Rights of Ex-Patients in the Community: The Next Frontier?*

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Perhaps the most significant comment which can be made about the topic of "rights in the community" is simply, that it is a topic. Although the "right to treatment" concept is less than two decades old,1 questions as to the adequacy of treatment date back, at the least, to the Middle Ages:2 "right to refuse treatment" theories3 might appear new or "radical" to some;4 however, the origins of the concept date back to Blackstone.5 Of course, insanity defense questions have plagued the judicial system since Lord Bracton wrote in the 1200's.6 Yet, the seemingly relatively-innocuous topic of "rights of the mentally handicapped7 in the community" was not even conceptualized as a topic for cocktail party conversation until the past several years;8 although its recent growth has hardly been meteoric,9 and in spite of general backsliding by the United States Supreme Court in the general area of "rights to services in the community,"10 it has become an area of significance to all practicing mental health attorneys and to mental health professionals as well. Hopefully, it will be one of those areas in which there is general agreement between the two, and, much more importantly, it is likely that it is the one area in which further rights development will realistically be one giant step on the rocky and often Sisyphus-like road towards "normalization" of former patients, as well as a first step towards the meaningful eradication of the stigma of the label of "psychiatric patient."

In many ways, of course, the whole bundle of community rights could not have even come into theoretical existence had not the right to treatment and least restrictive alternative litigation developed as they had. Those cases — which firmly entrenched the concepts of both procedural11 and substantive12 due process in the legal fabric of mental health law — were the first legal recognition of the overwhelming and virtually irreversible burden which saddled persons labeled deviant by the mental health and judicial systems. Cases such as Lessard v. Schmidt,13 Wyatt v. Stickney,14 and O'Connor v. Donaldson15 — when read together — established basic legal principles which would serve as the important groundwork for future legal developments: there is a constitutional right to liberty16 (the "natural state of individuals"),17 before one can be

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deprived of that right, the process of deprivation must comport with strict due process procedures\(^\text{18}\) to minimize the risk of error\(^\text{19}\) (and to place such risk on the committing agency, not the person at risk)\(^\text{20}\) so that institutionalization is seen as the last resort;\(^\text{21}\) if a person is to be institutionalized, that institutionalization cannot meet constitutional muster if it does not offer a person a reasonable opportunity to receive such care and treatment in a humane environment as to enhance that person's likelihood of being released;\(^\text{22}\) while institutionalized, similar due process concepts should mandate that a person is not stripped of his other civil rights simply because he is a mental patient;\(^\text{23}\) in fact, it is impermissible to presume a person incompetent to manage his affairs because of his status as a patient.\(^\text{24}\)

It is equally important to note that decisions such as \textit{Wyatt} and \textit{Lessard} cannot be viewed — even by the most resistant to change — as aberrant or idiosyncratic. Virtually every post-\textit{Wyatt} treatment case has cited it with approval;\(^\text{25}\) indeed, \textit{Wyatt} is seen as the progenitor of virtually all of the "Patients' Bills of Rights"\(^\text{26}\) which have been enacted in the past six years, and which the prestigious President's Commission on Mental Health has urged all states to adopt as well.\(^\text{27}\) Similarly, virtually every challenge to commitment procedures based on the \textit{Lessard} theory has been successful;\(^\text{28}\) in the rare instances where challenges to legislation have been turned back, invariably there has been a revision of court civil practice rules to comply with \textit{Lessard}-level mandates.\(^\text{29}\) Indeed, in turning down Florida's claim in \textit{O'Connor} that treatment issues were not justiciable by courts, the United States Supreme Court specifically rejected such a notion, pointing out it was "plainly unacceptable" to suggest that courts are powerless to determine "adequacy of treatment."\(^\text{30}\)

