Developments in Patients' Bill of Rights Since the Mental Health Systems Act

by
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Background

The Mental Health Systems Act of 1980 (MHSA)[1] was a comprehensive federal statute on the provision of mental health services, intended as a legislative realization of the 1978 Report of The President's Commission on Mental Health.[2] The Commission and the MHSA were important initiatives of President Carter; however, the MHSA did not survive the Carter Administration. Most of the statute was repealed, soon after President Reagan took office, by provisions of the Omnibus Budget Reconciliation Act.[3] One MHSA section that escaped repeal was section 501, the Patients' Bill of Rights.

The MHSA's Bill of Rights may have survived because it was considered relatively harmless. The section originally reported out of the Senate Committee had provided for enforcement of the rights of consumers of mental health services through individual causes of action and funding curtailments, but, as amended on the Senate floor and finally adopted, all of the enforcement provisions were deleted.

The Senate debate on section 501 indicated that Congress assumed that existing state laws on patient rights were generally sufficient.[4] The provisions of the MHSA's Bill of Rights as enacted were therefore not made mandatory, and merely recommended that the states "review and revise, if necessary," their mental health laws in light of the MHSA rights. In a previous study,[5] however, we found great disparity between the level of rights protection granted in most state statutes at that time, and the rights Congress recommended. The Congressional assumption as to the then current level of state statutory protection of patients' rights was in error. Substantial amendment of state laws would therefore have been needed to meet the standard declared by the MHSA. (Judicial decisions and administrative regulations in a number of states had recognized additional rights not surveyed in our previous study.)

Five years have now passed since the MHSA was enacted. The current study tests whether the Congressional recommendation to "review and revise" state rights statutes has been carried out. Case law and administrative regulations remain outside the scope of the study.

Method

We attempted to determine whether any legislature had conducted a full-scale "review and revis[ion]" of its mental health rights laws since 1980, anywhere in the 50 states and the District of Columbia. We examined the statutes to determine if any jurisdiction had adopted additional rights, or amended existing ones, for consumers of mental health services. We also sent several waves of questionnaires to the commissioner of each state department of mental health and the president of each state mental health association (MHA). We asked these informants whether and how their state laws had been revised as a check on our independent research. We also asked them if there had been revisions, whether the content of the MHSA's recommendations, or the fact of Congress' request, had played a part in the changes of their state's law. In addition, we invited their comments on Congress' choice of a recommendation to the states.

The return rate on our questionnaires was satisfactory: 48 out of 51 jurisdictions (94 percent) on the DMH survey and 22 out of 51 (44 percent) on the MHA survey. At least one DMH or MHA responded in 50 out of 51 of the jurisdictions (98 percent), including all of the states where our research showed that amendments had been

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Research underlying this article was supported by an endowment established by the UPS Foundation — the charitable arm of the United Parcel Service — and by the National Institute of Mental Health, NIMH Training Grant 5 T24 MH5901. We thank our diligent research assistants Thomas Milhaupt and Lorie Dewhirst, J.D., candidates at the USC Law Center. We also thank the state mental health officials and mental health association leaders who cooperated in the survey.

adopted.

The MHSA's Bill of Rights specifies its provisions in 25 subsections. State statute changes since 1980 correspond to 17 of them, which are summarized in Table 1.

Findings

National trend

Our study revealed no widespread movement toward reviewing and revising state statutes to adopt the consumers' rights recommended by the MHSA. Thirteen states have amended their patients' rights statutes since 1980; 38 (including D.C.) have not. The most changes were made by Mississippi (10 changes), Maryland (nine), Hawaii (eight) and Kentucky (eight). The other nine states made five or fewer changes. Of the 13 states that have amended their state codes since 1980, only Hawaii statutes now provide consumers virtually all the rights recommended in the MHSA.

