reviews of the utilization of federally funded benefits and services by the mentally handicapped in order to assess the quality and quantity of services provided and to determine their effectiveness in meeting the needs of the mentally handicapped and in promoting independent living.*

Commentary:

Facts available on the number of mentally handicapped individuals who are eligible for or receiving benefits from the various federally funded programs are inadequate to assess need for services or appropriate utilization. The lack of data also hampers program reviews to determine appropriateness and quality of services. An adequate data base should be established to provide the basis for periodic assessment of the effectiveness of these programs in meeting the needs of the handicapped and in providing them equal access to benefits, and for making necessary changes in program administration or legislation. Regular periodic reviews of programs and provider standards must focus on the effect of these programs and standards on the clients.

It would be tragic if the Panel's recommendations resulted in a mere redistribution of funds and of funding sources or solely in increasing the number of providers, but had no impact on improving actual patient/client care and treatment. Periodic program reviews should help to assure that reforms in Federal mental health benefit programs are focused directly on the ultimate beneficiaries of these services.

7-9. *The Right to Treatment and to Protection From Harm, The Right to Treatment in the Least Restrictive Setting and The Right to Refuse Treatment and the Regulation of Treatment*

Recommendation 1.

> *The President's Commission in its final report should endorse the underlying legal and ethical bases for the right to treatment and to protection from harm, the right to treatment in the least restrictive setting and the right to refuse treatment and the regulation of treatment. The Federal and State governments should be encouraged to protect these rights by legislation and other appropriate action.*

7. *The Right to Treatment and to Protection From Harm*

Commentary:

While the Supreme Court has not directly decided whether there is a constitutional right to treatment (for mentally ill persons) or to habilitation (for mentally retarded persons), the overwhelming weight of legal authority is that (at least) all involuntarily confined mental patients have a "constitutional right to receive such treatment as will give them a reasonable opportunity to be cured or to improve (their) mental condition" (*Wyatt v. Stickney*).[101] To fulfill this treatment right, a State must provide a humane physical and psychological environment, qualified staff personnel in sufficient numbers and individualized treatment or habilitation plans for each client.[102]

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[101] *Wyatt v. Stickney*, 325 *F. Supp.* 781, 784 (M.D. Ala. 1971), 334 *F. Supp.* 1341 (M.D. Ala. 1971), 344 *F. Supp.* 373 (M.D. Ala. 1972), 344 *F. Supp.* 387 (M.D. Ala. 1972), aff'd *sub. nom. Wyatt v. Aderholt*, 503 *F.*2d 1305 (5 Cir. 1974).

[102] *Wyatt*, 334 *F. Supp.*, at 1343. To satisfy these conditions, the *Wyatt* court ordered State officials to implement *detailed* sets of standards (developed from recommendations submitted by all parties and *amici curiae* in 25 different areas (mental health) and 49 areas (mental retardation), including environmental conditions, medical treatment, physical facilities, staff ratios, compensation for employment, treatment/habilitation plan specifications, nutritional requirements, and plans for transitional care). 344 *F. Supp.* at 379-386; 344 *F. Supp.* at 395-407. The *Wyatt* court also appointed a seven-member "human rights committee" for each affected institution to review "all research proposals and all treatment/habilitation programs to ensure that the dignity and human rights of residents are preserved," and to advise and assist residents who allege their legal rights have been infringed. 344 *F. Supp.* at 376; 344 *F. Supp.* at 392.

In affirming the trial court's ruling in *Wyatt*, the Fifth Circuit Court of Appeals relied largely on its decision several months earlier in *Donaldson v. O'Connor.*[103] The Fifth Circuit panel in *Donaldson* had noted:

> [P]ersons committed under what we have termed a *parens patriae* ground for commitment must be given treatment lest the involuntary commitment amount to an arbitrary exercise of government power proscribed by the due process clause . . . . The second part of the theory of a due process right to treatment is based on the principle that when the three central limitations on the government's power to detain—that detention be in retribution for a specific offense; that it be limited to a fixed term; and that it be permitted after a proceeding where fundamental procedural safeguards are observed—are absent, there must be a *quid pro quo* extended by the government to justify confinement. And the *quid pro quo* most commonly recognized is the provision of rehabilitative treatment, or, where rehabilitation is impossible, minimally adequate rehabilitation and care beyond the subsistence level custodial care that would be provided in a penitentiary.[104]

Donaldson surveyed the procedural contexts in which attacks on the nature of nonpenal confinement arose and found that there must be a *quid pro quo* for confinement in circumstances "where the conventional limitations of the criminal process are inapplicable."[105]

Although the *Donaldson* case was heard by the Supreme Court and was vacated and remanded on other grounds, this action should not be seen as an explicit or implicit rejection of the right to treatment rationale.[106] *Wyatt* has also been followed in other significant Federal cases, such as *Welsch v. Likins,*[107] *Davis v. Watkins,*[108] and *Gary W. v. State of Louisiana.*[109] It should also be noted that the constitutional right to treatment for involuntarily committed mental patients has re-

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[103] *Donaldson v. O'Connor*, 493 *F.*2d 507 (5 Cir. 1974), vacated and remanded on other grounds sub. nom. *O'Connor v. Donaldson*, 422 *U.S.* 563 (1975). See footnote 106, below.

[104] 493 *F.*2d at 521-522.

[105] *Id.* at 524.

[106] 422 *U.S.* 563 (1975). In the course of its opinion, the Supreme Court vacated the Court of Appeals' judgment which affirmed a jury verdict of both compensatory and punitive damages. In remanding the case for reconsideration only of the monetary damages issues, the Court noted that "our decision vacating the judgment of the Court of Appeals deprives that court's opinion of precedential effect, leaving this Court's opinion and judgment as the sole law of the case," *id.*, note 12, at 577. However, after its *Donaldson* decision, June, 1975, the Supreme Court denied *certiorari* in *Burnham v. Georgia*, 422 U.S. 1057 (1975), a companion case to *Wyatt v. Aderholt, supra*, in which the Fifth Circuit's *Donaldson* rationale for a right to treatment was explicitly reaffirmed. That rationale, as adopted in *Wyatt* and *Burnham*, accordingly remains the law of the Fifth Circuit.

[107] 373 *F. Supp.* 487, 493 (D. Minn. 1974), further proceedings at 550 *F.*2d 1122 (8 Cir. 1977).

[108] 384 *F. Supp.* 1196, 1203-1212 (N.D. Ohio 1974).

[109] *Gary W. v. Cherry*, sub nom. *Gary W. v. Louisiana*, 437 *F. Supp.* 1209 (E.D. La. 1976). But see *Morales v. Turman*, 562 *F.*2d 993 (5 Cir. 1977).

ceived an unusual amount of scholarly discussion and support.[110]

Mentally handicapped residents of institutions also have a constitutional right to protection from harm. This was the theory under which the consent decree was approved in the "Willowbrook" case, making clear that persons who live in State mental institutions are owed certain affirmative constitutional duties by the State and its officials.[111] While consent decrees ordinarily have little precedential effect, the impact of the *Willowbrook* decree was substantially enhanced when the court issued a formal order ratifying the decree and an additional memorandum discussing its constitutional basis. In this memorandum the late Judge Orrin B. Judd noted that:

> During the three-year course of this litigation, the fate of the mentally impaired members of our society has passed from an arcane concern to a major issue both of constitutional rights and social policy. The proposed consent judgment resolving this litigation is partly a fruit of that process.
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> * * *
>
> [The steps, standards and procedures in the consent decree] are not optimal or ideal standards, nor are they just custodial standards. They are based on the recognition that retarded persons, regardless of the degree of handicapping conditions, are capable of physical, intellectual, emotional and social growth, and . . . that a certain level of affirmative intervention and programming is necessary if that capacity for growth is to be preserved, and regression prevented.
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> * * *
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> The consent judgment reflects the fact that protection from harm requires relief more extensive than this court originally contemplated, because harm can result not only from neglect but from conditions

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[110] The first articulation of the right is found in Birnbaum, "The Right to Treatment," 46 *A.B.A.J.* 499 (1960). In the last 15 years more than 50 law review articles have been published on the subject, virtually all of them supporting a constitutional right to treatment or release for the involuntarily confined. *See, e.g.*, Comment, "Developments in the Law—Civil Commitment of the Mentally Ill," 87 *Harv. L. Rev.* 1190 (1974).

Note also that in addition to the due process basis, the constitutional right to treatment is also seen as resting on the cruel and unusual punishment clause (found specifically applicable to mental hospitals in *Rozecki v. Gaughan*, 459 *F.*2d 6 (1 Cir. 1972), and developed in the context of jail and prison conditions suits).

Although criteria for measuring the "adequacy" of treatment have not been specifically articulated by the courts, it has been suggested by respected commentators that "effectiveness" is a reasonable standard, and that such adequacy must be determined by "an inquiry into the adequacy of the *individual's* treatment." Halpern, "A Practicing Lawyer Views the Right to Treatment," 57 *Geo. L.J.* 782, 792 (1969) (emphasis added). See also Schwitzgebel, "Right to Treatment for the Mentally Disabled: The Need for Realistic Standards and Objective Criteria," 8 *Harv. Civ. Rights—Civ. Lib. L. Rev.* 513, 520 (1973) and, generally, Sadoff, Cohen and Cohen, "Right to Treatment," 3 *Bull. Am. Acad. Psych. & L.* 59 (1975). Cf. Birnbaum, "A Rationale for the Right," 57 *Geo. L.J.* 752 (1969). And see Hoffman and Dunn, "Beyond *Rouse* and *Wyatt*: An Administrative-Law Model for Expanding and Implementing the Mental Patient's Right to Treatment," 61 *Va. L. Rev.* 207, 303-10 (1975).

[111] *New York State Association for Retarded Children v. Rockefeller*, 357 *F. Supp.* 752 (E.D.N.Y. 1973); *New York State Association for Retarded Children v. Carey*, No. 72-C-356/357 (E.D.N.Y., April 30, 1975), *approved* 393 *F. Supp.* 715 (E.D.N.Y. 1975) [hereinafter *NYSARC*].

> which cause regression or which prevent development of an individual's capabilities.[112]

The court held, in effect, that relief very much like the *Wyatt* Standards—but with a greater emphasis on deinstitutionalization and community-based residential and habilitation programs—was required by the Eighth Amendment for mentally retarded persons under State custody, regardless of whether the incarceration was characterized as "voluntary" or "involuntary."

At a minimum, as the Third Circuit has noted:

> It is far too late in the game for the serious assertion of the proposition that the federal Constitution is not implicated with respect to the physical conditions to which a state subjects persons it chooses to confine by virtue of a civil or criminal judgment of commitment.[113]

Among the rights owed to institutionalized patients or residents under even the most limited reading of the Eighth and Fourteenth Amendments are "a tolerable living environment," protection from physical harm, correction of conditions which violate "basic standards of human decency," the opportunity to exercise and participate in recreation and the "necessary elements of basic hygiene."[114] Additionally, patients and residents are owed a duty by those charged with their custody "to preserve . . . [their] life, health and safety beyond any duty owed to the general public."[115] Clearly, their confinement must be therapeutic, not punitive.[116]

In addition to prohibitions on certain *physical* intrusions, psychological oppression and acts causing mental distress are similarly within the proscription of the Eighth Amendment. The Second Circuit recently noted, "psychological oppression is as much to be condemned as physical abuse, and this Court has previously determined that acts causing mental suffering can—even absent attendant body pain—violate the Eighth Amendment."[117]

Even if there were not a Federal constitutional right to treatment or to protection from harm, States would be free to create such a right by statute. In fact, a number of States now provide a statutory right to

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[112] 393 *F. Supp.* at 716-718.

[113] *Scott v. Plante*, 532 *F.*2d 939, 947 (3 Cir. 1976).

[114] See, for example, *NYSARC, supra*, 357 *F. Supp.* at 764, 765 (tolerable living environment, basic hygiene); see also such prison cases as *Hamilton v. Love*, 328 *F. Supp.* 1182 (E.D. Ark. 1971) (protection from physical harm); *Brenneman v. Madigan*, 343 *F. Supp.* 128, 133 (N.D. Cal. 1972) (basic standards of human decency); *Hamilton v. Schiro*, 338 *F. Supp.* 1016, 1017 (E.D. La. 1970) (exercise and recreation).

[115] *Roberts v. State*, 307 N.E.2d 501, 505 (Ind. Ct. App. 1974).

[116] *Kesselbrenner v. Anonymous*, 33 *N.Y.*2d 161, 350 N.Y.S.2d 889, 892 (Ct. App. 1973).

[117] *United States ex rel Shuster v. Vincent*, 524 *F.*2d 153, 160 (2 Cir. 1975). The recent Supreme Court decision in *Ingraham v. Wright*, 430 *U.S.* 651 (1977), generally limiting the protection of the Eighth Amendment to persons convicted of a crime, left a specific exception for involuntarily institutionalized individuals.

treatment or protection from harm either for persons involuntarily committed to State mental institutions or for all persons residing in such institutions. Another basis for a right to treatment is an ethical obligation, translated into actuality by allocations of fiscal resources for mental health purposes. It is the consensus of the Panel that society in general has an ethical duty to provide adequate and effective services for all mentally handicapped persons in need of them including voluntary as well as involuntary patients. The rationale for this ethical obligation is the notion that society may ultimately be measured in a moral sense from the way it treats its most vulnerable and disadvantaged citizens.

Models for statutory rights to treatment and protection from harm include recent enactments from Florida and Wisconsin.[118]

Fla. Stat. Ann §394.459(1), (2), (4)(a):

> Right to treatment—The policy of the state is that the department shall not deny treatment for mental illness to any person, and that no services shall be delayed at a receiving or treatment facility because of inability to pay.
>
> Quality of treatment—Each patient in a facility shall receive treatment suited to his needs, which shall be administered skillfully, safely, and humanely with full respect for his dignity and personal integrity. Each patient shall receive such medical, vocational, social, educational, and rehabilitative services as his condition requires to bring about an early return to his community. In order to achieve this goal the department is directed to coordinate the programs of the division with all other divisions of the department.

Wis. Stat. Ann. 51, 61 (1)(m):

> [All patients] have a right to a humane psychological and physical environment within the hospital facilities. These facilities shall be designed to afford patients with comfort and safety, to promote dignity and ensure privacy. Facilities shall also be designed to make a positive contribution to the effective attainment of the treatment goals of the hospital.[119]

It is also suggested that State laws include specific language applicable to mentally retarded persons—for example, the current New Jersey provision:

N.J.S.A. 30:6D-9:

> Every service for persons with developmental disabilities offered by any facility shall be designed to maximize the developmental poten-

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[118] If the Commission recommends relatively simple language such as that in the statutes cited herein, it is suggested that a relatively lengthy commentary accompany such a recommendation, in order to underscore the significance of the rights involved.

[119] This section of the Wisconsin law, however, is subject to denial or limitation following an administrative hearing subject to court review. *Wis. Stat. Ann.* 51.61(3). It is recommended that such limitations *not* be permitted by the States.

> tial of such persons and shall be provided in a humane manner in accordance with generally accepted standards for the delivery of such service and with full recognition and respect for the dignity, individuality and constitutional, civil and legal rights of each person receiving such service, and in a setting and manner which is least restrictive of each person's personal liberty.

In the past several years Congress has exhibited a heightened awareness of the vulnerability of mentally handicapped citizens and of their need for Federal protection. For example, section 201 of the Developmentally Disabled Assistance and Bill of Rights Act[120] states, "Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities," and "the Federal government and the States both have an obligation to assure that public funds are not provided to any institution or other residential programs for persons with developmental disabilities that . . . does not provide treatment, services, and habilitation which is appropriate to the need of such persons."

Implementation of specific treatment standards could be facilitated at the Federal level by making adherence to such standards a requirement for receipt of Federal funds, as is now done to some extent under the Medicaid and Medicare programs.[121]

8. *The Right to Treatment in the Least Restrictive Setting*

Commentary:

The principle of the "least restrictive alternative" has been invoked by courts when they are informed of governmental actions that infringe basic individual rights rooted in the First, Fourth, Fifth, Eighth, Ninth and Fourteenth Amendments. The basic rights capable of triggering an inquiry into whether governmental limitations are consistent with the "least restrictive alternative" principle have included freedom of association, freedom to travel, freedom to practice one's religion, freedom to exercise the franchise and privacy between marriage partners.[122] Once a court determines that a basic right has been infringed by governmental action, the next inquiry is whether the government has demonstrated a "compelling state interest" to justify the infringement, and whether the means chosen to vindicate such a com-

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[120] 42 U.S.C. § 6010, Public Law 94-103.

[121] See, for example, 45 C.F.R. §§ 249.12 and 249.13.

[122] *Shelton v. Tucker*, 364 *U.S.* 479 (1960) (association); *Aptheker v. Secretary of State*, 378 *U.S.* 500 (1964) and *Shapiro v. Thompson*, 394 *U.S.* 618, 637 (1969) (travel); *Sherbert v. Verner*, 374 *U.S.* 398, 407 (1963) (religion); *Carrington v. Rash*, 380 *U.S.* 89, 96-97 (1965) (franchise); *Dunn v. Blumstein*, 405 *U.S.* 330, 335-337 (1972), and *Griswold v. Connecticut*, 381 *U.S.* 479, 485-486 (1975) (privacy between marriage partners).

pelling interest are the least restrictive of personal liberty consistent with the particular governmental objectives.

The Supreme Court in *O'Connor v. Donaldson*,[123] discussed earlier under the right to treatment, by expressly citing *Shelton v. Tucker*,[124] acknowledged the appropriateness of applying the principle of the "least restrictive alternative" to involuntary commitments. The constitutional principle holds that: "[E]ven though the government purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle fundamental personal liberties when the end can be more narrowly achieved."[125]

The applicability of the doctrine of the least restrictive alternative to the circumstances of the civilly committed mental patient becomes immediately apparent when the massive curtailments of personal rights and liberties inherent in civil commitment are considered. Thus, when a person is committed to a psychiatric hospital, his/her constitutionally protected rights to travel and freely associate with others are inevitably curtailed, and protected rights to peacefully assemble, communicate, practice religion and enjoy sexual privacy are likewise constricted. And, of course, s/he is in danger of losing "the most basic and fundamental right . . . the right to be free from unwanted restraint."[126]

In the civil commitment context, the applicability of the doctrine is two-fold in nature:

> the recognition of an affirmative state obligation to require a search for alternatives to institutional commitment *ab initio* . . . [and] . . . a . . . duty . . . to limit confinement to the least restrictive institutional setting and to discharge the committed patient outright, or to less restrictive community treatment alternatives, once continued institutionalization could no longer be therapeutic.[127]

Thus, "committing courts and agencies must refrain from ordering hospitalization whenever a less restrictive alternative will serve as well or better the State's purposes."[128] And, in at least six cases, it has been held that the Federal Constitution requires an affirmative demonstration that no suitable less restrictive alternative exists prior to involuntary hospitalization.[129]

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[123] 422 *U.S.* 563, 575 (1975).

[124] 364 *U.S.* 479 (1960), cited at 422 *U.S.* at 575.

[125] 364 *U.S.*, above, at 488.

[126] *Lessard v. Schmidt*, 349 *F. Supp.* 1078 (E.D. Wis. 1972), vacated on other procedural grounds, 414 *U.S.* 473 (1974), on remand 379 *F. Supp.* 1376 (E.D. Wis. 1974), vacated and remanded on procedural grounds 421 *U.S.* 957 (1975), reinstated 413 *F. Supp.* 1318 (E.D. Wis. 1976).

[127] Saphire, "The Civilly Committed Public Mental Patient and the Right to Aftercare," 4 *Fla. St. U.L. Rev.* 232, 280-281 (1968).

[128] Chambers, "Alternatives to Civil Commitment of the Mentally Ill: Practical Guides and Constitutional Imperatives," 70 *Mich. L. Rev.* 1108, 1145 (1972).