As discussed above, of course, this development of mental health rights law must be seen as a logical culmination of the expansion of such parallel fields as civil rights, consumer rights, criminal procedure and inmates' rights: \(^\text{30A}\) to a large extent, mental health law is at the crossroads of all of those paths, as an outgrowth of a process by which lawyers have become able to contribute to "public consciousness of inequities or shortcomings in the society"\(^\text{30B}\) through "substantive concerns with issues of social policy."\(^\text{30C}\)

The logical progression from \textit{Brown v. Board of Education}\(^\text{30D}\) to \textit{Gideon v. Wainwright}\(^\text{30E}\) to \textit{O'Connor v. Donaldson}\(^\text{30F}\) should thus be clear. Patients and former patients are merely replicating the experiences of thousands of other American citizens who have, in recent years, begun to seek relief through the courts as a means of redressing civil grievances.\(^\text{30G}\) Again, it must be underscored that this new court involvement must be considered in relation to those traditionally institutionalized in large, public psychiatric hospitals (and thus, those to be released from such facilities) — the poor, the minorities, the voiceless, those persons traditionally isolated from the mainstream of the
majoritarian, democratic political system. This backdrop is significant, of course, for reasons far beyond the specific issues resolved in the cases in question. It is of incalculable symbolic value in any attempt to predict how courts will respond to similar challenges raised on behalf of patients (and former patients) to practices in the community which deprive them of their civil rights. Again, this shift in focus was underlined by the Task Force Panel on Legal and Ethical Issues in its report to the President's Commission on Mental Health:

"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 to basic civil rights and privileges that they too often experience in the community."

Although the report is probably unduly optimistic in two of its assumptions — that abuse and deficiencies in institutions will be reduced commensurately with reduced institutional populations, and that advocates will be able to "shift" their efforts from one population to the other — it is important, nonetheless, as a first serious recognition on the Federal level that "rights in the community" will continue to grow in importance in both the immediate and long-term future.

In examining "rights in the community," then, it appears that there are at least two bundles of issues involved which must be looked at through slightly different filters: issues which arise directly involving an individual's status as ex-patient (or as one still receiving psychiatric services), and those which arise as a corollary to such a status. Although the legal theories propounded in both types of cases may have similar bases, and although constitutional due process and equal protection considerations may apply in all matters, it is clear that, socially and politically, different variables may be present in the two types of cases.

At the outset, it should be noted that a group of cases has arisen under the general (if somewhat imprecise and overbroad) rubric of "right to aftercare." These cases have, by and large, emanated from the right to treatment litigation, and have focused on the need to extend treatment rights theories to community settings. The first, and most significant, arose in Washington, D.C., in the context of the hardly-atypical world of St. Elizabeth's Hospital: hundreds of patients, including many elderly persons, were being improvidently held at the facility because, in the pat phrase of both the institutional and the community social service providers: "There's nowhere else for them to go." In that case, Dixon v. Weinberger, the Federal District Court found that, under D.C. law, the plaintiffs had a statutory right to aftercare, and that that right had been violated as a result of the D.C. Government's failure to provide suitable Rights of Ex-Patients
alternative facilities for those St. Elizabeth's Hospital patients who no longer met statutory criteria for hospitalization. The court ruled that there was a specific affirmative obligation on the part of District officials to place those patients "determined suitable for placement in alternative facilities in proper facilities that are less restrictive alternatives to the hospital... such alternatives including but not being limited to nursing homes, foster homes, personal care home's and halfway houses."33A

Although Dixon was originally viewed as, perhaps, another breakthrough on the level of a Wyatt or a Lessard, it has not yet lived up to that reputation. In the first instance, bluntly, many of the ordered transfers simply never took place: although the hospital agreed during the trial that about 43% of the patients were ready for community living, and although clinical staff even identified nearly 1300 candidates for deinstitutionalization (out of a population of 2700), hospital officials soon backtracked, claiming that only 402 of those patients were truly appropriate candidates for placement. Although many of the original targets for deinstitutionalization remain in the hospital, they have been reclassified as "unacceptable for community living because of inappropriate, although not dangerous, social behavior such as wandering, disrobing, throwing temper tantrums, and verbally abusing others."34 Again, the special HEW assistant secretary in charge of improving mental health services at St. Elizabeth's has repeated, "Where are we going to put all these people?"35