Nationally, there were amendments to state law involving 17 MHSA rights. The provisions most changed (five states each) involved the rights to a treatment plan; consumer participation in planning; consumer access to records; and after-care referral. Other common changes (four states each) revised provisions relating to the right to treatment in a least restrictive setting; treatment planning participation; freedom from restraint or seclusion; confidentiality of records; the right to private conversations, telephone, mail and visitors; information regarding other rights; and access to an advocate.

Of the 59 individual changes made, 34 constituted adoption of a right recommended in the MHSA by a state that had not previously granted it in any form. Nineteen changes were partial adoptions by states of MHSA rights previously not granted. Six changes were expansions by states of rights, where state law already had partially satisfied the MHSA definition of a right.

Table 1 also sets out the extent to which the 13 states taking action since 1980 have amended their codes as to each of the 17 MHSA provisions. The statutory citations of these changes are included as footnotes, so that readers of this article in any state will be able to confirm the text of the law and check for subsequent amendments or judicial interpretations.

Impact of the MHSA

The MHSA apparently had little influence in bringing about state revision of consumers' rights statutes. Of the 13 states making changes, officials in only one state (Hawaii) indicated substantial MHSA influence. Those in five others indicated it had significant or some influence, and those in seven states indicated that the MHSA had no material effect. Of the 37 states that have not pertinently amended their codes since passage of the MHSA, in 34 states the MHSA apparently had no influence. Ohio and Pennsylvania officials reported that their legislatures reviewed their state statutes in light of the MHSA, but did not revise them, as their consumers' rights laws were deemed sufficient. Informants in one state gave no reply.

Developments in case law appear to have influenced state review and revisions of consumers' rights statutes at least as much as the MHSA. Officials in Alabama, Louisiana, Massachusetts, and Utah indicated that court decisions, and not the MHSA, were a factor in securing consumers' rights. One respondent in Texas reported that both case law and the MHSA had influenced the legislature to amend its statutes.

Hawaii officials were strongly influenced by the MHSA. The Hawaii Mental Health Association stated that the legislature's "total revision of our weak statutory Bill of Rights [was] based *entirely* on the federal Mental Health Systems Act Bill of Rights," and that the MHSA "served as a catalyst to initiate our review of the state statutes." It also reported that "[we] use (and continue to use) the President's Commission report language in testimony, for background and for specific recommendations in patients' rights and on many other issues." The Hawaii Department of Health corroborated that assessment of MHSA influence on Hawaii law.

Our questionnaire also solicited comments on Congress' choice to pass a purely advisory act. The Minnesota Department of Mental Health and Mental Hygiene reflected the sentiment of several state officials who responded to this question. "In my judgment, such recommendations will not have very much significance in very many states and this compromise, I think, illustrates that something of this magnitude has to be a mandate or it is not likely to be readily assumed by most state and local governments and facilities."

Similarily, Illinois began a review of state provisions, but reported that "when [the MHSA] was essentially never implemented. . . this review did not proceed any further." A different view was stated by an Oregon official. "In my opinion, it is neither necessary nor appropriate for Congress to direct the states concerning state laws regarding patients' rights and patient advocacy."

Changes state-by-state

Tables 2 and 3 detail state law revisions since passage of the MHSA, which are of three types: full adoption of an MHSA-recognized right not previously granted clients in any form; partial adoption of an MHSA right not previously granted; and extension of a state consumer right toward MHSA standards. All these revisions are set forth — first the states with extensive changes (adopting or expanding eight or more rights as recommended by the MHSA), followed by states with less extensive revisions (five or fewer such changes).

Discussion

Several lessons may be learned from the states' responses to the MHSA. It is clear that eliminating the enforcement provisions from the MHSA severely limited its effect. Illinois, for example, abandoned its review of its statutes because of the amendment that made the act's Bill of Rights merely advisory. Moreover, some of the post-1980 state law revisions may have come about regardless of the MHSA. The comments of the Hawaii Department of Health and of the Texas Mental Health Association seem to indicate strong local support for these reforms, independent of the MHSA.