[129] *Lessard v. Schmidt*, above; *Covington v. Harris*, 419 *F.*2d 617, 623 (D.C. Cir. 1969);

In holding that patients already committed have a constitutional right to treatment geared to curing or improving their mental conditions, the *Wyatt* court included the least restrictive alternative doctrine among the mandatory minimum constitutional standards for adequate treatment.[130] The State was required not only to provide institutional treatment in the least restrictive setting, but also to provide "adequate transitional treatment and care for all patients released after a period of involuntary confinement."[131] Similarly, in *Davis v. Watkins*,[132] in addition to instituting a periodic review system for each patient's treatment plan, the court specified that such plans must provide for treatment in the least restrictive setting while the individual is confined, as well as preparation of pre-release and transitional treatment plans for the individual patient.

In *Gary W. v. Louisiana*,[133] the court made clear that the concept of the least restrictive alternative applies to children who are in State custody but not in mental hospitals. In that case the plaintiffs were mentally handicapped children who were placed by the State of Louisiana in Texas institutions. The judge in his ruling noted:

> . . . What is proper for a particular child includes consideration not only of whether the child should be placed in an institution or treated in the community; it also includes consideration of the kind and geographic location of the institution or place of treatment . . . . The persons preparing the treatment plans for each child will be required to consider the least restrictive alternative for that child . . . .[134]

The legally protected right to treatment in the least restrictive setting necessary was recently reaffirmed in *Dixon v. Weinberger*.[135] There the plaintiff class—patients confined in a federally administered mental institution in Washington, D.C.—raised both statutory and constitutional grounds for the relief sought, *i.e.*, "a judicial declaration that under the 1964 Act[136] they have a right to treatment which includes placement in facilities outside St. Elizabeths Hospital where such placement is determined to be consistent with the rehabilitative purposes of the 1964 Act . . . ."[137] Plaintiffs sought to impose a duty on defendants

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Dixon v. Attorney General of Commonwealth of Pennsylvania, 325 *F. Supp.* 966, 974 (M.D. Pa. 1971); *Wyatt v. Stickney*, 344 *F. Supp.* 373, 379 and 387, 396; *Welsch v. Likins*, 373 *F. Supp.* 487 at 501-502 (D. Minn. 1974); *Lake v. Cameron*, 364 *F.*2d 657 (D.C. Cir. 1966).

[130] 344 *F. Supp.*, above, at 379.

[131] *Id.* at 386.

[132] 384 *F. Supp.* 1196, 1197 (N.D. Ohio 1974).

[133] *Gary W. v. Cherry*, sub nom. *Gary W. v. State of Louisiana*, 437 *F. Supp.* 1209 (E.D. La. 1976).

[134] *Id.* at 1219.

[135] 405 F. Supp. 974 (D.D.C. 1975).

[136] The District of Columbia Hospitalization of the Mentally Ill Act, 21 D.C. Code § 501 *et seq.*

[137] 405 *F. Supp.* at 976.

to "initiate a plan for the development of alternative facilities and the placement of appropriate individuals therein."[138] Although the court deemed it unnecessary to reach the constitutional grounds, in light of the explicit right to treatment provided in the District of Columbia statute, "suitable care and treatment in light of present knowledge" was held to include placement in alternative facilities and, significantly, to create such facilities if they did not presently exist.

As with the right to treatment, there would be strong ethical and social policy reasons for adopting the principle of the least restrictive alternative even if there were no statutory or constitutional basis for this important principle. In fact, long-standing Federal policy has favored deinstitutionalization wherever possible.[139] In view of this well accepted Federal policy, it is ironic that the Department of Health, Education, and Welfare continues to be in violation of the *Dixon* court's order some two years after HEW, along with the District of Columbia government, was charged with implementing that decision. The Panel, therefore, urges that HEW promptly take all actions necessary to implement the *Dixon* ruling and to extend its application to all relevant Federal programs.

9. *The Right to Refuse Treatment and the Regulation of Treatment*

Commentary:

While a strong consensus has emerged concerning the rights to treatment and to protection from harm and to treatment in the least restrictive setting, discussed immediately above, the Panel recognizes that significant controversy exists in academic, mental health professional, judicial and public circles as to the "right to refuse treatment" and the issue of regulation of treatment.[140] Traditionally, decisions about therapies or medical procedures have been within the unfettered

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[138] *Id.*

[139] See, for example, the Community Mental Health Centers Act, 42 *U.S.C.* § 2689 *et seq.*: Grants to States for Comprehensive Public Health Services, 42 *U.S.C.* 246(d)(2)(D); reports of the Joint Commission on Mental Illness and Health, especially its final report, *Action for Mental Health.* New York: Basic Books, 1961.

[140] *Cf.* Staff of the Subcommittee on Constitutional Rights of the Senate Committee on the Judiciary, 93d Congress, 2d session, "Individual Rights and the Federal Role in Behavior Modification," (1974); "Note, Conditioning and Other Technologies Used to 'Treat'? 'Rehabilitate'? 'Demolish'? Prisoners and Mental Patients," 45 *S. Cal. L. Rev.* (1972); Shapiro, "Legislating the Control of Behavior Control: Autonomy and the Coercive Use of Organic Therapies," 47 *S. Cal. L. Rev.* 237 (1974); Friedman, "Legal Regulation of Applied Behavior in Mental Institutions and Prisons," 17 *Ariz. L. Rev.* 39 (1975); and Perlin, "The Right to Refuse Treatment in New Jersey," 6 *Psych. Annals* 300 (1976), with Treffert, "Dying With Your Rights On," (unpubl. paper presented at annual meeting of American Psychiatric Association, May 1974); Treffert, "Dying With Their Rights On," *Prism* (1974), at 47, as cited in Hoffman, "Living With Your Rights Off," in Bonnie, ed., *Psychiatrists and the Legal Process: Diagnosis & Debate* 231, 236 (1974); Rachlin, "One Right Too Many," 3 *Bull. Am. Acad. Psych. & L.* 95 (1975). See also Brooks, "The Right to Refuse Treatment," *Administration in Mental Health*, Vol. 4 No. 2, pp. 90-95 (1977).

discretion of the treatment professional responsible for a patient's or client's program. Recently, however, concern has arisen about imposition of potentially hazardous or intrusive procedures upon objecting recipients. As a result, attempts have been made to sketch out the situations in which even involuntary mental patients might refuse particular treatments or, alternatively, in which outside regulation and scrutiny of such procedures (including "customary" procedures such as psychotropic drugs) is required.

The right to refuse treatment stems from a composite of bases including the constitutional rights to freedom from harm, freedom of speech and thought, and personal privacy.[141] Advocates seeking to establish limitations upon forced therapy have brought cases challenging appalling situations— for example, that of patients who were subjected to the use of apomorphine, administered as part of an "aversive conditioning program . . . for not getting up, for giving cigarettes against orders, for talking, for swearing, or for lying,"[142] or that of other fully conscious patients whose breathing was temporarily stopped with succinylcholine as part of "aversive treatment."[143] The Eighth Circuit Court of Appeals ruled, in the apomorphine case, that the unconsented treatment violated the "cruel and unusual punishment" clause of the Eighth Amendment and the Ninth Circuit held that, if proved, the nonconsensual use of succinylcholine could raise "serious constitutional questions respecting cruel and unusual punishment or impermissible tinkering with mental processes."

Similarly, in the course of an opinion reversing a decision by a Federal district court which had dismissed a patient's *pro se* complaint alleging that he had been involuntarily medicated, the Third Circuit found "at least three conceivable constitutional deprivations that may accompany the involuntary administration of such substances by State officers acting under color of law to inmates of a state institution."[144] These included interference with the patient's First Amendment right to freedom of speech and association because of the potential effect of such drugs on his mental processes; deprivation of procedural due process in that the patient had not been given notice and a hearing to determine if he wanted to object to such treatment; and, "under certain circumstances," a possible claim under the Eighth Amendment's cruel and unusual punishment clause.[145]

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[141] See, for example, *Rozecki v. Gaughan*, 459 F.2d 6 (1 Cir. 1972), and *Kaimowitz v. Michigan Dept. of Mental Health*, No. 73-19434-AW, 42 *U.S.L.W.* 2063 (Mich. Cir. Ct., July 10, 1973).

[142] *Knecht v. Gillman*, 488 *F.*2d 1136, 1140 (8 Cir. 1973).

[143] *Mackey v. Procunier*, 477 *F.*2d 877, 878 (9 Cir. 1973).

[144] *Scott v. Plante*, 532 *F.*2d 939, 946 (3 Cir. 1976). The patient had received thorazine, compazine, mellaril, vesprin and trilofan during the course of his hospitalization.

[145] The court also pointed out that there might be a "fourth" deprivation regarding invasion

It is clear, then, that the mere characterization of a procedure as "treatment" will not insulate it from judicial scrutiny, especially when extreme or unusual intrusions are involved.[146]

For a consent to a therapy or medical procedure to be valid, it must be competent, knowing and voluntary. A mentally handicapped person may lack the competency or capacity to consent if he cannot understand the nature and consequences of a proposed procedure, or if for certain other reasons he cannot manifest this consent. For consent to be "knowing," a person should have all the information concerning the proposed procedure which he reasonably needs in order to make an intelligent decision. Such information would certainly include: the nature of the proposed procedure; its likelihood of success; the likelihood, nature, extent and duration of any positive impacts, harms or side effects; the reasonable alternative procedures available; and an explanation as to why the specific procedure recommended is the procedure of choice. In order to assure that the decision is truly voluntary, the person should be informed orally and in writing that no benefits or penalties will be contingent upon his agreement or refusal to undergo the proposed procedure. More specifically, there must be an explicit oral and written understanding by an institutional resident that his consent is not a precondition for release from the institution, that his decision should not be made to obtain approval from or to avoid reprisals by the staff and that he is free to withdraw consent at any point, without penalty.

Not everyone agrees that patients should have a right to refuse hazardous or intrusive treatments, even assuming agreement on which treatments fall within this category. But even many of those persons who question the concept of a right to refuse treatment recognize that there are problems, for example, of abuse or excessive use of psychotropic drugs and that there is a need for regulation of such procdures. Although most procedures remain unregulated by statute, a number of

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of a patient's "right to bodily privacy," but noted that the scope of such a right remains "ill-defined." *Id.* at 946, n.9.

[146] Varying proposals have been made as to the degree of scrutiny required, including, *e.g.*, the need for a ten-point consent form to be signed prior to the imposition of psychosurgery, Spoonhouse, "Psychosurgery and Informed Consent," 26 *U. Fla. L. Rev.* 432, 452 (1974), expansion of the list of therapies that should not be permitted prior to a hearing, Stone, *Mental Health and Law*: A System in Transition, DHEW Pub. No. (ADM) 75-176, U.S. Government Printing Office, Washington, D.C., 1975, p. 105, an analysis of "the degree of intrusiveness" and the "severity of its effects upon cognitive facilities" of potentially dangerous treatment, "Developments—Civil Commitment of the Mentally Ill," 87 *Harv. L. Rev.* 1190, 1345 (1974), a hierarchy of human needs based on Maslow's motivational theories, Note, "The Right Against Treatment: Behavior Modification and the Involuntarily Committed," 23 *Cath. U.L. Rev.* 774, 780-84 (1974), and a sliding scale of acceptability of therapeutic techniques through which a court would weigh competing factors on a "hierarchy of legitimacy," Gobert, "Psychosurgery Conditioning, and the Prisoner's Right to Refuse Rehabilitation," 61 *Va. L. Rev.* 155, 193-95 (1975). See generally, Friedman, *supra* note 140 and Perlin, *supra* note 140.

States have recently passed laws which limit the imposition of certain treatment procedures by requiring the informed consent of persons in institutions. The most frequently regulated procedures are psychosurgery and electroconvulsive therapy.[147] Administrative rules and regulations may also provide a basis for a right to refuse treatment.[148] Because States have differing statutes, rules and regulations, it is impossible to generalize as to the future, but it is clear that there is a trend toward increased regulation.

Obviously, the balance between legal and medical judgments is delicate with respect to choice of treatment. A useful clarification appears in a district court order regulating hazardous and intrusive procedures.

> It must be emphasized at the outset of this order that, in setting forth the minimum constitutional requirements for the employment of certain extraordinary or potentially hazardous modes of treatment, the Court is not undertaking to determine which forms of treatment are appropriate in particular situations. Such a diagnostic decision is a medical judgment and is not within the province, jurisdiction or expertise of this Court. But the determination of what procedural safeguards must accompany the use of extraordinary or potentially hazardous modes of treatment on patients in the state's mental institutions is a fundamentally legal question.[149]

Although reduction to specific statutory language is difficult, it is suggested that the following concepts be adopted:

1. During the period preceding a formal commitment hearing, a patient should have an absolute right to refuse treatment of any sort unless the patient is endangering his/her own life or the lives of others; provided, however, that no intrusive treatment should be imposed unless less restrictive means of treatment have been exhausted without success.

2. A voluntary patient should have the absolute right to refuse treatment, and there should be a meaningful spectrum of choices of potential treatments for such patients.

3. No involuntarily committed patient should be given any of the following treatments over his or her objection, at least without a due process hearing (there was disagreement on the Panel as to whether this

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[147] See, e.g., Note, "Regulation of Electroconvulsive Therapy," 75 *Mich. L. Rev.* 363 (1976); *Price v. Sheppard*, 239 N.W.2d 904, 908 (Minn. Sup. Ct. 1976); and *In re W.S.*, 152 N.J. Super. 398, 405-07, 377 A.2d 969 (Cty. Ct. 1977).

[148] See, e.g., "Guidelines for Psychotropic Drugs as Used by the Michigan Department of Mental Health," Michigan Department of Mental Health, 1977, and Michigan Department of Mental Health Administrative Manual, Chapter 4 Section 005 Subject 0002 (Psychotropic Drugs), October 6, 1976.

[149] *Wyatt v. Hardin*, Unpublished Order, Civil No. 3195-N (M.D. Ala., Feb. 28, 1975).

hearing should be before a judge or an administrative official or committee):

a. Electroshock therapy or any other convulsive therapy;

b. Coma or subcoma insulin therapy;

c. Behavior modification utilizing aversive therapy;

d. Inhalation therapy (CO^2, etc.);

e. Medically prescribed, highly addictive substances (e.g., methadone).[150]

4. An involuntarily committed but competent patient shall have the right to refuse medication unless the patient is an imminent danger to himself/herself/ or others.[151] If an involuntarily committed patient who is also incompetent expresses a desire to refuse medication, there should be a due process hearing—on short notice—to determine the need for such medication, in light of the factors set forth at "5" below.

5. At any due process hearing held in accordance with this section, the patient shall be physically present, represented by counsel and provided the right and opportunity to be confronted with and to cross-examine all witnesses alleging the necessity of such procedures. In the event that a patient cannot afford counsel, the court shall appoint an attorney not less than 10 days before the hearing.* At such a hearing, the court should consider all "treatment variables." Such variables would include the patient's legal status (as to issues of voluntariness and competency in both law and fact), the treatment setting, the modality of treatment, the motivation of the treater, the circumstances of the treatment, the intrusiveness of the treatment, the existence of legislative limitations, whether the patient is an inpatient or outpatient, the irreversibility of the treatment, the qualifications of the treater (whether he or she is a mental health professional), whether such treatment is lifesaving or not (and if it is, whether it is the patient's life or another's involved), whether the treatment is psychiatric or "medical" (*e.g.*, nonpsychiatric drug administration or surgery), and whether or not the situation is characterized as an emergency (again, both in fact and in

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[150] The Panel recommends that psychosurgery—which is considered highly dangerous and experimental—not be used in institutions and that it should be used elsewhere, if at all, only with the informed consent of the subject. See generally Section III. 10, "Experimentation with Mentally Handicapped Subjects," below. In addition, the courts have placed substantial, as well as consent-related, limits on such techniques as aversive conditioning and ECT. See *Wyatt v. Hardin*, supra.

[151] In the latter case, there should be a hearing mechanism which can be triggered on short notice at the request of the patient or his advocate.

* At least two panel members disagree with several aspects of these recommendations, believing in particular that having a second due process hearing after the initial commitment is excessively cumbersome and would result in unnecessary delay of treatment. They believe that treatment questions should be adjudicated at the time of the "initial" due process hearing. While they have no problem with the right to refuse ECT or psychosurgery, they have strong reservations about the right to refuse medications.

law).[152] Additionally, testimony should be taken as to all available alternatives to the treatment in question, as well as the potential efficacy, risk and restrictiveness of such treatment.

10. *Experimentation With Mentally Handicapped Subjects*

Recommendation 1.

> *An educational campaign must be directed to the general public with regard to individual opportunity and obligation to participate in the advancement of scientific knowledge. A disproportionate share of the risk for the benefit of society as a whole should not be assigned to "convenient"—often institutionalized—populations, including mentally handicapped individuals. Rather, to the extent possible, such persons should bear* less *risk than those who are more able to make free and uncoerced decisions.*

Commentary:

Everyone recognizes the importance of research in advancing our knowledge about the causes, prevention and techniques for curing or ameliorating mental handicaps. But news reports continue to remind us of excesses—sanctioned if not actually devised by governmental authorities—in the area of experimentation with human subjects. The history of abuses in experimentation includes several chapters involving institutionalized mentally disabled persons, such as the infamous Willowbrook (New York) hepatitis experiments (deliberate exposure of retarded children to hepatitis, on the basis of coerced parental consent); a similar but lesser known Willowbrook project using residents to test an ineffective shigella vaccine; the unconsented pneumonia, flu and meningitis experiments on residents of two State institutions in Pennsylvania; and the routine administration of Depo-Provera, an experimental and potentially harmful medication, to the female residents of mental institutions in Tennessee and elsewhere.[153] Such a recitation should also include the experimental psychosurgery, under the auspices of the State of Michigan, which was enjoined by the court in the case of *Kaimowitz* v. *Department of Mental Health*.[154]

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[152] See, generally, Perlin, 6 *Psych. Annals*, above, at 304.

[153] Goldby, S., "Experiments at the Willowbrook State School," 1 *The Lancet* 749 (1971); testimony of Dr. Max Werner, December 12, 1974, *New York State Association for Retarded Children and Parisi v. Carey*, No. 72-C-356/357 (E.D.N.Y.); "Kids Used as Guinea Pigs," *Pittsburg Post Gazette*, April 14, 1973; hearings, "Quality of Health Care—Human Experimentation, 1973," Subcommittee on Health, Senate Committee on Labor and Public Welfare, February 21-22, 1973.

[154] No. 73-19434-AW (Cir. Ct. of Wayne County, Mich., July 10, 1973).

On the other hand, such incidents actually represent a small deviation, so far as is known, from the general run of responsible and useful—or at least not harmful—experimentation with mentally disabled and other human subjects.[155] There is no question that some kinds of biomedical and behavioral research are necessary for continued advances in the diagnosis, prevention and treatment of mental and physical disabilities. Moreover, in the absence of a systematic approach, every patient or client becomes an experiment—yet nothing new is learned. Many drugs and procedures in current use are not considered experimental and are assumed to be of value simply because of familiarity or custom; but the only way truly to evaluate the effectiveness of these measures is through controlled clinical research.[156]

The basic issue, then, is the extent to which persons who have been deprived of their personal liberty on the basis of their alleged mental disability, or whose ability to give free and informed consent is otherwise questionable, should bear the burden of scientific progress on behalf of society as a whole. This issue is not just one of ethics. Where the individuals involved are in State institutions or confined pursuant to State law or where the research is conducted, supported or regulated by government agencies, it is also one of constitutional right.[157]

Persons confined to mental institutions are not incarcerated for the purpose of providing investigators with a captive population of research subjects, but rather to receive whatever services are necessary to enable them to return to society as quickly as possible.[158] Most institutions in the country, especially the large public institutions, are hard pressed to meet even minimal standards for safety, sanitation, staffing and habilitative and rehabilitative programs, and are hardly in a position to meet the increased demands imposed by the conduct of research projects. Moreover, such projects, if initiated, tend to attract concentrations of the best and most motivated institutional personnel (and the "best" patients or clients as well), to the detriment of patients or clients excluded from research projects as well as those subjected to the experimentation.