This inaction, it should be noted, has not gone uncommented upon. Inadequacy of compliance by Federal officials was the basis for a specific recommendation by the President's Commission's Task Force discussed above, that "HEW promptly take all actions necessary to implement the Dixon ruling and to extend its application to all relevant Federal programs."35A As of the writing of this paper, of course, this recommendation has not been implemented. Not surprisingly, attorneys for the Dixon patients are back in court on the question of the acceptability of the implementation plan finally drawn by D.C. and federal officials. One example of the conflict: HEW wants to convert vacant buildings of the old D.C. Children's Hospital into a "multiservice facility" for released patients; such a facility, its officials assert, "would not be an institution... but a protected environment to help its residents adjust to life in the community."36 Again, not surprisingly, the patients' lawyers oppose the idea: "To concentrate former mental patients in large vacant structures of a kind and size not commonly used by other members of the community and to isolate them from normal contacts that they would otherwise have, may well obstruct their reintegration into the community."37 The books, then, are hardly closed on the Dixon case.38

Another case brought on the same general basis as Dixon was settled successfully in 1978 in Maine, when officials of that state signed a settlement decree in Federal Court affirming the right of released mentally handicapped persons to receive, in the community, "habilitation,
including medical treatment, education, training and care, suited to their needs, regardless of age, degree of retardation or handicapped condition. Although attorneys for plaintiffs in the case hailed the decision as "the next important step" beyond the traditional right-to-treatment decisions, the ink is still barely dry on the decree, so it cannot yet be determined what empirical substantive effect it will have on whether state officials simply will, in fact, do what they have promised to do in court. Similar litigation has been concluded in Massachusetts, but again, it is still not yet clear if the state is complying.

Although it is not specifically articulated in either the District of Columbia or Maine cases, it appears that the decisions were premised, to some extent at least, on the legal theory which suggests that in situations where further inpatient confinement is "predictably antitherapeutic, further confinement must be deemed to effect a continuing violation of due process." That theory is the underpinning of the arguments forwarded by plaintiffs and amicus in a similar New Jersey case on the right to aftercare which has been awaiting trial for over three years; however, as of this date, there is still no indication of a trial date being set. Probably the most significant decision in this line, however, will prove to be an action brought on behalf of residents of a large Pennsylvania institution in Halderman v. Pennhurst State School and Hospital, where a Federal District Court held that the equal protection clause of the United States Constitution "prohibit[ed] the segregation of the retarded in an isolated institution such as Pennhurst where habilitation does not measure up to minimally adequate standards," and ordered that "immediate steps be taken to [thus] remove the retarded residents from Pennhurst," commensurate with the exercise of "great caution and care ... to make certain that each and every retarded resident who is removed from Pennhurst can be accommodated in a community facility which will provide minimally adequate habilitation." Again, although plaintiffs' attorney's prediction that the Halderman case will "spell the end of more than a century of incarceration for the retarded in the United States" is highly speculative, it is clear that the opinion is a drastically new and unprecedented approach — based upon a "right to non-discriminatory habilitation" (a theory arrived at by analogizing from such landmark civil rights cases as Brown v. Board of Education which outlawed racial segregation in public school systems) — which will undoubtedly spawn similar, imitative suits in other jurisdictions. When this happens, it is likely that — at least on a symbolic and theoretical level — the decision will have the same impact on deinstitutionalization issues that Wyatt had on matters involving treatment: it will "repaint the landscape for all time."