Furthermore, the remarks of the Oregon official reflect some state concern about the central issue with which

Table 1
MHSA Rights Adopted by State Laws Since 1980

§501 Section Number	Summary	States AZ	CA	CT	FL	HI	ID	IL	KY	MD	MN	MS	MT	TX	Totals
(1)(A)	The right to appropriate treatment and related services in a setting which is most supportive and least restrictive of a person's liberty.	N	N	N	A[6]	N	N	N	N	A[7]	N	P[8]	N	A[9]	4
(1)(B)	The right to an individualized, written treatment or service plan.	N	N	N	P[10]	A[11]	N	A[12]	N	N	N	A[13]	N	P[14]	5
(1)(C)	The right, consistent with one's capabilities, to participate in and receive a reasonable explanation of the care and treatment process.	N	N	N	A[15]	N	N	N	A[16]	A[17]	N	P[18]	N	A[19]	4
(1)(D)	The right not to receive treatment without informed, voluntary, written consent, except in a documented emergency or as permitted under applicable law for someone who has been civilly committed.	N	N	N	N	N	E[20]	N	P[21]	N	N	N	N	N	2
(1)(E)	The right not to participate in experimentation in the absence of informed, voluntary, written consent.	N	N	N	N	A[22]	N	N	N	A[23]	N	N	N	A[24]	3
(1)(F)	The right to be free from restraint or seclusion except in an emergency situation pursuant to a contemporaneous written order by a responsible mental health professional.	N	N	N	N	N	P[25]	N	A[26]	A[27]	N	P[28]	N	N	4

A—Post-1980 adoption of MHSA right; P—Post-1980 partial adoption of MHSA right; E—Post-1980 expansion of existing law to more fully adopt MHSA right; N—No post-1980 action

Table 1
MHSA Rights Adopted by State Laws Since 1980
(continued)

§501 Section Number	Summary	States AZ	CA	CT	FL	HI	ID	IL	KY	MD	MN	MS	MT	TX	Totals
(1)(G)	The right to a humane treatment environment that affords reasonable protection from harm and appropriate privacy.	N	N	N	N	N	N	N	P[29]	P[30]	N	N	N	A[31]	3
(1)(H)	The right to confidentiality of personal records.	N	N	N	N	A[32]	N	N	A[33]	A[34]	N	E[35]	N	N	4
(1)(I)	The right to have access to personal mental health records and have a lawyer or legal representative have reasonable access to records if the patient provides written authorization.	N	A[36]	N	N	A[37]	N	N	N	A[38]	A[39]	A[40]	N	N	5
(1)(J)	The right to private conversations, reasonable access to telephones and mail, and to visitation during regular visiting hours.	N	N	N	N	E[41]	N	N	P[42]	N	E[43]	E[44]	N	N	4
(1)(K)	The right to timely and meaningful information about one's rights at the time of and after admission.	N	N	N	N	N	N	E[45]	N	N	P[46]	P[47]	P[48]	N	4
(1)(L)	The right to assert grievances with regard to the infringement of rights.	N	P[49]	N	N	N	N	N	P[50]	N	N	N	N	N	2
	The right to have a fair, timely and impartial grievance procedure provided.	N	N	N	N	N	N	N	N	N	N	N	N	N	0

A—Post-1980 adoption of MHSA right; P—Post-1980 partial adoption of MHSA right; E—Post-1980 expansion of existing law to more fully adopt MHSA right; N—No post-1980 action

Table 1
MHSA Rights Adopted by State Laws Since 1980
(continued)