Because institutions are by nature removed from direct familial and public scrutiny, the potential for research abuses, intentional or

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[155] See Cardon *et al.* "Injuries to Research Subjects, A Survey of Investigators," 295 *New Eng. Jour. of Med.* 650 (1976).

[156] See remarks of Eisenberg, L., in Experiments and Research with Humans: Values in Conflict, at 96 (Washington, D.C. 1975).

[157] See *Knecht v. Gillman*, 488 *F.*2d 1136 (8th Cir. 1973); *Mackey v. Procunier*, 477 *F.*2d 877 (9 Cir. 1973); *Kaimowitz v. Department of Mental Health*, No. 73-19434-AW (Cir. Ct. of Wayne County, Mich., July 10, 1973). *Cf. Rochin v. California*, 342 U.S. 165 (1952); Schloendorff v. Society of New York Hospitals, 211 N.Y. 125, 105 N.E. 92 (1914).

[158] See *O'Connor v. Donaldson*, 422 U.S. 563 (1975); *Wyatt v. Stickney*, 344 *F. Supp.* 373 and 387 (M.D. Ala. 1972). aff'd sub nom. *Wyatt v. Aderholt*, 503 *F.*2d 1305 (5 Cir. 1974).

not, cannot be discounted. Finally, patients or clients in institutions may not be able to give truly informed consent to participate in experimentation, both because of their presumably disabled condition and because of the well-recognized coercive effects of institutionalization itself.

Recommendation 2.

> *(a) Covert experimentation involving risks ought never to be permitted, regardless of the asserted justification, and full disclosure of such matters as research risks, expected benefits and the right to refuse participation must be made to potential subjects and, where appropriate, to their parents, surrogate parents or legal guardians.*
>
> *(b) Experimentation which is neither directly beneficial to individual subjects nor related to such subjects' mental condition and which poses any degree of risk to such subjects should not be permitted with institutionalized mentally handicapped individuals.*
>
> *(c) Research performed for the direct benefit of a mentally handicapped subject after nonexperimental procedures, if any, have been exhausted should be permitted where the risk/benefit ratio is favorable and there are adequate procedures for obtaining the subject's consent or, where appropriate, the consent of the subject's parent, parent surrogate or legal guardian. High-risk experimental procedures such as psychosurgery should be permitted, if at all, only upon the informed consent of the subject himself; some such procedures ought to be prohibited altogether, at least with respect to institutionalized individuals.*

Commentary:

Covert experimentation, especially upon mentally handicapped individuals in institutions or the community, has no place in an ethical society. Nor, the Panel feels, does experimentation with institutionalized mentally handicapped persons which does not benefit them directly or relate to the prevention, diagnosis or treatment of their mental condition. There is no acceptable reason for testing a hepatitis or shigella vaccine, for example, on an institutionalized mentally disabled population when such physical ailments are not peculiar to mentally handicapped individuals and can be identified or induced as readily in experiments with subjects whose capacity and autonomy are not open to question.

On the other hand, research designed to improve an individual mental condition which has not responded to standard techniques ought to be permitted, with proper safeguards, upon mentally handicapped persons. (Ideally, the benefits of such experimentation will extend to others who suffer from a similar or related condition—*i.e.*, there is also an expected gain in general scientific knowledge about that specific condition.) In general, objections to such research by a patient or client should be honored, although the objection of a legally incompetent individual might be overridden (or an experimental procedure might be imposed upon a nonobjecting incompetent subject) where the potential benefit is great and the risk comparatively low. In such cases, appropriate consent should be obtained from parents or legal guardians. Certain procedures, such as psychosurgery, involve such a high degree of risk that they ought never to be employed on the basis of substituted consent, and in some situations should be prohibited altogether. Psychosurgery, even if intended for therapeutic purposes, should be included in any discussion of high-risk experimentation because it is such a drastic and irreversible procedure and because so much uncertainty exists as to its effects and the factors influencing such effects.

Recommendation 3.

> *At a minimum, research upon mentally handicapped individuals for the purpose of obtaining new scientific or medical information should be conditioned upon the following requirements:*
>
> *(a) The research protocol must undergo independent review for scientific merit of the research design and for competence of the investigator.*
>
> *(b) The institution, if any, in which the research is to be conducted must meet recognized standards for medical-care, direct care and other services necessary to meet the increased demands imposed by research activities, in addition to the ordinary requirements of adequate care and treatment.*
>
> *(c) The proposed research must not reduce the level of habilitative or rehabilitative services available either to research participants or to patients or clients not included in the project.*
>
> *(d) The experimentation must involve an acceptably low level of risk to the health or well-being of the research subjects;*
>
> *(e) The proposed research should relate directly to the prevention, diagnosis or treatment of mental disability and should seek only information which cannot be obtained from other types of subjects. Such information should be of high potential significance for the advancement of acknowledged medical or scientific objectives related to mental disability.*

(f) Research involving risk may be performed only on patients or clients who are actually competent to consent to participation therein and who have in fact given such consent. Substituted consent to procedures involving risk should not be permitted except in the most unusual and compelling circumstances and never in the face of objections, however expressed, by the patient or client himself. All consent should be subject to review and approval by an independent body, with an opportunity for patients or clients to be advised and represented in this process by an independent advocate (who may be an attorney).

(g) All subjects, and where appropriate their parents or guardians, should be provided with and informed of their right to any follow-up care necessitated by unforeseen harmful consequences of the research project.

Commentary:

The most problematic questions in this area arise with regard to research which does not directly benefit a particular group of subjects but which promises to produce important new knowledge concerning mentally handicapped persons generally. The questions become even more difficult, if not insoluble, when children—by definition incapable of informed consent—are involved as subjects of such experiments.

So long as privacy and confidentiality are respected, the Panel is not particularly concerned with nontherapeutic research which is merely observational in nature or which involves the mere use or sampling of urine, feces or other specimens normally available or obtainable at no risk to the subject. Other, more instrusive types of experimentation, however, should be subject to at least the strictures outlined above. Since there is no anticipated benefit to the individual subject, the objections of patients or clients ought to be binding, whatever the age or legal competence of the person involved, and substituted consent should rarely if ever be permitted. In most instances, affirmative consent—rather than absence of objection—should be a prerequisite for involvement in nontherapeutic research.

In view of the risk inherent in much experimentation and the potential vulnerability of mentally handicapped subjects, particularly in closed institutions, the importance of institutional review boards and other monitoring bodies cannot be overstated. Clearly, such bodies should not be limited to or dominated by peers of the investigating clinicians, but should include attorneys, citizen advocates and mentally handicapped individuals or their representatives.

Recommendation 4.

> *(a) Whatever schema is eventually put forward by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research should be considered as tentative and subject to continuous review.*
>
> *(b) A permanent National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, with a membership including mentally handicapped individuals and/or former patients or institutional residents and parents of children with mental handicaps should be established to evaluate and, if necessary, modify the policies resulting from the recommendations of the current Commission and to monitor the performance of institutional review boards and other bodies charged with protection of the rights of research subjects.*

Commentary:

In 1973, Congress established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (Public Law 93-348), charged with recommending standards for the protection of research subjects. Final recommendations on experimentation with the "institutionalized mentally infirm" and on the functions of institutional review boards are anticipated shortly. Final recommendations for research on children have already been submitted.[159] The testimony before and deliberations of the National Commission illustrate the complexity of the issues related to experimentation with human subjects, particularly "special" or "vulnerable" subjects such as some mentally handicapped individuals.

While unequivocal and unambiguous guidelines may be desirable, the area of human experimentation does not lend itself to simplistic answers. Even such basic concepts as "therapeutic" and "nontherapeutic" research, the terms "research" and "experimentation" themselves, "low" or "minimal" risk and "informed consent" need to be defined with new precision. Moreover, the trend toward deinstitutionalization of mentally handicapped individuals raises the question of the extent to which the protections afforded persons in traditional large institutions can or should be extended to those in other residential settings and to

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[159] *Report and Recommendations: Research Involving Children*, The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, DHEW Pub. No. (OS) 77-0004 (Washington, D.C.). See also the National Commission's recommendations on research involving prisoners, 42 F.R. 3075 (January 14, 1977), and the rules proposed by the Department of Health, Education, and Welfare, 43 F.R. 1049 (January 5, 1978). The Commission has also made recommendations in the area of psychosurgery. *Report and Recommendations: Psychosurgery*, DHEW Pub. No. (OS) 77-0001 (Washington, D.C.).

mentally handicapped individuals living in the community, including children enrolled in the public schools.

Because of the difficulty of these questions and the importance of balanced regulation in this area, the Task Panel feels that continued oversight and review is essential. In particular, for the reasons noted above, the functions of institutional review boards and other such monitoring bodies must be a primary focus of the ongoing review process.

11. *Civil Commitment*

Recommendation 1.

> *The civil commitment system as it exists in most States today should be drastically reformed. Responsible arguments can be made for modified abolition of civil commitment, for authorizing commitment only of "dangerous" persons or for time-limited involuntary commitment of persons who are mentally handicapped and also incompetent to make treatment decisions.*

Commentary:

Civil commitment involves a massive intrusion on personal liberty and autonomy. Compounding its risks is a record of widespread, well-documented and long-standing abuses. Therefore, the Panel believes, high priority must be given to reexamination and reform of the civil commitment system. The current system, in most States, lacks any consistent rationale, operates arbitrarily and capriciously at the whim of individual decisionmakers and can easily be used as an instrument of social control or as an expression of personal or societal animosity toward the person facing commitment.

Three basic arguments can be made: for abolishing commitment altogether, for restricting its use to instances where the likelihood of serious bodily injury is present, or for authorizing it in fairly broad instances by invoking the paternalistic power of the State. While the Panel feels that no civil commitment criterion should be broader than the one set forth under the third option ("safeguarded paternalism"), it also feels strongly that legal closure on the question of commitment criteria would not be premature and unwise.[160] These three basic options are discussed below:

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[160] A substantial number of Task Panel members were of the opinion that *if* appropriate modifications could be made in the criminal justice system to confine certain persons now found in the mental health system, they would personally support a "modified abolition" position. Even those Panel members, however, were reluctant at this point to recommend a single standard for adoption by all States.

(1) *Modified Abolition*

Under this option, civil commitment as it exists today would be virtually abolished; emergency confinement for a very brief period (*e.g.*, 48 hours) would be authorized for persons on the verge of or in the process of engaging in suicidal behavior.[161]

The rationale for the abolition of civil commitment is that involuntary detention (even when for purposes of "treatment") is incompatible with human and constitutional rights. People have the right to be different without risking involuntary detention because others disapprove of their way of life. This is not to deny that some people are unhappy, dissatisfied with their lives or unable to behave in ways which conform to community norms. Certainly, a full range of services (which should include mental health services) should be made available to such people (as to all people), but the option of whether or not to partake of any such services should remain with the individual. In many cases, people who today are subject to involuntary commitment have already had experiences with mental health care, and have determined that such care has not been helpful to them.

The "modified abolition" approach would recognize that paternalistic justifications for civil commitment typically fall prey to overbroad application and to circular reasoning ("the person is mentally ill and incompetent to make treatment decisions because he disputes the doctor's recommendation") and that public-protection (police power) justifications are undercut by the inability of mental health professionals to predict dangerousness accurately and by their well-documented tendency to err on the side of overpredicting dangerousness. Furthermore, there is a feeling that even in jurisdictions which technically authorize commitment only upon a showing of serious dangerousness, courts can and do distort the "dangerousness" criterion so as to justify commitment under a tacit standard of "in need of treatment."

Moreover, modified aboliton of civil commitment would not ignore real and serious mental health problems. The literature suggests that suicidal behavior can be as effectively thwarted by brief emergency intervention (which this approach would authorize) as by the far more intrusive device of ordinary commitment.[162]

The abolition of involuntary commitment would end the present subterfuge in which large (but unknown) numbers of patients who are

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161. Arguments for the abolition of involuntary civil commitment have been set forth by, among others, Thomas Szasz. See, for example, *The Myth of Mental Illness* (1961) and *The Manufacture of Madness* (1970) for a detailed examination of the incompatibility of involuntary commitment with a free society.

162. See, e.g., Greenberg, "Involuntary Psychiatric Commitments to Prevent Suicide," 49 *N.Y.U. L. Rev.* 227 (1974).

technically on "voluntary" status are actually hospitalized against their will. Patients are quite commonly told that, unless they sign "voluntary" admission forms, they will be committed by the court and will end up spending even more time in the hospital.[163]

The most troubling matter with respect to abolition of involuntary commitment is the possibility that truly dangerous mentally disordered persons, who are permanently incompetent to stand trial on serious criminal charges or who are acquitted of such charges by the operation of the insanity defense, would have to be released and allowed to continue their criminal behavior. A "modified abolition" approach must take cognizance of such contingencies and must, through a restructuring of the criminal law or through partial reliance on the mental health system, guard against the immediate or indiscriminate release of such persons.

If public-protection (police power) civil commitments were generally abolished, the consequences to society would probably not be nearly as drastic as some would fear. First of all, since mental health professionals routinely overpredict dangerousness by gross margins, most persons now committed pursuant to the police power would, absent coercive intervention, probably not commit serious dangerous acts. The small number who would commit such acts would be subject to criminal prosecution. The majority of those would eventually be competent to stand trial and, given the restrictiveness of the insanity defense, might well be convicted. As other sections of this report urge, such persons should be able to receive mental health treatment on a voluntary basis within the correctional system.

It is possible, of course, that if police power commitments are eliminated or even sharply curtailed, the mentally disordered who were formerly committed may now be "criminalized" by being charged with relatively minor criminal offenses (disorderly conduct, disturbing the peace, trespass, etc.). However, such a result ought not to be presumed inevitable without empirical verification in jurisdictions which sharply curtail or virtually abolish their civil commitment systems. Moreover,

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163. An unpublished study by E. Oliver Fowlkes, the director of the Mental Patients' Advocacy Project at Northampton (Mass.) State Hospital, indicates that approximately half of "voluntary" patients did not want to be in the hospital. Fowlkes also found, ironically, that involuntary patients were released after shorter hospital stays than were those who signed voluntary admission forms. Moreover, the later in the emergency "hold" period a patient signed a voluntary admission form (i.e., the more pressure brought to bear on him or her?) the longer was the stay. But compare Zwerling, I. *et al.*, "A Comparison of Voluntary and Involuntary Patients in a State Hospital," 45 *Am. J. Orthopsychiatry* pp. 81-87 (1975), in which the authors found upon a three month follow-up after admission that patients in involuntary status were more than twice as likely as those in voluntary status to have remained in the hospital (23.1% to 10.6% of their respective group). And see Gilboy and Schmidt, " 'Voluntary' Hospitalization of the Mentally Ill," 66 *Northwestern U.L. Rev.* 429 (1971), where the authors found that even patients denominated as "voluntary" were detained after they requested to leave the hospital.

even if such "criminalization" were to occur, it might still be preferable to the current system. The criminal courts provide stringent procedural protections, criminal sanctions are unlikely to be more severe than are current periods of civil confinement and application of the criminal sanctions in a sense encourages persons to take responsiblity for their own behavior.

It is also possible that, with limitation of police power commitments, persons now civilly committed pursuant to that power will be charged with criminal offenses and will then be offered the option of being "diverted" from the criminal system to the mental health system. As with "criminalization" in general, the rise of mental health diversion programs is a matter about which we now have little empirical evidence. As such programs begin, they will require careful scrutiny to ensure voluntariness and confidentiality. But if such conditions are ensured, diversion may be an acceptable—perhaps preferable—alternative to criminal conviction or to involuntary civil commitment.

(2) *"Dangerousness" as a Basis for Commitment*

A second option would be to authorize involuntary commitment only upon a showing of serious mental disorder coupled with a substantial likelihood that the proposed patient, if not committed, would in the near future cause or suffer death or serious bodily harm. To reduce overpredictions of dangerousness, such a standard would require a prediction of future dangerousness to be predicated upon a recent behavioral indicator (an overt act, an attempt or a serious threat) of the individual's propensity to do serious bodily harm to himself or to others.

The convergence of a variety of theoretical and pragmatic concerns makes it unlikely that society will in the near future opt for abolition—even modified abolition—of civil commitment. Society seems unwilling, for example, to permit distressed persons to take their own lives. Also, society seems unwilling to release persons who are mentally ill and demonstrably dangerous and who engage in criminal behavior but who, because of their incompetence to stand trial or because of the availability of the insanity defense, may be able to escape criminal confinement.

Thus, while these concerns might be dealt with as set forth above, the "dangerousness" approach, favored by many courts,[164] authorizes commitment only of persons found to be seriously mentally disordered

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[164] See, for example, *Lynch v. Baxley*, 386 *F. Supp.* 378 (M.D. Ala. 1974); *Lessard v. Schmidt*, 349 *F. Supp.* 1078 (E.D. Wis. 1972) (see footnote 126, Section III.8, for subsequent history.

who, without commitment, are likely to cause or suffer serious bodily harm in the near future. Moreover, to reduce errors and aid in specificity—avoiding the arbitrariness that flows from vagueness—this approach requires that the proposed patient must have demonstrated dangerous potential in the recent past (through, *e.g.*, an overt act or attempt).

The "dangerousness" approach would avoid the above-mentioned circularity of more paternalistic standards and the slipperiness of a broad "in need of treatment" criterion, under which it has often been possible to accomplish the commitment of an individual simply because he is annoying, obnoxious, or different.[165] This option would also have the following advantages: the tightened commitment standard would ensure that the limited public mental health resources are expended on high priority cases; in view of the danger of overpredicting dangerousness, commitment would not be authorized to prevent societal risks less serious than death or serious bodily injury (*e.g.*, danger to *property*); overprediction of dangerousness would be further reduced by requiring, as some courts constitutionally mandate, that predictions of dangerousness be supported by evidence of recent overt acts.

(3) *"Safeguarded Paternalism"*

A third scheme for involuntary commitment might operate as follows: Commitment for a rather brief (*e.g.*, six-week) period could be authorized if it is established at a properly conducted hearing that the person suffers from a severe mental illness, reliably diagnosed (*e.g.*, a psychosis, an organic syndrome); the immediate prognosis is for major distress for the person if treatment is not forthcoming; treatment, likely to be effective, is available; and the risk/benefit ratio of treatment is such that a "reasonable person" would consent to it. At the expiration of the brief initial-commitment period, a new hearing would be required to extend the order for care for an additional period of the same length. At the end of a 6-12 week period, it would be evident in virtually all cases whether the period of involuntary commitment had in fact served the patient's best interests. If the patient had not profited from treatment and was unwilling to accept further treatment voluntarily, further involuntary treatment would probably not be advantageous. At that time the patient would be released.[166]

Contrary to the opinion that "dangerousness" should be the only condition for involuntary civil commitment, in some jurisdictions the need for care and treatment has been approved as a valid criterion for

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[165] See, generally, *O'Connor v. Donaldson*, 422 U.S. 563 (1975).

[166] See, e.g., Stone, *Mental Health and Law: A System in Transition*, DHEW Pub. No. (ADM) 75-176, U.S. Government Printing Office, Washington, D.C., 1975.

civil commitment.[167] The option set forth here would avoid some of the shortcomings of current "dangerousness" standards, such as the difficulty of predicting dangerous behavior and the tendency of some committing courts to pervert the standard in particular applications. Moreover, a "dangerousness" standard honestly applied could prevent commitment of many mentally ill persons who could profit from treatment but who may, because of their illness, be unable to understand their need for such treatment. This could be viewed as an undesirable result, in light of increasing evidence in recent studies that severe psychiatric illness can be reliably diagnosed[168] and that patients are helped rather than simply victimized by involuntary civil commitment.[169]

Recommendation 2.