Aftercare cases, of course, are not the only area of community rights directly involving the ex-patient's status as a former patient, especially if he/she is still receiving psychiatric services at, e.g., a community mental health center. There has been little litigation yet brought on behalf of such
patients; this probably due to a combination of factors, including lack of access to counsel (those few governmentally-funded programs that exist concentrating primarily on representation of institutionalized patients or persons threatened by a loss of liberty)\(^5\) and to a traditional (still common) feeling that, with spaces at such community facilities at such a premium, once a patient was discharged from a hospital to a community center, he/she would not want to "rock the boat" and imperil his/her preferred status as outpatient.\(^4\) It is inevitable, though, that with each year, more actions will be brought to vindicate rights directly related to one's status as a participant in such facilities.

The few cases actually litigated have concentrated on issues involving the records of a patient's stay at an institution: the degree of confidentiality required, and the applicability of expungement statutes to such records. In a consent decree in one Pennsylvania case, a federal court ruled that city outpatient clinics must adopt stringent rules "with respect to maintaining the confidentiality of the medical records of all persons who have undergone or are presently undergoing treatment"\(^5\) at such centers; in another case in that state's local courts, it was ordered that a former patient was entitled to copies of "all medical records" which were amassed during his hospitalization at a private inpatient psychiatric clinic.\(^6\) Similarly, in those states which have enacted expungement laws, the court trend is generally towards a liberal interpretation of such criteria as "cured" or "restored to reason"\(^6\) as to expand the potential class of ex-patients who might avail themselves of the prophylactic effects of the statutes; in fact, some legislatures are now amending such laws to include patients "in substantial remission" as part of the class that can seek such expungement.\(^6\)

The *tabula*, however, is particularly *rasa* in the knottier area of treatment rights: do community-based patients, *e.g.*, have the right to "minimally adequate treatment"\(^6\) in such facilities? Do they have the right to refuse treatment?\(^5\) If they do receive treatment, can the facility exert the sanction of expulsion (or, in the increasingly common fact pattern through which a person is diverted to a Community Mental Health Center as a probationary term in lieu of jail for a petty offense or misdemeanor, if he/she refuses treatment, can he/she be sent to jail on the theory that he/she has violated a term of probation)? Are community facilities governed by state enacted "Patients' Bills of Rights" which establish rights to due process hearings prior to the involuntary imposition of electroshock? Can First Amendment rights of freedom of speech and expression be abrogated by such centers? If a therapist feels it is detrimental to the patient's best interest, can he/she contact the local welfare or unemployment office and suggest the patient be denied benefits? Although these questions are all couched hypothetically, it is clear that all of these circumstances have arisen in the recent past. It is not a particularly radical prediction to suggest that many of them will be the subject of litigation in the ensuing years.
These issues to the side, however, there remains the entire bundle of rights in the community which arises in contexts *corollary* to the subject’s status as ex-patient. Although there is, at this point in time, at least, “no presently recognized right to services”59 for any American citizens in the community, case after case has been brought vindicating the civil rights and basic rights of citizenship of individual mentally handicapped persons (and classes of such persons). In this context, the mental health lawyer takes the view that the central issue is one of “welfare entitlements” and that, based on the theory of recent United States Supreme Court developments in this area,60 what used to be characterized as “governmental largesse” should be considered a right rather than a privilege: within this framework, the lawyer’s role is to maximize the gains of otherwise-qualified persons in demanding their right to such entitlements.60A Importantly, there is usually a high degree of consensus between mental health advocates and service providers on the need for vindication of such rights and on the importance of such rights to formerly-hospitalized persons.60B

Thus, courts have outlawed status discrimination against former patients in such areas as voting rights,61 drivers’ license suspensions,62 zoning,63 employment,64 and welfare65 and SSI benefits.66 It is true that these decisions have been generally idiosyncratic and reactive; however, they are most likely an important first step on a legal path which will eventually see litigation on behalf of former patients in all areas of community living, including such uncharted areas as professional licensure, admission to institutions of higher education, and availability of adequate housing.66A New approaches to litigation will also be necessary in such areas as discrimination by nursing homes against former patients66B and extension of the concept of “fair share” housing plans to the mentally handicapped:66C creativity must be the byword.