§501 Section No.	Summary	States AZ	CA	CT	FL	HI	ID	IL	KY	MD	MN	MS	MT	TX	Totals
(1)(M)	The right of access to, including private communications with, any available rights protection service or qualified advocate.	N	P[51]	N	N	A[52]	N	N	N	N	P[53]	A[54]	N	N	4
(1)(N)	The right to exercise other rights without reprisal, including denial of appropriate treatment.	N	N	N	N	A[55]	N	N	N	N	N	N	N	N	1
(1)(O)	The right to referral as appropriate to other providers of mental health services upon discharge.	A[56]	N	A[57]	P[58]	N	N	N	N	A[59]	N	A[60]	N	N	5
(2)(B)	The right to confidentiality of and access to records continues following one's discharge.	N	P[61]	N	N	N	N	N	P[62]	A[63]	N	N	N	N	3
(3)(C)	The patient has a right that his attorney or legal representative has reasonable access to the patient/client, the facility at which the patient resides and, with written authorization, the patient's medical and service records.	N	N	N	N	A[64]	N	N	N	N	N	N	N	N	1
TOTALS		**1**	**4**	**1**	**4**	**8**	**2**	**2**	**8**	**9**	**4**	**10**	**1**	**5**	**59**

A—Post-1980 adoption of MHSA right; P—Post-1980 partial adoption of MHSA right; E—Post-1980 expansion of existing law to more fully adopt MHSA right; N—No post-1980 action

Table 2
States With Extensive Changes in Consumer Rights Adopted Since the MHSA

State	Change
Hawaii	Fully adopted seven additional consumers' rights recommended in the MHSA: the rights to an individualized treatment plan, nonparticipation in experimentation, confidentiality of records, access to records, access to an advocate, freedom from reprisal, and legal counsel's access to the consumer. Expanded one MHSA-recommended right: a consumer's right to visitors unless he is considered dangerous.
Kentucky	Eight changes made in its mental health code provisions since 1980. Fully adopted three recommended MHSA rights: a consumer's right to participate in planning and treatment services, freedom from restraint or seclusion, and the right to confidentiality of records. Now provides recipients five additional rights representing partial adoptions of MHSA recommendations: provides a general right to informed consent for treatment, but consumers' decisions may be overruled if no permanent side effects will result from the refused mode of treatment or if no less restrictive modes of treatment are available; consumers may keep, maintain, and use personal possessions and money and receive visitors; consumers have the right to assert grievances through *habeas corpus*; former consumers may seek expungement of their records but are not explicitly guaranteed access to them.
Maryland	Made nine changes in its consumer rights statutes since the MHSA, of which seven constitute full adoption of MHSA guidelines: the rights to treatment and least restriction of liberty, participation in planning treatment services, nonparticipation in experimentation, freedom from restraint or seclusion, confidentiality of records, access to records, and referral upon discharge. Partially adopted two rights recommended in the MHSA: the right to protection from harm and abuse and confidentiality of records for former consumers.
Mississippi	Has made ten changes affecting mental health consumers, of which four constitute full adoption of their MHSA counterparts: the rights to an individual treatment plan, consumer access to records, consumer access to an advocate, and referral upon discharge. Four revisions constitute partial adoption of MHSA guidelines: the rights to treatment best adapted to rendering further treatment unnecessary, to have one's treatment plan reviewed with the patient, freedom from restraint, and to be informed of rights in writing at admission. Expanded two previously existing rights provisions since the passage of the MHSA: patients' records are confidential and not merely available to the general public for inspection; visits or calls with a personal physician, attorney, or spiritual advisor are unrestricted, and other mail and telephone use is permissible if the medical welfare of the consumer is not harmed.