> *(a) Whatever substantive commitment standard is adopted, evenhanded administration should be promoted by the use of specific definitions and criteria.*
>
> *(b) The Department of Health, Education, and Welfare should fund studies to ascertain the differential effects of commitment criteria in jurisdictions which have adopted different models of involuntary civil commitment.*

Commentary:

Whatever standard is ultimately adopted, the Panel feels strongly that corrective action should result in the adoption of statutory language which is pragmatically precise, *i.e.*, which describes with particularity the types of conditions and behaviors, if any, that can lead to loss of personal liberty. Only if this is done will there be any confidence that the commitment criteria are being administered in a fair and evenhanded fashion.

Courts and legislatures recently addressing questions of civil commitment have generally agreed that the commitment power must be circumscribed to some extent, but the debate over particular criteria remains heated. This is as it should be, since the question of involuntary commitment criteria involves not only legal considerations, but also ethical and social judgments as to the types of behavior society is (or should be) willing to tolerate.

It is most important, however, that the ongoing dialogue be informed by empirical studies of how different commitment criteria are

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[167] See, for example, *Fhagen v. Miller*, 29 N.Y.2d 348, 278 N.E.2d 615, 328 N.Y.S.2d 393, *cert. denied*, 409 U.S. 845 (1972).

[168] Helzer et al., "Reliability of Psychiatric Diagnosis II: The Test/Retest Reliability of Diagnostic Classification," 34 Archives of General Psychiatry 136, 141 (1977).

[169] See, for example, Gove and Fain, "A Comparison of Voluntary and Committed Psychiatric Patients," 34 Archives of General Psychiatry 669-676 (1977).

operating in various States. HEW should (through NIMH or other appropriate branches) fund such studies, perhaps paying particular attention to States that have rather recently revised their commitment codes (*e.g.*, Iowa, Michigan, Ohio, Pennsylvania, Wisconsin).

Recommendation 3.

Voluntary mental health and supportive services should be made easily available to those who seek them.

Commentary:

Any limitations on involuntary mental health treatment ought to be accompanied by an expansion of opportunities for truly voluntary care and services provided in appropriate settings. Just as States should not force confinement and treatment on persons who neither need nor want such "help," so they should facilitate provision of appropriate services to persons who voluntarily seek assistance.

Recommendation 4.

(a) Commitment procedures should be adopted to ensure fair resolution of the issues at stake.

(b) Procedural protections should include, but not necessarily be limited to, initial screening of potential commitment cases by mental health agencies, a prompt commitment hearing preceded by adequate notice to interested parties, the right to retained or assigned counsel, the right to a retained or assigned independent mental health evaluator, a transcript of the proceedings, application of the principle of the least restrictive alternative, a relatively stringent standard of proof (at least "clear and convincing" evidence), durational limits on confinement (with the ability of a court to specify a period of confinement short of the statutory maximum) and the right to an expedited appeal. At the commitment hearing, the rules of evidence shall apply and the respondent should have the right to wear his own clothing, to present evidence and to subpoena and cross-examine witnesses. Ideally, the petitioner should also be represented by counsel.

Commentary:

Both due process considerations and sound social policy dictate that commitment—with its massive intrusion on liberty and autonomy—should be authorized only if fair procedures are employed to resolve the major issues. Several courts have held many of the procedures recommended above to be constitutionally compelled.[170] Certain other of the above procedures (such as initial screening by mental health agencies to divert certain persons from the commitment process and to direct them to services more suitable to their needs) have been required by recent legislation.

Moreover, at this stage of our psychiatric and jurisprudential history the recommended rights can hardly be viewed as controversial. Indeed, the rights to a prompt hearing, to counsel, to an independent evaluator and to durational limits on confinement (the necessity for periodic review) were supported several years ago in a position statement published by the American Psychiatric Association.[171] Still, there remains considerable laxity in actually according those rights to proposed patients. The Panel feels strongly that these procedural protections should be provided without delay and that whatever costs may be involved in securing such protections should not detract from funds currently available for mental health services.

Many Panel members believe that these same procedural protections ought to be afforded by statute to minors as well as adults, and that so called "voluntary" commitments of minors by their parents ought not to be permitted. Evidence suggests that while institutionalization may be appropriate and necessary for some children, for others it has been used by parents either punitively or because they are unaware of any alternatives and by the State for similar reasons. Whether these due process protections are required as a matter of constitutional law is presently before the Supreme Court in *Parham* v. *J.L. and J.R.*[172]

Explicit criteria and procedural protections should also be available for children in State custody as a result of court or parental action, who are placed in residential settings other than mental hospitals. Increasingly, mentally handicapped children are not only committed to mental hospitals, they are placed out of their homes in foster care and group settings, either under the auspices of the child welfare system or through purchase of service contracts negotiated by mental health departments. This trend is likely to continue and become stronger as the obligation to place the child in the least restrictive setting and the pressures for deinstitutionalization increase.[173]

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[170] See, for example, *Lessard v. Schmidt*, 349 *F. Supp.* 1078 (E.D. Wis. 1972) (subsequent history omitted).

[171] 128 *Am. J. Psychiatry* 1480 (1972).

[172] *Parham v. J.L. and J.R.*, 412 *F. Supp.* 112 (M.D. Ga. 1976). The case was argued on appeal to the United States Supreme Court in the fall of 1977 and has recently been set for reargument.

[173] See *Children Without Homes: An Examination of Public Responsibility to Children in Out of Home Care*, the Children's Defense Fund, 1977.

Children placed in these alternate settings are no less in need of a strong protective framework. For many of them, particularly when the placement is through child welfare, custody is typically transferred to the State, either on a temporary or permanent basis. In the former instance, parents retain residual rights but are often effectively cut off from making decisions about their children by the policies and practices of public agencies. Other children lack concerned parents and linger, without stability and permanence, in out-of-home care. Therefore, both as a matter of policy and legality it is important that these children too be protected by access to counsel, required periodic and dispositional reviews, placement only if absolutely necessary—in the least restrictive setting and in as close proximity as possible to he child's own home—and by requirements for efforts to ensure that children who cannot be reunited with their natural families are placed with permanent families through adoption, if at all possible, regardless of the child's handicapping condition. To this end, no Federal funds should be made available to the States for out-of-home care of mentally handicapped children unless these protections are afforded.

12. *Mental Health Issues Affecting Persons Accused or Convicted of Crimes*

Recommendation 1.

Mental Health Services to Prisoners

(a) Mentally handicapped persons incarcerated in jails and prisons should have reasonable access to quality mental health services which are delivered on a truly voluntary basis with confidentiality comparable to that which exists in private care. This can occur only if participation in treatment is unrelated to release considerations. Medicaid reimbursement should be extended to include voluntary jail and prison mental health care.

(b) In order for mental health services to be truly voluntary and optimally effective, prisons must first establish minimally adequate physical and psychological environments. The Department of Justice should place a high priority on allocating Federal grant funds to the improvement of prison living conditions.

(c) Prisoners from racial or ethnic minority groups should have access to mental health professionals from similar backgrounds.

(d) If a mentally handicapped prisoner is transferred involuntarily from a prison to a mental hospital, the involuntary transfer should be preceded by procedural protections equivalent to those available in ordinary civil commitment. Indeed, such "commit-

ment-like" procedures should be followed even before a prisoner receives involuntary mental health treatment within a correctional institution itself.

(e) In cases where a mentally handicapped prisoner desires mental heath treatment and where mental health and correctional authorities concur that a hospital setting would be appropriate and beneficial to the prisoner, procedures should be developed for effectuating a voluntary hospital admission. The prisoner's good-time and parole opportunities ought not to be jeopardized by the transfer—in fact, good-time and parole opportunities should not be jeopardized even for involuntarily committed prisoners.

(f)(1) Mental health professionals, as a general rule, should decline to provide predictions of future criminal behavior for use in sentencing or parole decisions regarding individual offenders.

(2) If a mental health professional decides that it is appropriate in a given case to provide a prediction of future criminal behavior, s/he should clearly specify:

- *(a) The acts being predicted;*
- *(b) The estimated probability that these acts will occur in a given time period; and*
- *(c) The factors on which the predictive judgment is based.*

Commentary:

One recent study[174] has estimated that 37 percent of jail inmates in five California counties suffered from a mental disorder. Excluding those with personality disorders (20.9 percent) and mental retardation (.5 percent), 16 percent of all jail inmates would still be judged to have psychotic or nonpsychotic disorders. Another well-known study[175] found that 9.5 percent of the prison population nationwide was mentally retarded. Thus, research makes clear that a high percentage of jail and prison inmates (markedly higher than that in the nonprison population) is mentally handicapped. In light of these studies, each State should conduct a mental health survey among city and county jail inmates and State and Federal prisoners to determine incidence/prevalence rates and need for service.

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[174] Arthur Bolton Associates, "A Study of the Need for and Availability of Mental Health Services for Mentally Disabled Jail Inmates and Juveniles in Detention Facilities," prepared for the California Department of Health, October 1976.

[175] Brown and Courtless, "The Mentally Retarded in Penal and Correctional Institutions," 124 *Am. J. Psychiatry* 1164 (1968).

Recent research also reveals that an appalling level of physical and sexual abuse often characterizes prison life. Meaningful mental health services cannot be delivered to mentally handicapped persons in prisons until the basic physical and psychological improvement of prisons has enforced minimal standards of human dignity and self-respect. After adequate living conditions in prisons are specified, the question of providing minimum standards for the provision of mental health services in prisons becomes valid.

Medicaid does not reimburse health or mental health services provided to prisoners or inmates of Federal, State or local correctional institutions. In order to make it possible for prisoners to receive mental health services that they desire, or to continue in therapy that had been initiated prior to incarceration, statutory changes should be made so that Medicaid can reimburse for those services requested by a prisoner.

Access to services on a voluntary basis (*i.e.*, whether or not the inmate enters treatment has no effect on parole-release date or on in-prison benefits) and in a confidential manner is essential to avoid a coerced participation which will undermine useful treatment. It has been estimated on the basis of the study cited above that 42 percent of the approximately 3,000 mentally disordered Mexican-Americans booked into jail in a given year in Los Angeles County speak only or mainly Spanish. Yet not one of the 20 mental health professionals in the Los Angeles county jail is bilingual or bicultural. Therefore, even in a relatively progressive and comprehensive prison mental health system, such as that in Los Angeles County, Spanish-speaking inmates have no therapists available to them with relevant language or cultural background. One of the Panel's recommendations attempts to ameliorate this kind of problem by ensuring that mentally handicapped persons have access to therapists who speak their primary language and who understand their culture. In areas where there is a scarcity of bilingual/bicultural mental health professionals, recruitment efforts at local graduate/professional schools should be encouraged.

With regard to the issue of prison-to-hospital transfers, a number of cases have held that because of the possibility of mistake, stigma and a lengthier period of confinement, a prisoner who is to be involuntarily transferred to a mental hospital should first be granted a civil commitment-type hearing. Despite such constitutionally-grounded decisions, rooted also in sound social policy, some jurisdictions seemingly continue to effectuate such transfers unilaterally and summarily, treating the transfers as equivalents of mere administrative "placement and classification" decisions. The Panel believes that all jurisdictions should afford prisoners for whom forced hospitalization is sought procedures equivalent to those accorded nonprisoners undergoing civil commitment.

Indeed, to avoid circumvention of such safeguards simply by involuntarily treating prisoners *in a penal setting*, due process procedures should also be followed in certain other instances. When a prisoner is involuntarily transferred to a psychiatric unit of a prison, for example, or even when a prisoner is forcibly and intrusively treated without being transferred at all, the possibility of stigma, the adverse consequences of mistake, and the major change in the conditions of the inmate's confinement all point to the need for adequate procedural safeguards.[176]

When a mentally handicapped prisoner *desires* transfer to a mental hospital and mental health and prison authorities concur that such treatment would be beneficial, a number of unnecessary legal hurdles now serve as barriers to effective mental health care. In some jurisdictions, for example, voluntary admission for prisoners is simply unavailable, necessitating that the transfer occur, if at all, only through commitment. Because of the added stigma of commitment and because commitment may involve a lengthier period of confinement than simply serving a prison sentence, the unavailability of a voluntary procedure may discourage delivery of needed and appropriate mental health care.

Other legal disincentives to appropriate care involve laws, regulations or practices involving good-time credits and parole eligibility for prisoners who are voluntarily or involuntarily transferred to mental hospitals. Although the cases are now fortunately beginning to go the other way, the traditional situation denied prisoners good-time credits while they were hospitalized and denied them, merely because of their hospitalization, the opportunity to be paroled, *even* if the parole was conditioned upon the patient's remaining *in the hospital* until hospital authorities believed discharge into the community was warranted. Those practices, which are unjust and which serve as legal impediments to mental health care for prisoners, have been eradicated in some States by recent legislation or case law.[177] The Panel recommends that all States be encouraged to rid their laws of such access barriers.

Traditionally, predictions by mental health professionals concerning who will do future dangerous acts have been an important factor in parole decisions. The Panel rejects the argument that "somebody has to make these predictions" in determining sentence length, and that they

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[176] See Wexler, D., *Criminal Commitments and Dangerous Mental Patients*, pp. 57-58 (1976); Roth, L., "Correctional Psychiatry," (Chapter 30) *in* Petty, Curran, and McGarry (eds.), *Modern Legal Medicine and Forensic Science*, in press.

[177] See Wexler, *supra*, at 58-61.

necessarily will be made at an even lower level of validity—or a higher level of bias—if mental health professionals "abdicate" their role as predictors of future crime.[178] While that is a risk with which one should be concerned, it is also possible that nobody will make predictions, and that the criminal justice system, deprived of the opportunity to pass off difficult ethical and policy questions as matters of scientific acumen, will begin to confront more honestly the value premises on which it goes about imposing prison sentences. As observors have noted:

> Whether the setting is a maximum-security prison or merely Juvenile Hall, the paradox is the same: the degree to which the offender has supposedly been reformed by these institutions is judged on the basis of his saying and doing the right things . . . . Reform when seen as something different from compliance inevitably becomes self-reflective . . . . This game is won by the "good actors": the only losers are those inmates who refuse to be reformed because they are too honest or angry to play the game . . . .[179]

The Panel makes this recommendation more for ethical than empirical reasons. The research suggests that the validity of psychological predictions of dangerous behavior, at least in the sentencing and release situations we are considering, is extremely poor, so poor that one could oppose the use of such predictions on the strictly empirical grounds that mental health professionals are not competent to make such judgments.[180] An analogous conclusion was reached by a Task Force of the American Psychiatric Association: "Neither psychiatrists nor anyone else have reliably demonstrated an ability to predict future violence or 'dangerousness'. Neither has any special psychiatric 'expertise' in this area been established."[181] Our position goes further. We suggest that even in the unlikely event that substantial improvements in the reprediction of criminal behavior were documented, there would still be reason to question the ethical appropriateness of extending an offender's sentence beyond what he "deserves" in order to achieve a utilitarian gain in public safety.[182] It is clear, however, that there are no facile answers to this most difficult question of ethics and public policy, especially when one takes into account "justice" to the potential victims of violent crime—who, like their offenders and unlike the legislators,

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[178] See American Psychological Association, *Task Force on Psychology and Criminal Justice*. Washington, D.C.: American Psychological Association, 1978.

[179] Watzlawick, Weakland and Fisch, *Change: Principles of Problem Formation and Problem Resolution*, 1974, p. 69.

[180] See Monahan, The prediction of violent criminal behavior: A methodical critique and prospectus. In National Research Council (Ed.) *Deterrence and Incapacitation: Estimating the Effects of Criminal Sanctions on Crime Rates*. Washington, D.C. National Academy of Sciences, 1978.

[181] American Psychiatric Association. *Clinical Aspects of the Violent Individual*. Washington, D.C. American Psychiatric Association, 1974, p. 20.

[182] von Hirsch, *Doing Justice: The Choice of Punishments* (1976).

judges and mental health professionals making decisions in the criminal justice system, are often poor and nonwhite.[183]

Because reasonable persons may disagree with the position we have adopted with regard to offering predictions for judical and parole board decisionmaking, we would urge those who do believe it ethical to participate in such decisions to be explicit about what information it is that they are providing. Others would then be in a position to evaluate more objectively the nature of the scientific contribution, and to draw their own policy conclusions.

Recommendation 2.

> *(a) Evaluations to determine whether a defendant is competent to stand trial should be performed promptly and should, if possible, be performed in the defendant's home community and on an outpatient basis. Outpatient dispositions should be considered in certain instances even for defendants found, after evaluation and hearing, to be incompetent to stand trial.*
>
> *(b) A defendant who, because of psychotropic medication, is able to understand the nature of the proceedings and to assist in his defense, should not automatically be deemed incompetent to stand trial simply because his satisfactory mental functioning is dependent upon the medication, and should have the option of going forward with his trial.*
>
> *(c) Recent proposals by legal commentators to abolish the incompetency plea (and to substitute for it a trial continuance and then a trial with enhanced defense protections) are deserving of further study.*
>
> *(d) At a minimum, the limitations imposed by* Jackson v. Indiana *upon the nature and duration of incompetency commitments ought to be acknowledged and enforced nationwide.*

Commentary:

Often, defendants alleged to be incompetent to stand trial have been automatically confined—sometimes to a maximum security institution—for a period of psychiatric evaluation that could last for 30 to 90 days or longer. However, recent studies have concluded that competency examinations can usually be conducted within a matter of days and that fully 70 percent of such evaluations can be conducted adequately on an outpatient basis.[184] Accordingly, to avoid unnecessary

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[183] Shah, Dangerousness: A paradigm for exploring some issues in law and psychology. *American Psychologist* (in press).

[184] de Grazia, Diversion from the Criminal Process: the "Mental Health" Experiment. 6 *Conn. Law Rev.* 432, 436 (1974).

stigmatization, deprivation of liberty and expense, the Panel recommends that, so far as possible, such evaluations be conducted quickly, locally and without hospitalization.

Indeed, outpatient dispositions may sometimes be appropriate even for defendants finally adjudicated to be incompetent to stand trial. For example, an incompetent defendant with roots in the community who is charged with a nonviolent offense would profit clinically from outpatient therapy more than from an institutional environment.[185] Statutes and court rules relating to competency should, then, make room for outpatient dispositions of such persons.

The Panel's second recommendation in this area relates to—and rejects—the "rule" established in some jurisdictions or by some judges that "medically induced" competence is "artificial" competence and accordingly ought not to be treated as legal competence to stand trial. Courts following such an "automatic bar" rule insist that defendants be withdrawn from medication prior to trial. If the defendant's mental condition then deteriorates, he is again ruled incompetent and is again hospitalized. The automatic bar to trying defendants whose competence is medically induced has recently—and deservedly—been challenged as an unwise policy and as an unconstitutional practice.[186] Defendants whose competence has been restored by medication should have the option of proceeding with a trial to determine their guilt or innocence.

The Panel believes worthy of further study the recent proposal of Professor Robert Burt and Dean Norval Morris to abolish the incompetence doctrine. In its place, Burt and Morris would substitute a trial continuance of up to six months. If the accused does not regain competence within that period, Burt and Morris would require the State either to dismiss the charges or to bring the accused to trial with extra protections designed to compensate in part for his incompetency (*e.g.*, increased defense discovery rights and a heightened prosecutive burden of proof).[187]

Some of the current abuses of incompetency commitments would be eliminated simply by enforcement of the Supreme Court's decision in *Jackson* v. *Indiana*.[188] In *Jackson*, the Court said defendants found

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[185] See, for example, *People ex rel. Martin v. Strayhorn*, 61 Ill. 2d 296 (1976).

[186] See Winick, *Psychotropic Medication and Competence to Stand Trial*, 2 Am. Bar Foundation Research Journal 769 (1977).

[187] Burt and Morris, *A Proposal for the Abolition of the Incompetency Plea*, 40 U. Chi. L. Rev. 66 (1972). While the Panel felt that the Burt/Morris proposal deserves serious study, there was no consensus on the issue of whether incompetent persons should be allowed to go to trial. Some Panel members felt that to allow an incompetent defendant to stand trial could raise serious due process questions and might be unconstitutional.