In addition to litigation, former patients and their advocates have been turning to legislatures to enact bills similarly banning such status discrimination. Many “Patients’ Bills of Rights” now include blanket antidiscrimination language.66D Section 504 of the Rehabilitation Act of 197367 further appears to open new doors in the areas of recreation, employment, education and social services (although the issue of whether that section implies a so-called “private cause of action”68 is still not settled). The President’s Commission’s Task Force recommendation that the Civil Rights Act of 1964 be amended to include persons with mentally handicapping conditions as a protected class69 has still not been acted upon by Congress; yet individual states are just beginning to amend their counterpart *state* antidiscrimination laws to include the mentally handicapped and/or the former patient.70 Again, it is still not clear what ultimate effect these statutory changes will have on the way such persons are treated in the community.

Finally, of course, it is acknowledged by all concerned that litigation, legislation, executive orders and court rules will have little empirical
effect if nothing is done to attempt to reverse the pattern of social and cultural stigma as a result of which discrimination persists and "a large portion of the public 'continues to be frightened and repelled by the notion of mental illness,' "70A a stigma specifically acknowledged recently by the United States Supreme Court in the Addington (burden of proof) case.70AA The President's Commission aptly noted that this stereotypic stigmatization was a major stumbling block in the path of meaningful community treatment,70B noting, again accurately, that "people with chronic mental disabilities are the most rejected and stigmatized of all, particularly because disproportionate numbers of them are also elderly, poor or members of racial or ethnic minorities."70C As the focus on legal issues shifts in some significant part to the community, these issues cry out for greater clarification and understanding.

What is clear, however, is this: the litigation and legislation discussed above have helped create a climate in which the question of "rights in the community" can no longer be seen as a merely intellectual abstraction or topic for law review commentary; that new climate should help rid society of the heretofore prevalent atmosphere in which, in the words of former Assistant United States Attorney General, Patricia Wald, the handicapped person has been perceived as "someone to whom attention need not be paid,"71 and should replace it with a new sense that each person, whether or not a former patient, is ensured that "equal access to justice [which] is the cornerstone of the American judicial system."72

References

7. This, of course, includes those perceived as handicapped. See, e.g., 29 U.S.C.A. § 706 (6) (c); 45 C.F.R. § 84.3, implementing 29 U.S.C.A. § 794.
8. The first cases arose in the early 1970's in matters involving the need for due process prior to suspension of former patients' drivers licenses. See, e.g., Jones v. Penny, 387 F. Supp. 1131 (M.D. Ala. 1974); Freitag v. Carter, 489 F. 2d 1377 (7 Cir. 1973)
9. See generally, cases discussed at notes 61-66, below
13. See note 11, above
14. See note 12, above
It is of some significance, however, that the law books have not been particularly
supplemented by new cases. As of July 1979, Shepherd's Citations reveals no example of
Dixon having been cited in any other reported opinion.

Landmark decree signed protecting rights of mentally retarded in Maine, Mental Health Law
Project Press Release (July 14, 1978), at 1

