

PART

2

RIGHTS AND INDEPENDENCE

CHAPTER IV

THE RETARDED CITIZEN AND THE LAW

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Between October 1971 and July 1973 at least forty-one court actions were initiated in the federal and state courts of the United States on behalf of persons classified as mentally retarded. None known to this writer has been filed before 1971. Nine of these actions were based on the "rights to treatment," seventeen on the "right to education," five on the "right to live in the community," four on the "right to just compensation" and so forth.¹ These cases and the rights they enumerate have come so rapidly onto the socio-legal scene that full implications and the origins of their terms may be buried before they are fully discovered.

To determine where we have been, where we are, and where we might be going in this dynamic social action area, this chapter will attempt to step back from the current cases and evaluate relationships between changes in legal rights and changes in mental retardation policy.

The following broad trends appear again and again in the law and will be highlighted in this chapter: a trend from the broad categorization of mentally retarded persons to a focus on individual differences; a trend from a perception of mentally retarded persons as being incapable of growth beyond narrow limits to a focus on their developmental potential and particular strengths; a trend from a perception of mentally retarded persons as significantly different from "normal persons" to a focus on the degree to which we all share the same aspirations, feelings, and fears; and, perhaps most importantly, a trend from enforced dependency toward self-determination and responsibility.

Rather than attempt an unrealistically comprehensive survey of all the laws affecting mentally retarded persons and of the way these persons are perceived by society as exemplified in those laws, this chapter will focus on several particular areas

¹Paul Friedman, *Mental Retardation and the Law: A Report on Status of Current Court Cases.* U.S.D.H.E.W., Office of Mental Retardation Coordination, April and July 1973.

of legal rights. Examples will come from Constitutional and from state law. From these examples, the chapter will draw inferences about the future of the law in these and other substantive areas and about the future of society's perceptions of persons it calls mentally retarded.

The first major section of the chapter will attempt to discern the meanings of the major term, "rights." The ascription of rights to a class or persons has social as well as legal significance, the one mutually reinforcing the other.

The second section will discuss the most critical unresolved issues which must underlie any discussion of the rights of persons classified as mentally retarded: What is the meaning of "rights" for an individual not only handicapped by his being classified as mentally retarded, but often so intellectually or behaviorally impaired that he cannot advocate on his own behalf? What implications does this dilemma bear for advocacy systems of all kinds: citizen advocacy, legal advocacy, consumer group movements, and so forth?

The third section will discuss the due process clauses of fifth and fourteenth amendments of the United States Constitution which serve as a particularly fertile field for developing the concepts of the rights of persons called mentally retarded. While several other constitutional law areas are serving as bases for legal action in the mental retardation area, the due process clauses seem to illustrate best the relationship between legal rights and social policy change.

The next section will give an overview of guardianship, one particular area of state law in which law reform efforts have closely paralleled changes in public policy and social perceptions of persons called mentally retarded.

THE NATURE AND ORIGIN OF RIGHTS

What is a "right?" What does it mean to "have rights?" What does "having rights" mean for persons society classifies as mentally retarded? When we look at the changing ways in which questions concerning rights have been answered over the years, what does this history say about the way that society perceives mentally retarded persons?

In one sense, a "right" is a legal power. To speak of the "right to vote," we mean that the law grants the authority to certain persons (citizens, over age eighteen, and so on) who meet certain conditions (residency, registration, and so on) to

have their voices heard and counted in certain areas of social decision-making, governmental elections, or referenda. To have the right to vote does not mean that one is legally obligated to vote; in fact, any attempt at coercion by government or individuals in this country would be strictly illegal. The law has merely granted an individual that particular power.

From another point of view, the concept of "rights" means something quite different. To say that one person has the right to vote is also to say that all other persons and the government have a legal duty, at the minimum, not to interfere with that exercise in any way. In many ways, moreover, the government must provide opportunities and facilitate the exercise of the right to vote: for example, the location of polling places of registration must not prevent segments of the community from voting. Thus we might also say that a right is an expectation based on a shared standard that other persons will act or refrain from acting in certain ways. Some rights seem to focus almost entirely on the perspective of rights as authority or power. The right to practice one's religion, for example, does not depend on any state action. On the other hand, the right to education, for example, is based primarily on the expectation, justified by statutes and constitutional provisions, that the state must bring education equally to all potential recipients.

Where do rights come from? They derive from many sources. The sources of those rights derived not from governmental action, but from philosophical-religious mandates underlying our society are the most difficult to evaluate. Such human rights (or rights seen to derive from our humanness rather than from government action) are seldom defined or codified, but are seen as implicit in the development of civilization. Examples of generally accepted human rights are the right to have and raise children, the right to privacy, the right to a decent life.