[188] 406 U.S. 715 (1972).

incompetent to stand trial could not be committed indefinitely, but only for a period reasonably necessary to determine whether they could be restored to competency in the foreseeable future and, if so, for an additional period reasonably necessary for the restoration of such competence. Very few States have implemented this constitutional directive, with the result that incompetent defendants remain incarcerated for years without any resolution of the charges against them and without any hope of improvement in their mental condition. Enforcement of *Jackson*—by appropriate State legislation or perhaps as a condition of Law Enforcement Assistance Administration funding—would at least force States either to bring these defendants to trial or to take some other action to remove them from their legal limbo.

Recommendation 3.

> *(a) Laws authorizing the involuntary commitment of sexual psychopaths and other "special" offenders (such as "defective delinquents") should be repealed.*
>
> *(b) Persons who are now being committed as sexual psychopaths or "special" offenders should instead be*
>
> > *(1) Processed through and treated in the criminal justice-correctional system, or*
> >
> > *(2) Given the option whether to be treated within (i) the correctional system or (ii) a therapeutic system in which the period of confinement could not exceed the applicable criminal law maximum sentence.*

Commentary:

There are two principal problems with current laws regarding the commitment of "special" offenders such as "sexual psychopaths" and "defective delinquents." First, such a commitment, unlike criminal confinement, is ordinarily for an indeterminate period. Second, the criteria for commitment—indeed, the very terms "sexual psychopath" and "defective delinquent"—are so vague as to make arbitrary whether a particular person will be processed through the "special" system or through the ordinary criminal system.

Three basic law-reform options have been proposed to deal with these problems. One is simply to apply the criminal law maximum sentences to offenders committed pursuant to special statutes. That option is not enthusiastically endorsed by the Panel, for while it would solve the length-of-confinement problem it fails to address the problem of arbitrary selection.

A second option would abolish special offender commitments and process such persons through the criminal justice system. That step would, of course, negate both problems (indeterminate confinement and arbitrary selection) and would be acceptable if there were an accompanying upgrading of available mental health services in correctional facilities.

A third option would overcome indeterminate confinement problems and most selection problems without totally abolishing special treatment programs. It would require the maximum criminal sentence (or the sentence, if any, actually imposed on the offender) to apply both to correctional and therapeutic confinements. Problems of arbitrary selection would be largely overcome by giving the offender the option of therapeutic or penal placement.[189]

IV. ASSURING PATIENTS/CLIENTS OF THEIR RIGHTS: BILLS OF RIGHTS AND OTHER MECHANISMS

1. *Bills of Rights*

Recommendation 1.

The President's Commission should recommend to the legislatures of the individual States that legislation be enacted providing a "Bill of Rights" for all mentally handicapped persons, both those who are institutionalized and those residing in the community.

Commentary:

Following the seminal decision by Judge Frank Johnson in *Wyatt v. Stickney*,[190] approximately 14 States have enacted legislation establishing "bills of rights" for psychiatric patients[191] and 12 have promulgated similar legislation for mentally retarded persons.[192] These statutes reflect the specific standards established in *Wyatt* for treatment of mentally handicapped persons[193] and other judicial opinions that, in the words of the *Harvard Law Review*, "have sketched the outlines of a constitutional right to protection of bodily integrity from unwanted

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[189] See, generally, Wexler, *Criminal Commitments and Dangerous Mental Patients*, 33-38, 70 (1976).

[190] 325 *F. Supp.* 781 (M.D. Ala. 1971), 334 *F. Supp.* 1341 (M.D. Ala. 1971), 344 *F. Supp.* 373 (M.D. Ala. 1972), 344 *F. Supp.* 387 (M.D. Ala. 1972), aff'd sub. nom. *Wyatt v. Aderholt*, 503 *F.*2d 1305 (5 Cir. 1974).

[191] See "The *Wyatt* Standards: An Influential Force in State and Federal Rules," 28 *Hosp. & Commun. Psych.* 374 (1977).

[192] American Bar Association Commission on the Mentally Disabled, draft unpublished document pertaining to the rights of institutionalized developmentally disabled persons, in progress. All States surveyed which have enacted a bill of rights for developmentally disabled persons have in place a bill of rights for the mentally ill; but some States which have enacted a bill of rights for the mentally ill have not enacted such a measure for the developmentally disabled.

[193] 344 *F. Supp.* at 379-386; 344 *F. Supp.* at 395-407.

State intrusion."[194]

The need for such legislation should be self-evident: The extent of discrimination against mentally handicapped persons needs no lengthy recitation. The pattern of abuse, disenfranchisement and disregard[195] eloquently underscores the need for vigorous, enforceable, prophylactic legislation in each of the States. It should be pointed out that enactment of a "bill of rights" in no way consigns the mentally handicapped to "second class citizen" status. Rather, it is an acknowledgement of the historical fact that such persons have been perceived and treated as second class citizens—or worse—by much of society. Because of this history, prophylactic legislation is necessary.[196]

After analysis of several of the significant State enactments,[197] the Panel has concluded that an adequate bill of rights for mentally handicapped persons should include at least seven basic components:

(a) A statement that all mentally handicapped persons are entitled to the specified rights;
(b) A statement that rights cannot be abridged solely because of a person's handicap or because s/he is being treated (whether voluntarily or involuntarily);
(c) A declaration of the right to treatment, the right to refuse treatment and the regulation of treatment, the right to privacy and dignity, the right to a humane physical and psychological environment and the right to the least restrictive alternative setting for treatment;
(d) A statement of other, enumerated fundamental rights which may not be abridged or limited;
(e) A statement of other specified rights which may be altered or limited only under specific, limited circumstances;
(f) An enforcement provision; and
(g) A statement that handicapped persons retain the right to enforce their rights through *habeas corpus* and all other common law or statutory remedies.

A brief analysis follows.*

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[194] "Developments—Civil Commitment of the Mentally Ill," 87 *Harv. L. Rev.* 1190, 1345 (1974).

[195] In the words of Patricia Wald, the handicapped person is perceived as "someone to whom attention need not be paid," Wald, "Basic Personal and Civil Rights," in Kindred *et al.*, eds., *The Mentally Retarded Citizen and the Law* 3, 18 (1976).

[196] The analogy to the passage of the Civil Rights Act of 1964 and 1965 is probably a useful point of comparison in this regard.

[197] See, *e.g., N.J.S.A.* 30:4-24.1 *et seq.*; *Ariz. Rev. Stats.* § 36-504 *et seq.*; *Minn. Stat.* § 253A.17; *Fla. Stat.* § 394.459 *et seq.*; *Wis. Stat.* 51.61 *et seq.*

* We note that Federal regulations for Skilled Nursing Facilities and Intermediate Care Facilities, including ICF/MRs, contain a patient bill of rights. The same bill-of-rights context was

(a) The statute should explicitly state that every handicapped person is entitled to all rights set forth in the act and should retain all rights not specifically denied. But for its reference to "patient in treatment" (thus potentially limiting its applicability to institutionalized patients), the New Jersey provision could serve as a model for the draft statute.

> Every patient in treatment shall be entitled to all rights set forth in this act and shall retain all rights not specifically denied him under this Title. A notice of the rights set forth in this act shall be given to every patient within 5 days of his admission to treatment.[198]

(b) The statute should explicitly indicate that the fact that a person is receiving treatment or rehabilitative services cannot by itself justify deprivation of his or her civil rights. This section should specify that there may be no presumption of incompetency because a person has been examined, evaluated, treated or admitted to an institution. It should also specifically ban discrimination because of an individual's status as patient or resident. The kinds of rights to which persons remain entitled regardless of their status as patients include but are not limited to the right to register for and to vote at elections; rights relating to the granting, forfeiture, or denial of a license, permit, privilege, or benefit pursuant to any law; the right to dispose of property, the right to sue or be sued, and the right to obtain housing.[199]

(c) The statute should specify that all persons have a right to treatment in a humane physical and psychological environment, a right to freedom from harm, a right to refuse treatment and a right to the regulation of treatment procedures, a right to basic privacy and dignity and the right to the least restrictive setting for treatment. These rights and the right to be free from discrimination in education, employment, housing and other matters have been discussed in detail earlier in this report.

(d) The statute should also specify certain treatment rights and conditions of treatment rights which may not be denied under any circumstance—for example, all patients have the

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recently proposed for Federal regulations for general and psychiatric hospitals by Rep. William Cohen (R-Maine), but this amendment to statutorily provide for a bill of rights for patients in a Medicare or Medicaid provider facility was withdrawn prior to passage of recent amendments.

[198] *N.J.S.A.* 30:4-24.2b.

[199] For example, the draft statute might well combine language from the New Jersey and Arizona statutes as well as a portion of the *Wyatt* decision. See *N.J.S.A.* 30:4-24.2a and 24.2c, *Ariz. Rev. Stats.* 36-506, and *Wyatt*, 344 *F. Supp.*, above, at 379.

absolute rights (1) to be free from unnecessary or excessive medication, (2) not to be subjected to experimental research, shock treatment, psychosurgery, or sterilization, without their express and informed consent after consultation with counsel or an interested party of their choice, (3) to be free from physical restraint and isolation and (4) to be free from corporal punishment.[200] In addition to the above rights, at a minimum patients and residents should have the absolute right to correspond with public officials, attorneys, clergymen and to the appropriate advocacy office[201] and the absolute right to religious freedom.[202]

(e) The statute should also specify other environmental and conditional rights guaranteed to all patients which can only be abridged in specific situations for a limited time and subject to an independent, neutral review mechanism. Thus, the New Jersey law, for example, provides the full panoply of *Wyatt*[203] rights: privacy and dignity, use and wearing of personal possessions and clothes, use of personal money, individual private storage space, daily visitors, reasonable access to telephones, access to letter-writing materials and uncensored correspondence, regular physical exercise, outdoor visitation, interaction with the opposite sex, freedom of religion and adequate medical treatment.[204] Further, the statute should stipulate that patients have the right to control their own assets[205] and the right to compensation for work done.[206]

Many of these rights have already been the subject of discrete court litigation.[207] Nonetheless the Panel feels that they are of such significance that they should be statutorily mandated.

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[200] See, for example, *N.J.S.A.* 30:4-24.2d (1) through (4).

[201] See *N.Y. Mental Hygiene Law* § 15.05(a); see also, 50 *Penn. Stat.* § 4423(1); *Minn. Stat.* § 253A.17(2).

[202] See, *e.g.*, 50 *Penn. Stat.* § 4423(2); *Ariz. Rev. Stats.* § 36-514(4).

[203] See *e.g.*, *Wyatt*, 344 *F. Supp.*, above, at 380-381.

[204] See *N.J.S.A.* 30:4-24.2e(1) and (3) through (12).

[205] See, for example, *Vecchione v. Wohlgemuth*, 377 *F. Supp.* 1361, 1369 (E.D. Pa. 1974), further proceedings 426 *F. Supp.* 1297 (E.D. Pa. 1977), aff'd. 588 *F.*2d 150 (3 Cir. 1977), *cert. den. sub. nom. Beal v. Vecchione*, — U.S. —, 98 S. Ct. 439 (1977); and *Board of Chosen Freeholders of Hudson County v. Connell*, Civ. No. 83870, 9 *Clearinghouse Rev.* 585 (N.J. Hudson Cty. Ct. 1975), 9 *Clearinghouse Rev.* 732 (N.J. Hudson Cty. Ct. 1976).

[206] See, for example, *Souder v. Brennan*, 367 *F. Supp.* 808 (D.D.C. 1973); *Ariz. Rev. Stats.* § 36-510; *N.Y. Mental Hygiene Law* § 15.09.

[207] See, for example, *Schmidt v. Schubert*, 422 *F. Supp.* 57, 58 (E.D. Wis. 1976) (visitation policy); *Brown v. Schubert*, 347 *F. Supp.* 1232, 1234 (E.D. Wis. 1972), supplemented 389 *F. Supp.* 281, 283-284 (E.D. Wis. 1975) (right to send mail); *Gerrard v. Blackmun*, 401 *F. Supp.* 1180, 1193 (N.D. Ill. 1975) (right to private communications with counsel); *Winters v. Miller*, 446 *F.*2d 65, 69-71 (2 Cir. 1971) (freedom of religion); *Carroll v. Cobb*, 139 N.J. Super. 439, 354 A.2d 355 (App. Div. 1976) (right to register to vote).

(f) The statute should contain a strong enforcement provision. None of the existing statutes includes such a section; the only step toward such a mechanism is the absolute right to a hearing, built into the New Jersey law, in the case of experimental research and similar treatments in matters involving persons adjudicated incompetent.[208] Optimally, there should be a grievance mechanism comporting with procedural due process, appointment of counsel and an automatic hearing procedure established in the case of denial of any of the rights enumerated in a draft bill.

Regardless of the specific enforcement provision adopted, the Panel feels that a strong, vigorous, independent advocacy system is absolutely mandatory to represent and advise patients at all stages of their institutionalization and on all other matters discussed in this recommendation.[209] It would not be an overstatement to suggest that any "bill of rights" would be meaningless to patients without such an advocacy system.

(g) The statute should include language similar to the following:

> Any individual subject to this Title shall be entitled to a writ of habeas corpus upon proper petition by himself, by a relative, or a friend to any court of competent jurisdiction in the county in which he is detained and shall further be entitled to enforce any of the rights herein stated by civil action or other remedies otherwise available by common law or statute.[210]

Although the statutory sections are not complete, they are useful as a model for a bill which can be recommended for endorsement and ultimate enactment. Endorsement of such a bill by the President's Commission on Mental Health would help to ensure "equal access to justice" for mentally handicapped persons.[211, 212]

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[208] See *N.J.S.A.* 30:4-24. 2d(2).

[209] As indicated in the section on "advocacy," above, it is essential that patients and former patients have input into both the advocacy system and suggested draft legislation.

[210] N.J.S.A. 30:4-24.2h.

[211] Herr, *Advocacy Under the Developmental Disabilities Act* 88 (1976).

[212] It has also been suggested that consideration be given to amending Federal law to make future Medicaid/Medicare certification and other third party payment mechanisms contingent upon individual State adoption and implementation of approved "bills of rights."

We note here that the Federal government can play a direct role in fashioning bills of rights, through administrative directive, regulation, or statute, for patients in Veterans' Administration facilities, and we suggest that the Commission give consideration to such a mechanism. The *Wyatt* Standards could, in the absence of a State bill of rights, serve as a guide for minimally adequate standards. Should the State have enacted or should it subsequently enact a bill of rights with standards higher than those in the VA bill of rights, the higher State standards would prevail.

Recommendation 2.

> *The President's Commission should recommend to the States that all currently existing laws establishing rights of patients, of persons in treatment and of residents of hospitals, facilities for the retarded or similar institutions should be prominently displayed in all living areas, wards, hallways and other common areas of all such facilities, and should be incorporated into all staff-training and staff-orientation programs as well as in educational programs directed to patients, staff, families and the general public. Explanation of rights to patients should be clearly and simply stated and in a language the patient understands; the explanation should be read to any patient who cannot read.*

Commentary:

If there is any expectation that the rights in question will be enforced, it is absolutely necessary that patients and residents be apprised of them and that treatment staff be made aware of them and their significance.[213] This recommendation is a modest first step towards that goal.

It also follows that recognition of rights precedes enforcement and that therefore the education of all citizens as to their rights is imperative. Specifically, persons receiving mental health services and, where appropriate, their guardians, should be informed of the rights they have and of all possible methods of enforcement. Further public information to inform the general population of the rights of mentally handicapped citizens could eliminate some old myths and lead to a better climate in which these rights could be enjoyed.

2. *National Initiatives in Legal and Ethical Issues*

Recommendation 1.

> *NIMH and other appropriate HEW components should establish special offices concerned with legal issues affecting the mentally ill and the developmentally disabled, respectively. These offices should be charged with (1) keeping the staff of NIMH and HEW informed about legal and ethical issues affecting mentally handicapped persons, (2) providing continuing advice from that perspective on program and policy issues, (3) promoting advocacy on behalf of the mentally handicapped, (4) promot-*

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[213] See, for example, for a discussion of the lower level of staff comprehension of patients' rights, Laves and Cohen, "A Preliminary Investigation Into the Knowledge and Attitude Toward the Legal Rights of Mental Patients," 1 *J. Psych. & L.* 49 (1973). See also *N.J.S.A.* 30:4-24.2b.

ing attention to legal issues in Federal programs for the mentally handicapped, and (5) promoting interdisciplinary exchange.

Commentary:

There is at present no real focus at the Federal level on how legal and ethical issues relate to program and service issues as they affect programs and planning at the national level. While a support center in mental health law at the Legal Services Corporation or other efforts to stimulate legal advocacy will develop heightened sensitivity to mental health and law issues in the bar, it is also necessary to introduce a concern for legal and ethical issues directly into the Federal process. Accordingly, offices staffed by qualified lawyers and lay advocates and given direct access to top administrators should be established at NIMH and at various components of HEW charged with delivering, developing or monitoring services for mentally or developmentally disabled persons. The functions of such offices would include analyzing new legal cases, legislation and other relevant developments and disseminating such information inside and outside HEW; assisting HEW staff and the public in developing training and research projects aimed at enhancing awareness of legal and ethical issues and bettering our understanding of the interrelationship between legal and ethical issues and program and service issues; identifying for the leadership of HEW policy issues arising from legal developments and the options for response to such developments; and monitoring State compliance with required advocacy systems.

Recommendation 2.

NIMH and other appropriate HEW components should fund innovative programs at law schools and mental health professional schools or other appropriate institutions which are designed to develop persons with policy, administrative and direct-service responsibilities in both the mental health and the legal system who will be knowledgeable about the delivery of services and the legal and ethical issues involved with patient care. Financial support should also be given for innovative inservice training programs at service facilities which are designed to provide continuing education for service providers concerning legal and ethical rights and for training projects for lawyers, judges, and non-lawyer advocates. These agencies should also support research into legal and ethical issues and problems, such as those highlighted in this report.

Commentary:

In that virtually all program, service, prevention and research initiatives in the mental health area will raise important legal and ethical issues, it is important to begin to develop practitioners and teachers in each profession who possess the necessary conceptual knowledge of the other and who have the practical skills required to foster interdisciplinary collaboration for the benefit of mentally disabled persons. The recent development of mental health law as a specialty within the legal profession has generated a wide range of judicial actions and legislative reforms. New "rights" established by the courts, along with protections and entitlements under Federal and State laws and regulations, have profound effects upon the administration and delivery of mental health services, both in institutional and community settings. Lawyers and treatment professionals today find themselves increasingly in a novel, often conflicting relationship in their separate efforts to improve their clients' access to suitable services, consistent with protection of rights. A strong need for cross-disciplinary planning, administration and service delivery exists, but there is an acute scarcity of both legal and mental health professionals with the necessary depth of understanding of the sensitive issues at the intersection of their disciplines, and there is a need for comprehensive training programs in professional schools, and law schools, as well as in-service training programs, to alleviate such a shortage.

Many Federal training programs have focused on the training of mental disability service providers, both professional and non-professional. Only a very few isolated projects have trained lawyers or judges, despite their growing impact on the lives of mentally disabled clients. Our earlier recommendations on advocacy addressed the need for the Legal Services Corporation to provide backup support and training for Legal Services lawyers in the special problems of the mentally disabled and for similar LEAA support for training of public defenders in representing the mentally disabled in the criminal justice system. To complement these efforts, support should be made available through HEW for the training of lawyers who do not fit into the Legal Services or public defender systems, judges and nonlawyer advocates.

HEW should also encourage and fund research on law and mental health issues, the training of researchers to assure the conduct of quality research and evaluation of the various approaches undertaken.

V. ETHICS

As will have been observed, there are ethical dimensions to virtually all of the legal-rights issues generating the recommendations made in this report. Obviously, ethical concerns may extend far beyond legal analysis into areas where there are no laws (e.g., an ethical obligation to be a good Samaritan) or may even conflict with what is currently the law (e.g., conscientious objection). One's legal obligations derive strictly from constitutional, statutory or regulatory pronouncements, but one's ethical obligations have no such clear moorings. There is always (ultimately) a "yes" or "no" answer to the question of whether actions are in violation of the law. But for moral problems involving a conflict among values, resolution must depend upon discussion and consensus.