Table 3
States With Five or Fewer Additional Rights Adopted Since the MHSA

State	Change
Arizona	Now provides consumers with referrals upon discharge, constituting full adoption of an MHSA-recommended right.
California	Grants consumers four additional MHSA rights, one of which constitutes full adoption of an MHSA right not previously afforded consumers in this state — access to records. Three other changes are partial adoptions of MHSA rights: protection of the right of consumer to be informed of the right to assert grievances through *habeas corpus*, a general right to counsel, and records access by former consumers.
Connecticut	Fully adopted the right to referral upon discharge.
Florida	Four subsequent changes made, of which two are full adoptions of MHSA rights: the rights to treatment and least restriction of liberty and to participation in planning treatment services. Other two changes are partial adoptions — consumers now are entitled to an individualized, written, (though not updated) treatment plan and are entitled to seek post-discharge treatment from a professional or agency of choice.
Idaho	Partially adopted one MHSA right — consumers have the right to freedom from seclusion. Expanded a previously adopted right: previously a facility could override a patient's right to refuse specific modes of treatment for good cause, but now a facility may do so only if the patient is incapable of giving consent or in an emergency.
Illinois	Fully adopted one additional MHSA right — the right to an individual treatment plan, and has expanded another MHSA right — consumers are now to be informed of their rights in sign language if necessary.
Minnesota	Fully adopted the right of consumer access to records. Partially adopted two other MHSA rights: consumers now have a right to be informed of other rights at admission and a general right to counsel. Expanded a patient's mail privileges to include the right to send and receive sealed mail unless restricted by the head of the facility.
Montana	Partially adopted one MHSA right — consumers now have the right to be informed of their rights at admission in writing.
Texas	Fully adopted four MHSA rights: the rights to treatment and least restriction of liberty, to participate in planning services, to nonparticipation in experimentation, and to a humane treatment environment. Has also partially adopted another MHSA right — consumers now have the right to an individualized (though not written or periodically updated) treatment plan.

Congress was concerned — at what level of government consumers' rights should be protected.

The limited state response to the MHSA's Bill of Rights may not be due solely to its advisory nature. Even mandatory federal laws in other fields, attempting to require changes in state statutes or social welfare programs, have not always been followed by the expected changes. And even the provision of federal funding tied to compliance with detailed requirements may do no more than produce short-term, superficial results. For example, such is the opinion of many observers about the history of the implementation of a predecessor of the MHSA — the federal Community Mental Health Centers program — where many believe that the statute not only failed to produce the results expected, but may well have been harmful.

Among other examples in recent years of the phenomenon of state failure to follow federal statutory requirements are laws with the objectives of creating jobs for the hard-core unemployed, building new towns, and creating behavior guidelines for teachers. Bardach concluded that "the character and degree of many implementation programs are inherently unpredictable. Even the most robust policy. . . will tend to go awry. The classic symptoms of underperformance, delay, and escalating costs are bound to appear."

The MHSA's Bill of Rights was neverthelesss important as a step in legitimatizing the very idea of rights for those who receive mental health services. Its content may have had influence on practice, legal advice, regulations, or court decisions, even if it was not incorporated in state statutes.

Our study shows that while Congress deferred to the states to allow them primacy on revision of consumers' rights, most state legislatures have not taken up the invitation to review their laws to bring them up to the federal standards.

Conclusions

This study has tested the relationship between one *legal* change (the MHSA's Bill of Rights) and another (state law revisions) and has found the effect to be limited. We have not carried out any measurements of changes in mental health service *practices* in regard to patients' rights, though our estimate from informal observation and study of reports of service programs is that the changes since 1980 are not extensive. At the same time, we believe that the *attitude* of concern with patients' rights among professionals and the public is much greater now than it was a few years ago. Considering these three types of variables — legal changes, changes in practice among service agencies, and development of concern for rights — the likely causal relationships are interactive. While the legal change — the MHSA — may have influenced attitudes and practices as well as influencing other laws, the changing attitudes themselves helped bring about the MHSA itself, as well as influencing the other legal changes reported here and whatever changes in practice have occurred.