A second source of legal rights is the Constitution, really a social-political contract or charter among persons establishing a government. This contract concerns the general relationship among the members and between the members and the government. In the Bill of Rights, and in numerous other sections of the Constitution of the United States, one can find many of the bases for civil rights—rights enforceable by and against governments.

Perhaps the greatest number of rights affecting our lives derive from the concrete and specific actions of legislatures in passing laws within the framework and scope of the enabling charter, the Constitution. Laws generally compel private individuals and the executive branch of the government to perform

certain actions or to refrain from performing certain actions: to pay taxes, to provide medical services, or not to put other individuals at unreasonable risk, not to exclude a child from a regular school program without a hearing and showing of good cause.

The role of the judiciary—another major source of "rights" in the American system—is a complex and varying one. The legislature produces rules applicable to the population commonly and generally within the scope of the operating principles laid down for it by the Constitution. But the judiciary—usually acting within the context of a single direct clash between individuals, between governments, or between individuals and governments—interprets the rules and principles to resolve particular conflicts in the light of developing principles. Although legislation is usually quite general, one part of the mandate created by most pieces of legislation commands one or another executive branch agency to develop regulations to detail the law's operation. In most states, as well as in the federal government, regulations have the full force of law and are enforceable in court, subject only to a condition of consistency with constitutions and statutes. Perhaps because of the distinctly undemocratic way that the executive branch as a whole is chosen (only the top few of thousands being elected) and because of the impact of regulations on society, many safeguards, usually embodied in state and federal administrative procedures acts, have been built into the process of regulation-making. Typically these include public notices, hearings, waiting periods, and so forth.

The last source of rights to be mentioned does not necessarily depend on government action. This is the contract, the mutual agreement between private citizens or citizens and government. The contract typically spells out the respective rights and responsibilities of the parties to it: whether to give to receive services or goods, or whether to do or refrain from some action in return for some other goods, service, action or anything of value.

ADVOCACY OF RIGHTS

Most of the trends noted above concerning developing and exercising rights have principally affected persons capable of advocating on their own behalf.

But what of those other persons who, for whatever reason or cause, are incapable or unwilling to advocate on their own

behalf (or who are perceived as being incapable, which amounts to the same thing)? Does the concept of broadening responsibility and self-determination mean anything for a person unable to "self-advocate," unable to articulate his desires and interests sufficiently to trigger the legal responsibilities of those about him?

The notion of citizen advocacy responds partly to the needs of some mentally retarded persons for assistance in obtaining and exercising skills of self-advocacy or the right to responsibility. Although the advocacy terminology has by now been used in so many different contexts as to have lost much definitive meaning, one particular aspect of the notion deserves special note in this context: How does an individual (*any* individual—citizen, agency, professional, parent, attorney) determine the course of advocacy for an individual who has not expressed his interests and desires?

First, the advocate may choose to act in the "best interest" of client as "best interest" is articulated by another person—the family, friends, service workers, and so on, or a majority of these. Although this solution is probably the easiest—everybody has an opinion about what is best for his neighbor—it is also the most dangerous: it makes the advocate the agent of the sponsoring individual rather than of the client himself. It eliminates the independent monitoring-evaluation function that a true advocate can serve so well. Because the sponsoring individual is not disinterested, it is particularly risky: typically no advocate would be sought unless the sponsoring individual had already decided on a particular course regarding the client.

Second, the advocate may choose to act on the basis of certain articulated general assumptions, or principles of "best interest," such as "minimum necessary restriction," or "no deprivation without due process of law," or "equal protection," or "the most normal living and working environment possible," or "maximization of community integration," and so on. Even though this solution avoids the conflict of interest problem noted above, it raises a number of equally troublesome issues. Usually it is difficult to reconcile an approach based on general principles with another policy mandate in the field of mental retardation—individualization of services. Furthermore, when applied to particular circumstances, general principles often clash. For example, in a decision relating to the sterilization of mentally retarded young women, the human rights principle of the "right to family life" would clash with the similarly compelling equal protection principle of the "right of access to voluntary sterilization." In a decision relating to a prospective special class place-

ment, the principle of the "right of access to an individually appropriate education" might clash with the "right not be denied access to regular education." In all such cases of "decision by principle," what principles are to be relied upon, and who chooses them? Although most might not object to the principles above, how will people react to the statement of "the greatest good for the greatest number" or "to each according to his productivity?"