In previous sections of this report, ethical dimensions have been mentioned along with the discussion of legal rights. Where the Panel felt that the ethical resolution of a problem was clear, its recommendations have been noted. Obviously, where there is agreement about moral problems in mental health, what is needed is not so much further moral reasoning as the application of public opinion and other social strategies to increase accountability and reduce abuse. Where the Panel did not reach consensus on eithical issues, an attempt has been made to clarify the conflicts involved.

This section looks back over the full range of issues in an effort to highlight the interweaving of ethical problems throughout the field of mental health. At the same time, we attempt to provide a structure for thinking about such issues, because discussions of ethics and mental health frequently enumerate problems (e.g., issues raised by human experimentation, psychosurgery, breach of confidentiality) unsystematically without putting them in proper perspective or establishing a framework for their constructive discussion.

The time is ripe to address these issues because:

(a) Technologies in mental health matters may, in the future, permit more systematic modification of individual and group behavior.[214]

(b) Technology is permitting increased capacity for mental health information exchange, thus compromising personal privacy.[215]

(c) In today's society individuals are increasingly interdependent.

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[214] See generally, London P., Behavior Control. New York: Harper & Row, Inc., 1969. See final report, A Comprehensive Study of the Ethical, Legal, and Social Implications of Advances in Biomedical and Behavioral Research and Technology. Study conducted for the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, New Jersey Institute of Technology and Policy Research, Inc., 1977.

[215] See generally Personal Privacy in an Information Society. The Report of the Privacy Protection Study Commission. Washington: USGPO, 1977.

(d) There is a growing appreciation of our diminishing resources—natural and perhaps even personal. Demands for resource allocation will only escalate.[216]

The above factors may in the future make it difficult for society to appreciate the value of persons otherwise deemed marginal, unproductive, different or even "dangerous." A technological, "high risk," interdependent society, striving to maximize its resources, may be understandably reluctant to leave people alone.[217]

The following schema is proposed as an initial conceptualization for thinking about ethical problems in mental health care. While there is some overlap, most ethical problems in mental health care may reasonably be placed into one of four areas. The choices in each area impact upon other areas. More importantly, the choices impact upon the role of the mental health system vis-à-vis society. The problems in each area are briefly discussed below.

A. *Needs of Patients/Clients Versus Needs of Families Versus Needs of Society*

1. The "Double-Agent" Problem

No question arises more frequently in discussions of the ethics of mental health intervention than "Who is the client?" Often, the question is asked rhetorically, for any attempt to answer it is dismissed as a "value preference." Ethical considerations are especially complex when the individual's behavior is sufficiently uncontrollable or dangerous to justify confinement under either criminal or civil law. In such circumstances, there may be conflicts between the individual's values and behavioral goals and those of the society which has committed him. The mental health professional employed by a mental hospital or prison may be uncertain as to where his primary responsibilities lie—with a particular mental patient or prisoner, with the administration of the institution which pays his salary or with the community at large. When mental health professionals do try seriously to articulate who their client is—where their loyalties are given—they sometimes appear constrained to a multiple-choice answer, with the alternatives being (a) the "system" (or "society"), (b) the family and (c) the individual.

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[216] See generally Hiatt H.H., Protecting the medical commons: who is reasponsible? N. Eng. J. Med. 293:235-241, 1975.

[217] See, e.g., remarks of Lesse S., in *Looking to the year 2000*—out: today-oriented psychiatry—in: prophylactic psycho-bio-sociology, Frontiers of Psychiatry 4(18): 1, 2, 11, Nov. 1, 1974.

Yet there is no need to hang on the horns of this dilemma, because "Who is the client"? is not a multiple-choice question. It requires an essay answer.

For example, *both* the individual and society may be the clients of the mental health professional, but *in different roles and with varying priorities.* Mental health professionals may be full-time employees or "client-centered" or "consultee-centered" or "program-centered" consultants for prisons, industry, the military or schools.[218]

The needs of a particular organization may legitimately be different from the needs of the individual. The treatment, management or dispositon of persons within the system may be mainly for the purposes of accomplishing its mission (e.g., "preserve the fighting force") or, in a utilitarian fashion, for the greatest good for the greatest number of persons within the organization, rather than for the individual.

"Double-agentry" poses several potential ethical problems.[219] To the extent that patients or clients are uninformed of the therapist's mixed allegiances, they may bring false expectations to the treatment situation; they may be subject to unknowing harm rather than help through contact with the mental health professional. Such "double-agentry" which confounds the role of the treating professional may also discourage care-seeking behavior among those in need. The type of treatment given may be subsumed to overriding administrative considerations.

The problems posed in this area suggest some "solutions." The mental health professional must be informed and knowledgeable about the role s/he is expected to play within the organization. The patient/client should be similarly informed prior to beginning a treatment or "evaluation" relationship. Wherever possible "administrative-therapist" splits should be encouraged. Administrative, "dispositional" or consultation functions to the system, which are legitimate and useful (e.g., mental status evaluation for parole or in connection with an incompetency proceeding), should be provided by mental health profes-

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[218] See, e.g. Hussey H.H., Psychiatry in Military Services (editorial), Journal of American Medical Association 228:203-204, (1974), Roth L.H., Correctional Psychiatry, Chapter 30 in Modern Legal Medicine and Forensic Science, Petty, C.S. Curran, W.J., McGarry, A.L. (eds.) (In press).

[219] See, generally, Shestack, J.J., Psychiatry and the Dilemmas of Dual Loyalties, American Bar Association Journal 6: 1521-1524, 1974.

sionals who occupy no therapeutic role within the organization.[220]

But even given foreknowledge and an administrative/therapist split, some mental health practices may be *per se* unethical. For example, it has been suggested that removing "character-behavior" diagnoses as a sufficient ground for discharge from the military may be ethically required.[221] This is not to argue that the military should be forbidden to catalogue and thoroughly describe a man's behaviors which justify his administrative separation from the military.

In the role of a therapist providing treatment for an individual who wants to change his or her behavior, the professional must be primarily the agent of the individual. This would mean that therapy should only be given on a truly voluntary basis and that it should not be used as a means to pursue societal ends. But even this approach involves priorities rather than an absolute role prescription; in a limited number of defined situations allegiances must be reordered—for example, when a patient in therapy clearly indicates that a life-threatening act is imminent.

The question of where the mental health professionals' loyalties lie arises most often in the context of concerns for the confidentiality of information. While confidentiality dilemmas—which are only one manifestation of the larger issue of the professional's loyalties—are acute in some areas, such as in the criminal justice system, they appear to be a growing concern to all mental health professionals who engage in treatment.

Complicated issues arise when families request information concerning their disturbed members—information that may have been given in confidence. Requirements of peer review and third-party reimbursement (necessary for maintaining standards and in fairness to taxpayers who ultimately "pay the bill") pose other "legitimate" incursions into transactions that might ideally be wholly private.[222]

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[220] See e.g. Powledge F., The Therapist as Double Agent, Psychology Today, July 1977, pp. 44-48; McDonald M., The Ethics of Psychiatry, Psychiatric News, July 15, 1977, pp. 1, 7, 21.

[221] Hussey, 1974, above.

[222] See, generally, Record Keeping in the Medical-Care Relationship, Chapter 7 in Personal Privacy in an Information Society, 1977 (above); see, Confidentiality, A Report of the 1974 Conference on Confidentiality of Health Records, American Psychiatric Association, 1974.

Some balancing of individual versus family versus societal rights is again required. The limits of confidentiality in a therapeutic relationship must be specified beforehand. The crucial "minimal standard" in addressing confidentiality, as in addressing other dilemmas of loyalty, is that all parties with a claim on the professionals' loyalty be fully informed in advance of the existence of confidentiality, or lack of it, and of any circumstances which may trigger an exception to the agreed-upon priorities. The individual being evaluated or treated then has the option of deciding what information s/he is willing to reveal and what risks to confidentiality s/he is willing to bear.

2. Forced Treatment

Individuals may be isolated, treated or "changed" because they are "dangerous" to society or in order to lessen societal costs of their deviant behavior. Philosophical and ethical arguments may serve either to defend or to circumscribe these practices.[223]

The consensus of our Panel is that it is clearly unacceptable that mental health professionals and mental health concepts be used to suppress political dissent.[224] However, another treatment issue of more common concern is the locus of care and/or treatment, which may not be for the maximum benefit of the person but may be more suited to the needs of family members or even seemingly demanded by the community.[225] Is it moral for society or a family to force a mentally disturbed member who is dangerously aggressive to undergo a behavior modification program or take a tranquilizing drug? Does it make a difference if the mentally disturbed person is either competent or incompetent?

While there is no consensus on the ethical "solutions" to these problems of forced treatment, some approaches may be recommended to lessen tensions and to increase alternatives. When there is family dissension, when the thera-

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[223] See Robinson D.N., Harm, Offense, and Nuisance, Some First Steps in the Establishment of an Ethics of Treatment, American Psychologist 29:233-238 1974; Shapiro M.H., Legislating the Control of Behavior Control: Autonomy and the Coercive Use of Organic Therapies, Southern California Law Review 47:237, 356, 1974.

[224] See discussion of Soviet abuse of psychiatry, the collaboration of psychiatrists and the state in the hospitalization of possibly nonmentally ill persons, in Robinson R.L. World Congress Condemns Abuse, Psychiatric News, Oct. 7, 1977, pp. 1, 8, 19.

[225] See e.g. Rachlin, S., Pam, A., Milton, J., Civil Liberties versus Involuntary Hospitalization, American Journal of Psychiatry 132: 189-192, 1975.

pist's activities may benefit some members of the family but not others, the therapist can attempt to secure a "contract" for treatment of the whole unit. This approach places some burden upon the family as well as upon the therapist to balance out the needs of differing individuals. Strengthening of community support systems and aid to families generally (financial and personal) may ease their burden in caring for the mentally disabled. Assuming intervention is needed, the principle of the "least restrictive alternative" should be respected. Finally, in the absence of legal incompetence to consent or its equivalent, the right to refuse treatment should be afforded patients whenever possible.

3. Nontherapeutic Research

Despite some risks, nontherapeutic research will undoubtedly continue to be conducted with mental health patients or clients. As described in the section on experimentation, nontherapeutic research is not for the subject's immediate good but because of legitimate needs for society to advance knowledge and on behalf of future patients.[226] The ethical justification for nontherapeutic research is, however, most clear when the experimentation relates to the condition from which the patient/client suffers.[227] However, the nonpatient population must also bear its brunt of the cost of new knowlege.[228]

B. *Legitimate Uses of Mental Health Knowledge*

1. The Ethics of Intervention

When interventions take place in the absence of available knowledge or without adequate available resources or without full consideration of the risks and benefits of intervening, ethical issues are generated. The complex ethical issues emanating from the EPSDT intervention program are illustrative—is identification of children at risk justified if no special services are forthcoming? How

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[226] See Goodwin F.K., On Behalf of Brown B.S., Statement to the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1976, p. 2; see generally, Curran W.J., Current Legal Issues in Clinical Investigation, with Particular Attention to the Balance Between the Rights of the Individual and the Needs in Society, in Ethics in Medicine, 1977 (above), pp. 296-301.

[227] See Jonas H. Philosophical Reflections on Experimenting with Human Subjects, in Ethics in Medicine, 1977 (above), pp. 304-315.

[228] See e.g. McCormick R.A., Experimental Subjects, Who Should They Be? Journal of the American Medical Association: 235:2197, 1976.

should the risk of unnecessary alarm to parents be balanced against the increased knowledge which would be conveyed by making available to them the results of screening? Should screening devices be used if there is a danger of cultural bias, with consequent mislabeling and stigma? How should the need for data be weighed against the interest in privacy?[229]

While to articulate these conflicts is by no means to rule out prevention or other intervention efforts, thoughtfulness is required.[230]

The point is that there *is* an ethics of intervention, with harm as well as benefit in the calculus. There should be no unexamined assumptions that the failure of present "therapeutic" efforts will be remedied only by more adequate "preventive" efforts. That which is experimental in intervention also requires evaluation. As in general health care, more empirically generated guidelines for prevention are necessary.[231]

2. Behavior Control

Mental health knowledge may be wanted for purposes of societal protection.[232] But knowledge developed secretly or expressly for nontherapeutic purposes impacts upon professional identities and roles. Such knowledge development may thus ultimately compromise the therapeutic effectiveness of professionals who work in normative settings (guilt by association). Considering past controversies concerning the appropriateness of biological warfare or the recent exposé of secret CIA experiments with hallucinogens, it may be questioned whether the development of mental health knowledge in no way intended for therapeutic purposes is ethical.

Concerning "behavior control"[233] more generally, the relevant issues overlap with those considered earlier under

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[229] See e.g. discussion in Chapter 7, Ethical and Legal Considerations, in Developmental Review in the EPSDT Program (Early and Periodic Screening, Diagnosis and Treatment Program), The American Association of Psychiatric Services for Children, Inc., 1977, pp. 32-45., and Early Screening Programs. Special Section on Developmental Assessment. American Journal of Orthopsychiatry Vol. 48 1, Jan. 1971.

[230] See e.g. Eisenberg L., The Ethics of Intervention: Acting Amidst Ambiguity, Journal of Child Psychology and Psychiatry 16:93-104, 1975.

[231] See e.g. Culliton B.J., Mammograph Controversy: NIH's Entree Into Evaluating Technology, Science 198: 171-173, 1977.

[232] See Wittenberg C.K., CIA Chief Reveals Behavioral Experiments, Psychiatric News, September 2, 1977, pp. 14, 15, 34.

[233] Halleck S.L. Legal and Ethical Aspects of Behavior Control, American Journal of Psychiatry 131: 381-385, 1974.

the heading "Forced Treatment." The ethical concerns are most acute with regard to somatic and behavioral procedures the "effectiveness" of which is not dependent upon voluntary cooperation by the patient.

The need is for protective safeguards and means to assure that procedures do not "depersonalize" care. Such guidelines have been forthcoming—and should become a more prominent part of the training of mental health professionals.[234]

3. Screening by Status

Mental health knowledge has been proposed as relevant to predicting later performance, e.g., proposed mental health screening for politicians, judges, lawyers, safe drivers, in order to prevent later delinquency (pre-delinquency) and, more generally, for employees.[235]

But if "status" does not highly and accurately predict future performance, then ethical issues arise (i.e., invasion of privacy, stigma, unnecessary harm caused consequent to the status of mental disability, etc.). Some mentally ill or disabled persons are without doubt poor politicians, poor judges, poor doctors, poor lawyers, poor employees, unsafe drivers and even delinquents or criminals. But so are many other persons. In light of the problem of predicting human behavior and because of the costs of doing otherwise, it is reasonable to insist that "it is by their behavior you shall know them." In the absence of behavior, status is unreliable; in the presence of behavior status is often unneeded. Limiting prediction by status will, as much as any other approach, contribute to decreasing the stigma associated with mental disorder.

4. Forensic Testimony

Forensic testimony raises several problems. Expert testimony by mental health professionals may fail to distin-

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[234] See, e.g., Roos P., Human Rights and Behavior Modification, Mental Retardation, June 1974, pp. 3-6; Friedman, "Legal Regulation of Applied Behavior Analysis in Mental Institutions and Prisons," 17 Ariz. L. Rev. 39 (1975).

[235] See e.g. Hutschnecker A.A., A Suggestion: Psychiatry at High Levels of Government, the New York Times, Wednesday, July 4, 1973, p. C15, col. 2: Kuvin S.F., Saxe D.B., Psychiatric Examination for Judges, the New York Times, December 21, 1975, p. 13, col. 1: Refusal to Answer "Treatment for Mental Disorders" Question Not Fatal to New Jersey Bar Admission, 1MDLR 232, 1976; Shlensky R., Psychiatric Standards in Driver Licensing, Journal of the American Medical Association 235: 1993-1994, 1976; Few Cheers for "Bad Seed" Tests for the Young, the New York Times, April 19, 1970, Sec. 4, p. 13, col. 5; McDonald M.C., Civil Service Kills Controversial Question, Psychiatric News, December 3, 1975, pp. 1, 13.

guish fact from opinion.[236]

Mental health professionals should be discouraged from relating clinical findings to the final legal question, i.e., who is dangerous, insane, competent to stand trial.[237]

These judgments are, as a matter of policy and logic, social and legal and not professional. Conclusory testimony contributes to the legal decisionmaker (judge or jury) abdicating responsibility to reach legal conclusions. Considering the stakes involved—hospitalization versus prison, the rights of persons to manage their affairs, involuntary treatment and detention—the presentation of conclusory legal opinions by mental health professionals (made worse by inadequate description of the actual clinical findings) may constitute a misuse of mental health knowledge.

To raise questions concerning the role of mental health experts is not to deny tactical requirements of the adversary system.[238] The search for justice requires the use of experts. But it is worthwhile to indicate that legal decisionmakers may be unduly swayed when they have not been apprised of the limits and the logic of scientific knowledge of mental health professionals.

5. Privacy versus the Public's Right to be Informed

Mental health professionals may comment or write about the mental health, the behavior and the psychodynamics of persons whom they have never evaluated or even met. In an open society, such behavior, if it is wrong at all, may be only a "venial sin." But commentary from a distance, even if amusing, may disrupt both the privacy of the individual and the fairness of legal proceedings.[239]

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[236] See e.g. Dix G.E., The Death Penalty, "Dangerousness," Psychiatric Testimony and Professional Ethics, American Journal of Criminal Law 5:151-214, 1977, (abuse of psychiatric testimony concerning the prediction of violence and the application of the death penalty); see, Greenland C., Psychiatry and the Dangerous Sexual Offender, Canadian Psychiatric Association Journal 22: 155-159, 1977 (problems of conclusory testimony and "double-agentry" in the handling of sex offenders.

[237] See Shah S.A., Some Interactions of Law and Mental Health in the Handling of Social Deviance, Catholic University Law Review 23: 674-719, 1974.

[238] Attention has also recently been drawn to the use of mental health knowledge in selecting and influencing juries. (See e.g. Goldstein T., The Science of Jury Selection, the New York Times, Feb. 16, 1975, p. 6, col. 4; Salisbury T.E., Forensic Sociology and Psychology: New Tools for the Criminal Defense Attorney, Tulsa Law Journal 12: 274-292, 1976). While there would be argument whether this use of mental health knowledge poses ethical problems, it has been pointed out that "the new techniques give an advantage to the wealthy." Such a formalized contribution to lawyerly instincts may also result in eventual distortion of the legal process.

[239] See comments of Dr. James A. Brussel, Newsweek, Aug. 29, 1977, p. 28, about David Berkowitz (Son of Sam): "His motive is irrational . . . and that is enough to prove he is incompe-

6. The Turned-On Society

Mental health knowledge may be used not only to relieve problems, but for pleasure and to reduce everyday stress. The new Administrator of the Alcohol, Drug Abuse, and Mental Health Administration has discussed the increasing use of antianxiety drugs as follows:

> The Declaration of Independence promises us life, liberty and the pursuit of happiness. The American public has come to interpret this as including the absence of anxiety, guilt, and insomnia and looks to the health care system for the means to pursue happiness . . . . My prediction is that these trends will continue well into the future, not so much because the growth of new technology has raised expectations but because of an expansion of the definition of acceptable means for utilization of the health care system.[240]

To flag this area is to take no strong position concerning its ethical importance. Assuming, however, that the stresses of everyday life must be met by all and that in so doing we "grow," then using mental health knowledge to enhance the quality of life should be a subject for ethical debate.[241]

C. *Professionalism versus Consumerism*

1. Patients' Rights and Staff Rights

There is now a revolution of expectations of the mental health consumer, a revolution which may be generally subsumed under the name of "patients' rights."[242] Patients' rights and staff rights may, however, conflict. For example, do other patients or staff have a right to be free from intrusion by an especially aggressive patient? Such conflict may also result in poor patient/client care.[243] More thought is required concerning "rights and responsibilities" of both patients/clients and staff in mental health care.