Perlin: Deinstitutionalization, note 30A, above, at 31

Brewster v. Dukakis, Civil Action No. 76-4423F (D. Mass. 1977)
41. Saphire: The civilly-committed public mental patient and the right to aftercare, 4 Fla St U L Rev 232, 286 (1976)
42A. For discussions of the underpinnings of the doctrines in question see generally, Saphire, note 41, above: Ensinger and Reilly: The legal and social significance of aftercare systems: A review and analysis, 5 J Psych & L 229 (1977)
44. Although Halderman dealt specifically with mentally retarded persons, the principles in the court's holding are equally applicable to cases involving other mentally handicapped persons
45. Halderman, 446 F. Supp., above, at 1322
46. Id. at 1325
47. Id.
48. Ferleger: The future of institutions for retarded citizens: The promise of the Pennhurst case, Mental Retardation and the Law (July 1978), at 28, 31
49. Halderman, 446 F. Supp., above, at 1321
50. 347 U.S. 483 (1954)
51. See note 12, above
52. Perlin: Rights of the mentally handicapped, 4 Bull Am Acad Psych & L 77, 78 (1976)
53. See, e.g., N.J.S.A. 52:27E-21 et seq. (establishing jurisdiction of Division of Mental Health Advocacy in New Jersey's Department of the Public Advocate); see generally, 4 App., Task Panel Reports, note 31, above, at 1367
56A. See, e.g., In re Application for Expungement Records of D.G., 162 N.J. Super. 404, 407, 392 A. 2d 1257 (Cty. Ct. 1977) ("The terms 'recovered' and 'improved' in this case are interchangeable . . .")
57. Cf., e.g., Wyatt, above
58. Cf., e.g., Rennie, above
59. See Gilhool, note 10, above
60B. See generally, Perlin: Training lawyers as mental health advocates, in Symposium: National Conference in Developing Training Programs for Patient Rights (in press)
62. See, e.g., cases cited at note 8, above
64. Although the plaintiff in Gurmankin v. Costanzo, 411 F. Supp. 982 (E.D. Pa. 1976), aff'd 556 F. 2d 184 (3 Cir. 1977), was blind — rather than mentally disabled — the same principles would apply under 29 U.S.C.A §794
66A. Bills have been introduced into Congress, e.g., to amend Title VIII of the Fair Housing Act of 1968 to include the mentally handicapped as a protected class. See, e.g., H.R. 2540, S. 506 (96th Cong., 1st Sess.). Passage of such legislation is recommended at 4 App., Task Panel Reports, note 31, above, at 1391
66D. See, e.g., N.J.S.A. 30:4-24.2a
67. 29 U.S.C.A. §794
68. See Southeastern Community College v. Davis, — U.S. —, 99 S. Ct. 2361, 2366, n.5 (1979); but see also, NAACP v. The Medical Center, — F. 2d—, 47 U.S.L.W. 2811 (3 Cir. 1979) (decided seven days prior to Southeastern Community College)
Editor's Note: Since this paper was originally prepared, the Third Circuit Court of Appeals substantially affirmed the District Court's decision in *Halderman v. Pennhurst State School and Hospital*, 612 F. 2d 84 (3 Cir. 1979). Whereas the lower court had held that the equal protection clause supported a right to non-discriminatory habilitation "prohibit[ing] the segregation of the retarded in an isolated institution such as Pennhurst where habilitation does not measure up to minimally adequate standards," the Circuit eschewed the Constitution and based its holding instead on the Developmentally Disabled Assistance and Bill of Rights Act, ruling that, as part of the law's guarantee of treatment in the least restrictive environment, "the clear preference of the Act... is deinstitutionalization," and that institutionalization of the retarded would be appropriate only in those "probably comparatively rare [cases where] adequate habilitation could not be accomplished in any setting less restrictive than an institution."

The Circuit's only major modification of the District Court's decision reversed that portion of the lower court's order which ruled that Pennhurst must be entirely closed, reasoning that, as "there may be some individual patients who because of advanced age, profound degree of retardation, special needs or for some other reason, will not be able to adjust to life outside of an institution and thus will be harmed by such a change," and ordered a remand for "individual determinations as to the appropriateness of an improved Pennhurst for each patient," noting that, on remand, the court "should engage a presumption in favor of placing individuals in [community facilities]. It simultaneously warned that, if the facility is to remain open, "it must be dramatically improved so as to provide adequate habilitation," and cautioned that, before transfers could be made to community facilities, there must be "assurances that the sanitary, staffings and program deficiencies which were found at Pennhurst [will not be] duplicated on a smaller scale in [the community facilities]... where changes in the size of buildings and their location are not enough to meet the statutory requirements."

Subsequently, the United States Supreme Court has granted certiorari, and has stayed only that portion of the order which would have allowed transfers of Pennhurst patients to the community over the objections of the residents' parents. Oral argument is scheduled for the 1980-1981 United States Supreme Court term.