Third, the advocate may choose to act on the basis of what he concludes he would himself do, were he the client. For most advocates these mental gymnastics would likely end in the determination that the advocate *would* do (and therefore that the client *should likewise do*) what the right, proper, or reasonable thing to do would be under the circumstances, even though the advocate, no less than any other human being, quite likely often acts in ways which are neither right, proper, nor reasonable. Should an advocate authorize drug experimentation with his client in an institution, just because such participation would be admirable and worthy?

This dilemma of advocacy on behalf of multiply-handicapped persons cannot be readily resolved, if desolvable at all. In the developing advocacy notion, this dilemma must be squarely and consciously addressed in every contact between the advocate and his client; and the advocate must evaluate his decision from as many perspectives as possible.

One further related dilemma of advocacy bears mention in this context. The advocacy terminology has come to describe many different kinds of relationships: citizen advocacy, professional advocacy, parental advocacy, corporate advocacy, legal advocacy, class advocacy, and so on. Applied with diligence and good will, all of these advocacies should, however, necessarily lead in the same preordained direction. Each form of advocacy mentioned carries with it the seeds of conflict or interest, because the citizens, professionals, parents, corporate organizations, attorneys, and classes have interests and perceptions of need which will conflict with those of the client. What action a parent, professional or organization will take regarding a client will always be colored by his or its own interests. A parent's decision regarding institutional placement will be influenced, for instance, by the interests of all the family members in addition to the interests of the child awaiting the placement decision. Decisions right for a class of persons cannot be expected to be right for every member of that class. For example, shifting resources from the large residential institutions to community programs may be the best general decision for the

class of all persons requiring mental retardation services. But to advocate such a course is not clearly in the best interest of those members of the class who remain in the institution during the interim.

The foregoing examples are not meant to convey a distrust of the motives underlying varying advocacy approaches. But we should neither expect nor demand consistency among advocacy movements in the area of mental retardation; the future may well bring, on the contrary, a plurality and conflict of mental retardation advocacies which ultimately will prove vital and healthy.

DUE PROCESS AND THE RIGHTS OF RETARDED PERSONS

Where is the concept of the rights of mentally retarded persons going? One area of *constitutional* law seems to hold perhaps the greatest long-term hope for mentally retarded persons and the cause of their rights—the due process clause of the Fourteenth Amendment. This requires that no state deprive any person of life, liberty, or property without due process of law. The changing application of those brief words to persons classified as mentally retarded evidences the changing way that society, through the political mechanism of its courts, perceives these members. What does the clause mean? And what does it have to do with mental retardation?

First, the clause is directed specifically to action by states (action by the Federal government is already covered by the Fifth Amendment), and not to the action of private individuals. The doctrine of state action has, however, expanded greatly over the years and, although still in flux, today clearly includes the actions of persons acting "under color of" or under the apparent authority of state law, whether or not state law specifically authorizes actions. The doctrine also allows using state facilities, such as a court, to enforce a private claim, such as a restrictive covenant in a deed. Thus certain actions of parents and particularly of court-appointed guardians may be interpreted as state action in certain instances, as might the action of state agencies, private agencies which receive state licenses or support, and the courts. For example, action by a guardian in seeking to institutionalize, sterilize, or authorize medical experimentation upon his ward may be subject to constitutional limita-

tion and control to the same extent that such actions by the state itself are subject to constitutional control.

The second point of interest in the due process clause relates to the term "deprive." The term reaches not only absolute and total deprivations, such a taking of property or liberty, but more limited incursions or restrictions as well. The state can deprive a person of property by restricting its use, just as it does by taking ownership of it outright. For example, the zoning of land, restricting the uses to which the owner may put the land, is a deprivation of property subject to due process guarantees of hearing, notice, and so forth, not unlike the actual taking of land by the state for conservation purposes, which taking is also protected by the clause.

Third, the concept of "liberty" in the clause has come to mean much more than the absence of criminal incarceration. Increasingly, the term has come to represent the basic freedoms of the Bill of Rights, as well as the right to choose and work at an occupation, the right to travel, the right to be free of social restriction (for example, segregation), and the right to be free of legal restriction (guardianship, criminal prosecutions not involving incarceration, and so on). The future may well bring an expansion of the liberty notion into other spheres of restriction, whether *physical* (for example, institutionalization, chemical or body restraints), *social* ("special education" placement), or *legal* (guardianship).

Fourth, the motive or intent behind the particular restriction is increasingly being shown to be irrelevant. Supreme Court cases concerning juvenile court law have clearly mandated an objective assessment of state activities which have the effect of restricting, whatever the label or underlying philosophy. That institutionalization may benefit the individual and not punish him for misbehavior makes the placement no less a deprivation of liberty. That a guardian seeks the sterilization of his ward for the best and most logical reasons may fall outside the scope of inquiry into the individual's rights to privacy and family life.