2. Interprofessional Conflict

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tent." This type of public pronouncement from a mental health professional can raise many problems.

[240] Klerman G.L., Mental Illness, the Medical Model, and Psychiatry, The Journal of Medicine and Philosophy 2: 220-243, 1977.

[241] See also discussion in Brill N.Q., Preventive Psychiatry, Psychiatric Opinion 14(6): 30-34, 1977.

[242] See e.g. Ennis B. and Siegel L., The Rights of Mental Patients, An American Civil Liberties Union Handbook, Avon Books, New York, 1973, and Friedman P., Rights of Mentally Retarded Persons, 1976.

[243] See e.g. Gibson R.W., The Rights of Staff in the Treatment of the Mentally Ill, Hospital and Community Psychiatry 27: 855-859, 1976.

The needs of professionals (in competition with one another) may jeopardize the needs of the public. It is readily agreed that "[t]here should no longer be divisive wedges among professions striving toward the common goal of providing a high quality, comprehensive, and coordinated system of health care equally accessible to all."[244] Achieving such interprofessional cooperation is, however, often difficult. Increasing divisiveness among professional mental health groups is to be anticipated as groups struggle for inclusion of their services in any national mental health insurance plan.

There are, however, approaches which may promote interprofessional cooperation rather than divisiveness. Periodic interdisciplinary meetings of the mental health professions might jointly review present practices, codes of conduct, position statements and the increasing responsibilities of all the professions to the consumer. "Competency-based" approaches should be explored as one means of dividing tasks between mental health professionals and assuring that each group is reimbursed for its services.[245]

Formulation of interprofessional codes delineating the responsibilities and the prerogatives of professions, one to another, may serve to unite them.

3. Ethical Codes

Ethical codes may restrict a dissemination of knowledge about professionals, their competencies and their availability and other information needed by the consumer.[246] Over the long run, some autonomy of the health professions in setting standards of conduct, regulating norms of practice and determining qualifications is in the public interest. But while professionalism protects the public, it also poses difficult issues concerning the sharing of knowledge and power.[247] The professional-patient relationship is now in flux. Attention needs to be directed to

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[244] Position Statement on Psychiatrists' Relationship with Nonmedical Mental Health Professionals. American Journal of Psychiatry 130: 386-390, 1973.

[245] See e.g. Nelson S.H., Current Issues in National Insurance for Mental Health Services, American Journal of Psychiatry 133: 761-764, 1976.

[246] See e.g. discussion in F.D.A. Begins 'Trial' of M.D. Societies, Medical World News, Sept. 19, 1977, pp. 21-22; see discussion of *Bates v. State Bar of Arizona*, 45 U.S. Law Week 4895, 1977, in Supreme Court Holds Lawyers May Advertise, American Bar Association Journal 63: 1092-1098, 1977.

[247] See generally Freidson E., Professional Dominance: The Social Structure of Medical Care, Atherton Press, New York, 1970.

both problems and benefits which may flow from "contractual ethics" in the professional-patient relationship and in the obtaining of mental health services.[248]

There are ways, we believe, in which a strengthening of the Codes of Ethics in the various mental health disciplines might contribute to resolution of a variety of ethical problems. Such codes serve at least three related functions.

While it is difficult to separate the effect of a formal code of ethics from other sources of ethical conformity, such as the professional's personal moral commitments, the codes perform an important *socialization function* in the training of neophyte mental health professionals. They serve to inculcate normative standards against which to measure alternative responses to future ethical dilemmas. By virtue of their authoritative, "official" endorsements, ethical codes may provide influential symbolic models for the performance of ethical behavior.

Secondly, ethical codes serve an increasingly large *screening function* in admitting mental health professionals into practice. In California, for example, psychologists must virtually recite the American Psychological Association Code of Ethics by heart during the licensing examination. Knowing ethical standards, of course, does not necessarily imply abiding by them, but a lack of such knowledge may attenuate ethical conformity. In this sense, the increased stress placed on ethical codes in professional initiation rites may help to promote ethical behavior.

Finally, ethical codes serve an important *monitoring function*. Through the threat of sanction for their violation—either losing membership in the professional organization or State licensure—the codes act as a deterrent against unethical professional conduct.

How might these three functions of professional codes of ethics be strengthened? First, a course in professional ethics should be required as part of the graduate curriculum in each of the mental health disciplines. While there has been a substantial increase in the literature on the ethics of psychological intervention, this literature has yet to become part of the "mainstream" of graduate education in

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[248] See e.g. Masters, R.D., Is Contract an Adequate Basis for Medical Ethics? An Examination of the Concept for Health Care. The Hastings Center Report 5(6): 24-28, 1975.

the mental health disciplines. It is treated as something the practitioner or researcher will "pick up" as s/he encounters ethical dilemmas. Moral crises, however, are better prepared for than reacted to. In the wake of the poverty of moral reasoning ability demonstrated by many attorneys in the Watergate scandal, the American Bar Association in 1974 voted that every ABA-approved law school:

> shall provide and require for all student candidates for a professional degree, instructions in the duties and responsibilities of the legal profession. Such acquired instruction need not be limited to any pedagogical method as long as the history, goals, structures and responsibilities of the legal profession and its members, *including the ABA Code of Professional Responsibility*, are all covered.[249]

Rather than waiting for a moral Watergate to occur in the mental health field, graduate education in applied ethics, emphasizing the implementation of professional codes of ethics, should be a required part of the curriculum in each of the mental health disciplines.

Secondly, state licensure examinations in the mental health disciplines should stress knowledge of professional codes of ethics and their implementation in specific problematic situations. While some states are emphasizing knowledge of codes of ethics in their licensing examinations in psychiatry, psychology and social work, there is much variability by state and by disciplines. The Commission might lend its prestige to reinforcing this trend toward a greater emphasis on ethical issues in screening procedures.

Finally, professional organizations should strengthen their capacity to investigate and act upon complaints of violations of their codes of ethics. Advisory opinions should be offered to professionals requesting an interpretation of the code in specific fact situations. All professions are notorious for their lack of self-regulation and the tendency to protect their own no matter how incompetent. The mental health disciplines are no exception. It is essential that professional organizations be goaded into

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[249] American Bar Association Standards and rules of Procedure, Section 302(a)(iii).

taking more seriously their obligation to monitor the ethical behavior of their members.

D. *Health Care As A Right*

1. The Right To Treatment

"Ethical problems" arise when rights are compromised in the name of treatment or care, yet no treatment or care is forthcoming or even potentially available. The *quid pro quo* requires (at a minimum) adequate staff, a decent treatment environment and the availability of programs, and an individualized approach to care.[250]

2. The Availability and Distribution of Resources

The problem of health-care delivery is closely tied to plans for national health insurance. Many arguments have been advanced, yet it seems fair to say that a genuine "right to health care" has not yet been recognized.[251] A future goal under any national health plan would be to preserve some "freedom of choice" for the consumer while assuring a more efficient and more adequate volume of available services.[252]

But ethical questions also arise concerning the distribution of present resources, geographically (urban-rural) and as a function of age (children versus the aged), but also as a consequence of wasteful and jerry-built systems of care.

Even "catchmenting" and other strategies for service provision may compromise the care of some difficult patients. The patient may not be able to choose where care is to be received. There is a mismatch between the patient and the ability or willingness of a sole provider to meet these needs.

Attitudes toward mentally handicapped persons may also restrict the provision of services, particularly in the area of reproduction and sexual freedom. Mentally handicapped individuals should have access to family planning and birth control services, including sterilization, on the

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[250] See Position Statement on the Right to Adequate Care and Treatment for the Mentally Ill and Mentally Retarded, the American Journal of Psychiatry 134: 354-355, 1977; see generally Hoffman P.B., Dunn R.C., Beyond *Rouse* and *Wyatt*: An Administrative-Law Model for Expanding and Implementing the Mental Patient's Right to Treatment, Virginia Law Review 61: 297-339, 1975.

[251] See generally Blackstone W.T., On Health Care as a Legal Right: An Exploration of Legal and Moral Grounds, Georgia Law Review 10: 391-418, 1976.

[252] See As the Nation Moves Toward National Health Insurance, What About the Mentally Ill? American Psychiatric Association, 1977.

same basis as any other person, but no such handicapped individual should be sexually sterilized except upon his or her own volition.

Years after the infamous *Relf*[253] case in Alabama, there continue to be frequent instances of attempts by parents, guardians and officials of mental institutions to secure the sexual sterilization of mentally handicapped (particularly mentally retarded) persons in their custody or control. The Task Panel believes that sterilization, like other family and birth control services, should not be denied to those handicapped persons who are of age, are capable of understanding the nature and consequences of the procedure and can manifest at least a genuine desire to be sterilized.

However, although the courts have reached mixed conclusions, the Panel believes that the better view of the law[254] and ethical considerations forbid sterilization of a mentally handicapped individual—*i.e.*, the irreversible denial of such individual's fundamental right to procreate—except upon the consent of the person to be sterilized, if s/he is capable of giving such consent. This means that parents, guardians and others may not give substituted consent to sterilization of their handicapped children or charges and that a handicapped person who is incapable of consenting may not be sterilized at all. This policy can be implemented at the Federal level by appropriate regulations governing Medicaid and other public health programs and at the State level by appropriate legislation.

Cost-control mechanisms will become increasingly important. Through standard-setting, the quality of care is enhanced. But subtly and not so subtly, cost-control mechanisms (PSRO - Utilization Review) may also jeopardize care.

The practitioner who properly orients himself to the needs of the individual patient/client is nevertheless confronted with societal needs to conserve resources and to promote efficiency of care.[255] The choice must sometimes

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[253] *NWRO and Relf v. Weinberger*, 372 *F. Supp.* 1196 (D.D.C. 1974), 403 *F. Supp.* 1235 (D.D.C. 1975), *vacated as moot*, No. 74-1787/76-1053, (D.C. Cir., September 13, 1977).

[254] See *Wyatt v. Aderholt*, 368 *F. Supp.* 1383 (M.D. Ala. 1974).

[255] See generally Burnum J.F., The Physician as a Double Agent, The New England Journal of Medicine 297: 278-279, 1977; Fried C., Rights and Health Care—Beyond Equity and Efficiency, The New England Journal of Medicine 293: 241-245, 1975.

be made whether to discharge or retain a patient who has no proper place to go, but who nevertheless no longer qualifies for third-party reimbursement. The choice of "treatment" may be dictated by the availability of third-party reimbursement (inpatient versus outpatient care). There are also problems of recordkeeping. Medical records dovetail with administrative requirements. Records may document a need for active care (but distort the severity of the patient's condition) so that retention in a facility is permitted. At a future time this may work against the patient's interest.

The multiple problems now arising in the area of cost control may be only suggested. Monitoring of cost-control mechanisms is necessary so that these not jeopardize patient/client care.[256]

Research at the expense of services also raises ethical questions. But a legitimate research enterprise (which *is* in the best interests of the public and patient/clients) requires a critical mass of trained personnel and available funds.[257]

3. Treatment (Medical or Social) for the Severely Disabled

Respect for life includes respect for life of the severely disabled. The value of persons is not a function of their productivity. By respecting the differences and the needs of severely disabled persons, society inculcates the values of altruism, empathy and generosity. The mentally disabled have treatment rights not only because they are persons with feelings but because, like all other persons, their life is valuable to society. This perspective deserves consideration when, for example, it is debated whether to prolong the life of a severely retarded person.[258]

It has been reported that doctors at prominent university hospitals routinely have allowed newborn children to die, with at least the tacit consent of the parent, when such children are born with obvious mental or physical handi-

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[256] See e.g. Price, S.J., Katz, J., Provence, M., An Advocate's Guide to Utilization Review, Clearinghouse Review 11(4): 307-331, 1977.

[257] See Brown B.S., The Crisis in Mental Health Research, American Journal of Psychiatry 134: 113-120, 1977.

[258] See problems raised by *Jones v. Saikewicz* No. SJC-711 (Mass. Sup. Jud. Ct., July 9, 1976), No. SJC 76-116 (Mass. Sup. Jud. Ct., Nov. 30, 1977), in Corbett, K.A., Raciti, R.M., Withholding Life-Prolonging Medical Treatment for the Institutionalized Person-Who Decides? New England Journal on Prison Law 3: 47-82, 1976 (question whether to administer painful treatment for leukemia to a profoundly retarded 67 year old man; "the incompetent patient's right to life deserves at least the same protection that the law affords competent people").

caps. Not infrequently, instances come to light where parents or guardians explicitly refuse life-sustaining medical care to such infants or to their older children or wards. Such denial of needed medical measures is not generally based upon religious tenets, but rather on the assumption that the life of a handicapped person, such as one who is severely or profoundly mentally retarded, is somehow less valuable than that of a "normal" individual. This rather shocking notion is gaining increasing respectability in some quarters.

Some Guidelines for Problem Resolution

The above discussion illustrates some ethical problems in the area of mental health care. The options and choices have not been discussed in any detail. Identification of problems does point to some general guidelines for resolution. The aim is to respect—to the greatest degree possible—both the needs and the autonomy of all persons in society.

1. Clarify Roles and Allegiances
   While in exceptional circumstances the needs of society cannot be overlooked, therapists owe primary allegiance to their patient/clients. Given conflict and the likelihood of "mixed allegiances," the therapist may attempt to establish a treatment contract not with the individual but with the larger social unit including the individual, e.g., the family. With foreknowledge, the therapist works for the best interests of the family, not for individuals.

2. Identify Level of Decisionmaking
   Again, therapists owe primary allegiance to their patients/clients. They cannot, for example, be expected to do a "social cost-benefit analysis" concerning a patient/client's treatment. There are different levels of obligation—one for therapists, another for administrators.[259] The task of allocating resources is best done from "above," i.e., by administrators and planners.

3. Responsiblities to Inform
   The allegiances and roles of the mental health professional and his/her level of decisionmaking should be shared with patients/clients prior to intervention or evaluation. This is partly a requirement for "informed con-

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[259] Fried 1975; see also Burnum 1975, Hiatt 1975.

sent" prior to intervention or evaluation, partly a requirement for patient-education, partly a matter of achieving social consensus regarding proper mental health roles.

4. Respect the Patients'/Clients' Right to Decide
The technical expertise of the professionals and their professional recommendation should be shared with patients/clients. But patient decisionmaking, while incorporating professional expertise, is not synonymous with professional decisionmaking. The final decision—whether or not to accept treatment, and what type of treatment is desired—is a decision which, save in exceptional circumstances, belongs to the patient.[260]

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[260] See e.g. Imbus S.H., Zawacki B.E., Autonomy for Burned Patients When Survival is Unprecedented, The New England Journal of Medicine 297: 308-311, 1977; see Slack W.V., The Patient's Right to Decide, The Lancet, Vol. 2, July 30, 1977, p. 240.

Appendix A: List of Recommendations

The recommendations of the Task Panel on Legal and Ethical Issues are set forth below. The reader should be aware, however, that certain important areas such as ethical issues, discussed in Section V of our report, do not culminate in recommendations.

Advocacy

Recommendation 1.

The President's Commission should support legislation which would establish and adequately finance a system of comprehensive advocacy services for mentally handicapped persons.

Recommendation 2.

The protection and advocacy (P&A) systems established in each State under the Developmentally Disabled Assistance and Bill of Rights Act as of October 1977 should be carefully evaluated and this approach to advocacy services should be supported if it proves effective. If it does, mentally ill persons should either be brought within the jurisdiction of the "P&A" systems or else a parallel system which will represent mentally ill persons should be established.

Recommendation 3.

The President's Commission should support efforts by which currently existing legal aid, legal services and public defender programs and the private bar at large can more adequately represent mentally handicapped persons at every stage at which such persons have contact with the mental disability system. These efforts should be directed at providing a continuity of legal care and should include, but not be limited to, the following:

(a) Recommending to the Legal Services Corporation that it establish a national support center to assist local offices in representation of mentally handicapped persons, and that it run special training programs so that members of local offices can effectively and adequately represent mentally handicapped persons.

(b) Endorsing legislation which would give the United States Department of Justice standing to litigate on behalf of mentally handicapped persons whose civil and/or constitutional rights have been violated.

(c) Endorsing legislation which would mandate the Law Enforcement Assistance Administration of the Department of Justice to provide economic, staff and training support to State and local public defender and prisoners' rights programs so as to provide more effective and adequate representation for mentally handicapped persons who have been criminally charged and/or who are incarcerated in jail or prison facilities.

Education

Recommendation 4.

The Department of Health, Education, and Welfare should vigorously implement and enforce the requirements of the Education of All Handicapped Children Act, Public Law 94-142, (20 U.S.C. §1401 *et. seq.*) and the new regulations implementing section 504 of the Rehabilitation Act (45 C.F.R. Part 84). A program of financial assistance, similar to the Emergency School Aid Act, should be initiated to help school districts with the costs of compliance. The funds for such a program could be drawn from other education programs that have outlived their usefulness such as Emergency School Aid and the Impact Aid program.

Recommendation 5.

As part of their right to education, mentally handicapped individuals should be provided with compensatory education services beyond ordinary age limits, where past deprivation of education makes this necessary.

Recommendation 6.

Institutionalized mentally disabled children must also be provided with an appropriate education, in a community setting wherever possible, as the Education for All Handicapped Children Act of 1975 requires. Surrogate parents, not drawn from institutional staff, must be appointed to protect the rights of such children when the natural parents are unavailable.

Recommendation 7.

Colleges and universities must be encouraged and assisted to train teachers and other education personnel in methodologies appropriate for instruction of severely handicapped individuals and for management of handicapped students in a regular classroom setting.

Recommendation 8.

States must be encouraged, assisted and required, if necessary, to provide training for parents, guardians, surrogate parents and lay advocates in the use of special education due process procedures, as well as for the hearing officers designated to conduct due process hearings. HEW should collect and analyze the transcripts and records of a representative sample of such hearings and take appropriate action to ensure that educational placement decisions are made after full and fair consideration of all relevant factors, including the views of those representing the interests of the student.

Employment

Recommendation 9.

The Task Panel endorses the efforts of the Department of Labor to enforce section 503 of the Rehabilitation Act and encourages voluntary compliance with both 503 and 504 by private employers who are not regulated by these sections.

Recommendation 10.

Title VII of the Civil Rights Act of 1964 should be amended to prohibit discrimination on the basis of handicap.

Recommendation 11.

State minimum wage and civil rights laws should be amended to prohibit discrimination against the handicapped.

Recommendation 12.

Congress should be requested to condition revenue sharing upon an agreement by State governments that mentally handicapped persons who, as employees, perform work of consequential economic benefit to the States shall be paid either the minimum wage or else wages which are commensurate with those paid nonhandicapped workers in the same vicinity for essentially the same type, quality and quantity of work, whichever is higher. States should be required, as a condition of revenue sharing, to agree to the same principles as are currently embodied in 29 CFR Part 529.

In the alternative, the provisions of 29 CFR Part 529 should be incorporated in their entirety into HEW regulations 45 CFR Part 84, subpart B (employment practices) implementing section 504 of the Rehabilitation Act of 1973.

Housing Within The Community

Recommendation 13.

(a) State zoning laws should be enacted which preempt local zoning ordinances and permit small group homes for the mentally handicapped to be considered as permitted "single family residential uses of property."

(b) States revising their zoning laws to avoid discrimination against mentally handicapped persons should be alert to the problems of restrictive building codes and/or mutual private restrictive covenants which would undermine the goal of reform.

(c) State zoning laws should also prohibit the excessive concentration of group homes in any single neighborhood or municipality within a State.

Recommendation 14.

(a) Title VIII, Fair Housing, of the Civil Rights Act of 1968 should be amended to prohibit discrimination in housing on the basis of mental handicap.

(b) The Department of Housing and Urban Development should (1) encourage States and localities to allocate additional community block grant funds to develop more group care facilities and (2) make additional rental assistance funds available to mentally disabled persons living in group homes.

Guardianship

Recommendation 15.