Footnotes

1. Mental Health Systems Act of 1980, Pub. L. No. 97-35, §501, 95 Stat. 357 (1981). *See generally,* H.A. Foley & S.S. Sharfstein, *Madness and Government: Who Cares for the Mentally Ill,* 118-34 (1983).
2. President's Commission on Mental Health. *Report to the President.* Vol. I. Washington, D.C.: U.S. Government Printing Office.
3. Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, 95 Stat. 357.
4. 126 *Cong. Rec.* S. 9729, 9736 (Sen. Morgan); S. 9730 (Sen. Hatch); S. 9735 (Sen. Danforth); S. 9736 (Sen. Javits); S. 9744 (Sen. Roth).
5. Lyon, Levine and Zusman, *Patients' Bills of Rights: A Survey of State Statutes,* 6 Ment. Dis. L. Rep. 178 (1982).
6. Fla. Stat. §394.453(1) (1982).
7. Md. H.G. §10-701(c)(1) (1983).
8. Miss. Code Ann. §41-21-102(b) (1984).
9. Tex. Code Ann. 92 §5547-80b(1) (1983).
10. Fla. Stat. §394.459(2)(e) (1982).
11. Hawaii Rev. Stat. §334E-2(a)(7) (1984).
12. Ill. Rev. Stat. ch. 91½ §3-209 (1981).
13. Miss. Code Ann. §41-21-102(b) (1984).
14. Tex. Code Ann. 92 §5547-80(b)(4) (1983).
15. Fla. Stat. §394.459(2)(e) (1982).
16. Ky. Rev. Stat. §202A.191(1)(a), (b) (1982).
17. Md. H.G. §10-706(c) (1983).
18. Miss. Code Ann. §41-21-102(b) (1984).
19. Tex. Code Ann. 92 §5547-80(b)(4) (1983).
20. Idaho Code §66-346(c) (1981).
21. Ky. Rev. Stat. §§202A.191(1)(c), 202A.196 (1982).
22. Hawaii Rev. Stat. §334E-2(a)(10) (1984).
23. Md. H.G. §10-707 (1983).
24. Tex. Code Ann. 92 §5547-80(b)(3) (1983).
25. Idaho Code §66-345 (1981).
26. Ky. Rev. Stat. §202A.191(1)(h) (1982).
27. Md. H.G. §10-701(c)(3) (1983).
28. Miss. Code Ann. §41-21-102(1) (1984).
29. Ky. Rev. Stat. §202A.191(1)(d) (1982).
30. Md. H.G. §10-701(c)(4) (1983).
31. Tex. Code Ann. 92 §5547-80(b)(5) (1983).
32. Hawaii Rev. Stat. §334E-2(a)(14) (1984).
33. Ky. Rev. Stat. §202A.091 (1982).
34. Md. H.G. §10-701(d) (1983).
35. Miss. Code Ann. §41-21-97 (1984).
36. Cal. Health & Safety Code §25250 (6a) (1981).
37. Hawaii Rev. Stat. §334E-2(a)(15) (1984).
38. Md. H.G. §10-701(d)(3) (1983).
39. Minn. Stat. §253B.03(7) (1982).
40. Miss. Code Ann. §41-21-102(f) (1984).
41. Hawaii Rev. Stat. §334E-2(a)(21) (1984).
42. Ky. Rev. Stat. §202A.191(1)(e) (1982).
43. Minn. Stat. §253B.03(2) (1982).
44. Miss. Code Ann. §41-21-101 (1984).
45. Ill. Rev. Stat. ch. 91-1/2 §3-205 (1982).
46. Minn. Stat. §253B.03(10) (1982).
47. Miss. Code Ann. §41-21-102(9) (1984).
48. Mont. Code Ann. §53-21-114 (1983).
49. Cal. Welf. & Inst. Code §5424.1 (1982).
50. Ky. Rev. Stat. §202A.151 (1982).
51. Cal. Welf. & Inst. Code §§5325(h), 5326 (1983).
52. Hawaii Rev. Stat. §334E-2(a) (21) (1984).
53. Minn. Stat. §253B.03 (1982).
54. Miss. Code Ann. §41-21-102(2), (5) (1984).
55. Hawaii Rev. Stat. §334E-2(a)(3) (1984).
56. Ariz. Rev. Stat. §36-543(A) (1983).
57. Conn. Gen. Stat. §17-206c (1982).
58. Fla. Stat. §394.459 (14) (1982).
59. Md. H.G. §10-708 (1983).
60. Miss. Code Ann. §41-21-82 (1984).
61. Cal. Health & Safety Code §25252(a) (1981).
62. Ky. Rev. Stat. §202A.091 (1982).
63. Md. H.G. §10-712(c) (1983).
64. Hawaii Rev. Stat. §334E-2(a)(21) (1984).