(a) State guardianship laws should be revised to provide:

(1) increased procedural protections including, but not limited to, written and oral notice, the right to be present at proceedings, appointment of counsel, a clear and convincing evidence standard as the burden of proof, a comprehensive evaluation of functional abilities conducted by trained personnel, and a judicial hearing which employs those procedural standards used in civil actions in the courts of general jurisdiction of any given State;

(2) a definition of "incompetency" which is understandable, specific, and relates to functional abilities of people;

(3) the exercise of guardians' powers within the constraints of the right to the least restrictive setting, with no change made in a person's physical environment without a very specific showing of need to remove a person to a more restrictive setting; and

(4) a system of limited guardianships in which rights are removed and supervision provided only for those activities in which the person has demonstrated an incapacity to act independently.

(b) Public guardianship statutes should be reviewed for their effect in providing services to persons in need of but without guardianship services.

Confidentiality

Recommendation 16.

Federal and State laws should recognize the principle that patients must have access to their mental health records and the opportunity to correct errors therein.

Recommendation 17.

Except where otherwise required by law, confidentiality of mental health information must be strictly maintained by all persons who have contact with such information. Mental health professionals must alert their patients at the outset of therapy about special conditions under which complete confidentiality cannot be maintained. States should also enact strong penalties for the inappropriate release of confidential materials by mental health professionals without the patients' consent.

Recommendation 18.

Consent forms for release of information concerning patients' histories should be limited to particular items of information in their records relevant to the specific inquiry posed by third parties who have a legitimate need for such information. Blanket release forms should be prohibited, and nonspecific requests for information should not receive response. Consent to release information should be of limited duration and should be revocable by the patient at any time. A record should be maintained in each patient's file describing what information has been released, when, to whom and for what purposes.

Recommendation 19.

Employers' questions to job applicants and employees must be related to objective functioning skills directly relevant to the specific job for which the applicant or employee is being considered.

Recommendation 20.

Third-party insurers should be encouraged to utilize peer review or other similar mechanisms which allow an evaluation of the necessity and appropriateness of treatment to be conducted while the patient's identity remains anonymous. Centralization and sharing of personal information without the express, written consent of the patient or client should be prohibited.

Recommendation 21.

The Task Panel has reviewed and generally supports the report of the Privacy Protection Study Commission, *Personal Privacy in an Information Society*, concerning confidentiality of medical records. Implementation of that Commission's recommendations should be required not just in Medicare/Medicaid institutions as the report suggests but by all facilities maintaining mental health records.

Federal Benefits

Recommendation 22.

Existing Federal statutes, regulations and programs should be reviewed for instances of discrimination aqainst mentally handicapped individuals. Appropriate legislative or administrative action should be taken to eliminate barriers and other restrictive provisions or practices.

Recommendation 23.

(a) Federal assistance programs should be administered and governing legal provisions modified, where necessary, to implement the principle of placement or treatment in the "least restrictive alternative" and to foster deinstitutionalization of mentally handicapped individuals. Appropriate measures might include the following steps:

(1) A class of intermediate care facilities for mentally ill persons, comparable to those for mentally retarded individuals and others but limited to a maximum of 15 beds, should be created under the Medicaid program.

(2) "Clinic services" should be a required rather than an optional service in Medicaid; the limitations on outpatient physician services in Medicare should be eliminated; and both Medicare and Medicaid

benefits should be made available for inpatient and outpatient services in community mental health centers for the mentally handicapped of all ages.

(3) The thrust of the current Medicaid intermediate care program for mentally retarded persons should be directed toward community-based, rather than institutional, facilities for mentally retarded persons, and appropriate changes should be made in the ICF/MR regulations where necessary to facilitate use of Medicaid funds for community-based programs. Medicaid should also be amended to require home health services for children under 21.

(4) The Department of Health, Education, and Welfare should strictly enforce the Medicaid standards for residential institutions for mentally retarded persons set forth in 45 CFR §§249.12 and 241.13 and should ensure prompt decertification of those large institutions which do not meet the standards.

(5) Preadmission or admission certification, peer review and utilization review and relevant PSRO activities requirements should be enforced in all inpatient facilities under Medicare and Medicaid to ensure that hospital, skilled nursing (SNF) or intermediate (ICF) care is provided only on the basis of individual need and that alternative, less restrictive placements are considered and provided when appropriate.

(6) HEW should require State plans submitted pursuant to Title XX of the Social Security Act (42 U.S.C. 1397 *et. seq.*) to address specifically the problems and needs of mentally handicapped persons who live in the community or who could live in the community if financial or other assistance were available.

(7) HEW should require State Developmental Disabilities Councils and other agencies funded under the Developmentally Disabled Assistance and Bill of Rights Act (42 U.S.C. 6001 *et seq.*) to focus their activities on deinstitutionalization of developmentally disabled individuals and on creation of community-based living arrangements' day programming and support services for such individuals. HEW should specifically prohibit use of D.D. Act funds for construction, renovation or expansion of large institutional facilities.

(8) HEW should develop regulations which require State mental health plans mandated under Pub. L. 94-63 (42 U.S.C. 2689t) and State health plans required under Pub. L. 93-641 (42 U.S.C. 300m-2(a)(2); 42 U.S.C. 300k-1 *et seq.*) to evaluate resources for community programs for the mentally handicapped and to plan for the development of community resources that will ensure that mentally handicapped persons are enabled to live in the least restrictive setting consistent with their individual needs.

(9) Federal guidelines for State regulation of group homes (board and care homes) where SSI recipients are living should emphasize the need to encourage personal independence and to provide access

to necessary health care and social services. The Department of Health, Education, and Welfare should ensure rapid compliance with the interim regulations requiring counselling, and social and other services for children under 7 as well as for those children unable to attend school.

(10) Federal AFDC foster care funds for children should be available only if out-of-home placement is in the least restrictive setting and in as close proximity to the child's home as is consistent with the child's special needs.

(11) The Department of Health, Education, and Welfare should, within the Office of the Secretary, examine the impact of Supplemental Security Income, Medicaid, and other Federal programs on the deinstitutionalization of mentally handicapped children, and develop specific proposals for reducing inconsistent fiscal incentives and regulations.

(b) As a direct, initial, positive step, the Federal government should develop within 180 days of the Commission's report a coordinated response to and plan for implementation of the recommendations contained in the GAO report of January 7, 1977, "Returning the Mentally Disabled to the Community—Government Needs to Do More."

Recommendation 24.

Necessary steps should be taken to adapt and, where necessary, expand "generic" Federal programs so that they meet the needs of mentally handicapped individuals. Provisions in the laws creating such programs which are designed to assist the mentally handicapped should be fully and promptly implemented.

Recommendation 25.

Federal program and funding agencies should promptly promulgate and enforce regulations implementing section 504 of the Rehabilitation Act of 1973, which specifically prohibits discrimination against handicapped persons by any recipient of Federal funds.

Recommendation 26.

There should be periodic program reviews of the utilization of federally funded benefits and services by the mentally handicapped in order to assess the quality and quantity of services provided and to determine their effectiveness in meeting the needs of the mentally handicapped and in promoting independent living.

The Right To Treatment And To Protection From Harm, The Right To Treatment In The Least Restrictive Setting and The Right To Refuse Treatment And The Regulation of Treatment

Recommendation 27.

The President's Commission in its final report should endorse the underlying legal and ethical bases for the right to treatment and protection from harm, the right to treatment in the least restrictive setting and the right to refuse treatment and the regulation of treatment. The Federal and State governments should be encouraged to protect these rights by legislation and other appropriate action.

Experimentation With Mentally Handicapped Subjects

Recommendation 28.

An educational campaign must be directed to the general public with regard to individual opportunity and obligation to participate in the advancement of scientific knowledge. A disproportionate share of the risk for the benefit of society as a whole should not be assigned to "convenient"—often institutionalized—populations, including mentally handicapped individuals. Rather, to the extent possible, such persons should bear *less* risk than those who are more able to make free and uncoerced decisions.

Recommendation 29.

(a) Covert experimentation involving risks ought never to be permitted, regardless of the asserted justification, and full disclosure of such matters as research risks, expected benefits and the right to refuse participation must be made to potential subjects and, where appropriate, to their parents, surrogate parents or legal guardians.

(b) Experimentation which is neither directly beneficial to individual subjects nor related to such subjects' mental condition and which poses any degree of risk to such subjects should not be permitted with institutionalized mentally handicapped individuals.

(c) Research performed for the direct benefit of a mentally handicapped subject after nonexperimental procedures, if any, have been exhausted should be permitted where the risk/benefit ratio is favorable and there are adequate procedures for obtaining the subject's consent or, where appropriate, the consent of the subject's parent, parent surrogate or legal guardian. High-risk experimental procedures such as psychosurgery should be permitted, if at all, only upon the informed consent of the subject himself; some such procedures ought to be prohibited altogether, at least with respect to institutionalized individuals.

Recommendation 30.

At a minimum, research upon mentally handicapped individuals for the purpose of obtaining new scientific or medical information should be conditioned upon the following requirements:

(a) The research protocol must undergo independent review for scientific merit of the research design and for competence of the investigator.

(b) The institution, if any, in which the research is to be conducted must meet recognized standards for medical-care, direct-care and other services necessary to meet the increased demands imposed by research activities, in addition to the ordinary requirements of adequate care and treatment.

(c) The proposed research must not reduce the level of habilitative or rehabilitative services available either to research participants or to patients or clients not included in the project.

(d) The experimentation must involve an acceptably low level of risk to the health or well-being of the research subjects.

(e) The proposed research should relate directly to the prevention, diagnosis or treatment of mental disability and should seek only information which cannot be obtained from other types of subjects. Such information should be of high potential significance for the advancement of acknowledged medical or scientific objectives related to mental disability.

(f) Research involving risk may be performed only on patients or clients who are actually competent to consent to participation therein and who have in fact given such consent. Substituted consent to procedures involving risk should not be permitted except in the most unusual and compelling circumstances and never in the face of objections, however expressed, by the patient or client himself. All consent should be subject to review and approval by an independent body, with an opportunity for patients or clients to be advised and represented in this process by an independent advocate (who may be an attorney).

(g) All subjects, and where appropriate their parents or guardians, should be provided with and informed of their right to any follow-up care necessitated by unforeseen harmful consequences of the research project.

Recommendation 31.

(a) Whatever schema is eventually put forward by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research should be considered as tentative and subject to continuous review.

(b) A permanent National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, with a membership including mentally handicapped individuals and/or former patients or institutional residents and parents of children with mental handicaps should be established to evaluate and, if necessary, modify the policies resulting from the recommendations of the current Commission and to monitor the performance of institutional review boards and other bodies charged with protection of the rights of research subjects.

Civil Commitment

Recommendation 32.

The civil commitment system as it exists in most States today should be drastically reformed. Responsible arguments can be made for modified abolition of civil commitment, for authorizing commitment only of "dangerous" persons or for time-limited involuntary commitment of persons who are mentally handicapped and also incompetent to make treatment decisions.

Recommendation 33.

(a) Whatever substantive commitment standard is adopted, even-handed adminstration should be promoted by the use of specific definitions and criteria.

(b) The Department of Health, Education, and Welfare should fund studies to ascertain the differential effects of commitment criteria in jurisdictions which have adopted different models of involuntary civil commitment.

Recommendation 34.

Voluntary mental health and protective services should be made easily available to those who seek them.

Recommendation 35.

(a) Commitment procedures should be adopted to ensure fair resolution of the issues at stake.

(b) Procedural protections should include, but not necessarily be limited to, initial screening of potential commitment cases by mental health agencies, a prompt commitment hearing preceded by adequate notice to interested parties, the right to retained or assigned counsel, the right to a retained or assigned independent mental health evaluator, a transcript of the proceedings, application of the principle of the least restrictive alternative, a relatively stringent standard of proof (at least "clear and convincing" evidence), durational limits on confinement (with the ability of a court to specify a period of confinement short of the statutory maximum) and the right to an expedited appeal. At the commitment hearing, the rules of evidence shall apply and the respondent should have the right to wear his own clothing, to present evidence and to subpoena and cross-examine witnesses. Ideally, the petitioner should also be represented by counsel.

Mental Health Issues Affecting Persons Accused or Convicted Of Crimes

Recommendation 36.

Mental Health Services to Prisoners

(a) Mentally handicapped persons incarcerated in jails and prisons should have reasonable access to quality mental health services which are delivered on a truly voluntary basis with confidentiality comparable to that which exists in private care. This can occur only if participation in treatment is unrelated to release considerations. Medicaid reimbursement should be extended to include voluntary jail and prison mental health care.

(b) In order for mental health services to be truly voluntary and optimally effective, prisons must first establish minimally adequate physical and psychological environments. The Department of Justice should place a high priority on allocating Federal grant funds to the improvement of prison living conditions.

(c) Prisoners from racial or ethnic minority groups should have access to mental health professionals from similar backgrounds.

(d) If a mentally handicapped prisoner is transferred involuntarily from a prison to a mental hospital, the involuntary transfer should be preceded by procedural protections equivalent to those available in ordinary civil commitment. Indeed, such "commitment-like" procedures should be followed even before a prisoner receives involuntary mental health treatment within a correctional institution itself.

(e) In cases where a mentally handicapped prisoner desires mental health treatment and where mental health and correctional authorities concur that a hospital setting would be appropriate and beneficial to the prisoner, procedures should be developed for effectuating a voluntary hospital admission. The prisoner's good-time and parole opportunities ought not to be jeopardized by the transfer—in fact, good-time and parole opportunites should not be jeopardized even for involuntarily committed prisoners.

(f)(1) Mental health professionals, as a general rule, should decline to provide predictions of future criminal behavior for use in sentencing or parole decisions regarding individual offenders.

(2) If a mental health professional decides that it is appropriate in a given case to provide a prediction of future criminal behavior, s/he should clearly specify:

(a) The acts being predicted;
(b) The estimated probability that these acts will occur in a given time period; and
(c) The factors on which the predictive judgment is based.

Recommendation 37.

(a) Evaluations to determine whether a defendant is competent to stand trial should be performed promptly and should, if possible, be performed in the defendant's home community and on an outpatient basis. Outpatient dispositions should be considered in certain instances even for defendants found, after evaluation and hearing, to be incompetent to stand trial.

(b) A defendant who, because of psychotropic medication, is able to understand the nature of the proceedings and to assist in his defense, should not automatically be deemed incompetent to stand trial simply because his satisfactory mental functioning is dependent upon the medication, and should have the option of going forward with his trial.

(c) Recent proposals by legal commentators to abolish the incompetency plea (and to substitute for it a trial continuance and then a trial with enhanced defense protections) are deserving of further study.

(d) At a minimum, the limitations imposed by *Jackson v. Indiana* upon the nature and duration of incompetency commitments ought to be acknowledged and enforced nationwide.

Recommendation 38.

(a) Laws authorizing the involuntary committment of sexual psychopaths and other "special" offenders (such as "defective delinquents") should be repealed.

(b) Persons who are now being committed as sexual psychopaths or "special" offenders should instead be:

(1) Processed through and treated in the criminal justice-correctional system, or

(2) Given the option whether to be treated within (i) the correctional system or (ii) a therapeutic system in which the period of confinement could not exceed the applicable criminal law maximum sentence.

Bills of Rights

Recommendation 39.

The President's Commission should recommend to the legislatures of the individual States that legislation be enacted providing a "Bill of Rights" for all mentally handicapped persons, both those who are institutionalized and those residing in the community.

Recommendation 40.

The President's Commission should recommend to the States that all currently existing laws establishing rights of patients, of persons in treatment and of residents of hospitals, facilities for the retarded or similar institutions should be prominently displayed in all living areas, wards, hallways and other common areas of all such facilities, and should be incorporated into all staff-training and staff-orientation programs as well as in educational programs directed to patients, staff, families and the general public. Explanation of rights to patients should be clearly and simply stated and in a language the patient understands; the explanation should be read to any patient who cannot read.

National Initiatives in Legal and Ethical Issues

Recommendation 41.

NIMH and other appropriate HEW components should establish special offices concerned with legal issues affecting the mentally ill and the developmentally disabled, respectively. These offices should be charged with (1) keeping the staff of NIMH and HEW informed about legal and ethical issues affecting mentally handicapped persons, (2) providing continuing advice from that perspective on program and policy issues, (3) promoting advocacy on behalf of the mentally handicapped, (4) promoting attention to legal issues in Federal programs for the mentally handicapped, and (5) promoting interdisciplinary exchange.

Recommendation 42.

NIMH and other appropriate HEW components should fund innovative programs at law schools and mental health professional schools or other appropriate institutions which are designed to develop persons with policy, administrative and direct-service responsibilities in both the mental health and the legal system who will be knowledgeable about the delivery of services and the legal and ethical issues involved with patient care. Financial support should also be given for innovative in-service training programs at service facilities which are designed to provide continuing education for service providers concerning legal and ethical rights and for training projects for lawyers, judges, and non-lawyer advocates. These agencies should also support research into legal and ethical issues and problems, such as those highlighted in this report.

Appendix B: Research and Training Initiatives

Listed below, for the reader's convenience, are all the research and training recommendations found throughout this report:

Advocacy

Recommendation 2.

The protection and advocacy (P&A) systems established in each State under the Developmentally Disabled Assistance and Bill of Rights Act as of October 1977 should be carefully evaluated and this approach to advocacy services should be supported if it proves effective. If it does, mentally ill persons should either be brought within the jurisdiction of the "P&A" systems or else a parallel system which will represent mentally ill persons should be established.

Recommendation 3.

The President's Commission should support efforts by which currently existing legal aid, legal services and public defender programs and the private bar at large can more adequately represent mentally handicapped persons at every stage at which such persons have contact with the mental disability system. These efforts should be directed at providing a continuity of legal care and should include, but not be limited to, the following:

(a) Recommending to the Legal Services Corporation that it establish a national support center to assist local offices in representation of mentally handicapped persons, and that it run special training programs so that members of local offices can effectively and adequately represent mentally handicapped persons.

(c) Endorsing legislation which would mandate the Law Enforcement Assistance Administration of the Department of Justice to provide economic, staff and training support to State and local public defender and prisoners' rights programs so as to provide more effective and adequate representation for mentally handicapped persons who have been criminally charged and/or who are incarcerated in jail or prison facilities.

Education

Recommendation 7.

Colleges and universities must be encouraged and assisted to train teachers and other education personnel in methodologies appropriate for instruction of severely handicapped individuals and for management of handicapped students in a regular classroom setting.

Recommendation 8.

States must be encouraged, assisted and required, if necessary, to provide training for parents, guardians, surrogate parents and lay advocates in the use of special education due process procedures, as well as for the hearing officers designated to conduct due process hearings. HEW should collect and analyze the transcripts and records of a representative sample of such hearings and take appropriate action to ensure that educational placement decisions are made after full and fair consideration of all relevant factors, including the views of those representing the interests of the student.

Guardianship

Recommendation 15.

(b) Public guardianship statutes should be reviewed for their effect in providing services to persons in need of but without guardianship services.

Civil Commitment

Recommendation 33.

(b) The Department of Health, Education, and Welfare should fund studies to ascertain the differential effects of commitment criteria in jurisdictions which have adopted different models of involuntary civil commitment.

Mental Health Issues Affecting Persons Accused Or Convicted Of Crimes

Recommendation 37.

(c) Recent proposals by legal commentators to abolish the incompetency plea (and to substitute for it a trial continuance and then a trial with enhanced defense protections) are deserving of further study.

National Initiatives In Legal And Ethical Issues

Recommendation 42.

NIMH and other appropriate HEW components should fund innovative programs at law schools and mental health professional schools or other appropriate institutions which are designed to develop persons with policy, administrative and direct-service responsibilities in both the mental health and the legal system who will be knowledgeable about the delivery of services and the legal and ethical issues involved with patient care. Financial support should also be given for innovative in-service training programs at service facilities which are designed to provide continuing education for service providers concerning legal and ethical rights and for training projects for lawyers, judges, and non-lawyer advocates. These agencies should also support research into legal and ethical issues and problems, such as those highlighted in this report.

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