Finally, what does "due process" mean? Hundreds of scholarly works have intended to explicate these two words, but the basic concept can be summarized very briefly for this chapter's purposes: governmental action which affects individual liberties must conform to traditional notions of fundamental fairness. What is "fair" in the particular case depends on the historical importance of the liberty affected and on the scope and manner of the deprivation. For example, both murder trials and parking fine assessments are subject to due process protections, though fairness in the second situation dictates a much

less comprehensive scheme than in the first. Furthermore, when the state is acting to restrict the individual for his own or the social good, the nature and duration of the restriction must bear some reasonable relation to the purpose of the confinement. The restriction must last for the shortest time and under the least restrictive conditions possible to accomplish the purpose of the restriction. When the classification of an individual leads to his restriction or other detriment, that classification and the means by which it is made must be rationally related to a legitimate state objective.

GUARDIANSHIP: A CASE EXAMPLE

An example of the traditionally restrictive-protective posture of the law and society toward mentally retarded persons is guardianship and legal competency. Essentially, guardianship is a legal device common in state law by which control of a person's property or of property and person is given to a second person, governmental agency, or private corporation. The person losing control is usually called the "ward," and the person getting it is called the "guardian," the "committee," the "conservator," or the "custodian," depending on the state.

Not just by chance can guardians typically be appointed only by a court, and not by an administrative agency. Despite the benign motives usually behind the appointment, it and the restriction it entails for the ward have traditionally been viewed as a deprivation of liberty and property sufficient to bring the appointment within the due process guarantee of the Fifth and Fourteenth Amendments.

Traditionally, guardianship has had absolutely nothing to do with helping or protecting the ward in any way. When the device arose centuries ago in England, its function was to preserve the property of minors whose fathers had died, solely for the ultimate benefit of the King. When most guardianship laws were enacted in the United States in the nineteenth century, the absence of a king obviously implied some other legal function for the device.

Modern guardianship is directed primarily at preserving funds and protecting persons other than the ward from the effects of the ward's indiscretions and inability to handle his money. Both the language of the statutes and the nature of the court cases have clarified these functions.

The effects of a guardianship appointment vary from state

to state, but are always manifold. Typically, in the process of the appointment, the ward is determined to be legally incompetent to handle his affairs. Thus, he may be legally incapable of making a binding contract, buying on credit, buying for cash, renting an apartment, obtaining employment, even opening a savings account, or giving away or selling either his property or items he has produced. Furthermore, he is made unable to change his residence, to refuse or seek placement in an institution or other facility, to refuse or seek medical treatment including sterilization and abortion, to refuse or seek being made a subject in medical experimentation, and so on. These are the direct results of the appointment.

Numerous indirect restrictions result as well. In Massachusetts an individual under guardianship cannot, under statute, vote. In some states, wards cannot² obtain driving licenses, cannot obtain automobile insurance even if they have a license, cannot marry. They cannot, in short, act to take control of their own lives and destinies. Thus, while the specifics of guardianship laws and cases vary from state to state, the overriding themes remain constant: enforced dependency, expectation of lack of change, overly generalized classification lacking any rational relationship to the nature of the individual's handicap, and a narrowly medical evaluation model.

From the point of view of social policy and mental retardation, guardianship statutes typically have three major flaws: first, their position regarding the need for guardianship and the powers of the guardian is strictly "all or nothing." If it is determined that the individual is wholly incapable of taking care of himself or his property, then a guardian is appointed who has the broad powers regarding the ward's future. Under these circumstances, the restriction, or "protection," of the ward is complete. On the other hand, if it is determined that the individual is *not* wholly incapable of caring for himself and his property, then a guardian is not appointed and the individual is

² The use of the term "cannot" is admittedly an oversimplification for several reasons. First, there is the traditional legal distinction between contracts which are "void"—without legal force from the onset—and those which are "voidable"—or valid until challenged. Second, legal incompetency is not absolutely determinative of the legal disqualifications of the individual under many of the listed circumstances. In many states, the fact of the appointment of a guardian is merely evidence of legal incapacity involving, for example, the making of a will. Third, several of the disqualifications listed involve the necessity of the individual under guardianship having to be identified as such before the disqualification is effective. Screening procedures for voting, for example, are sufficiently loose that many persons under guardianship may vote, the likelihood being that the issue of guardianship will not be raised unless the individual raises it himself. Nevertheless, the disqualifying nature of many of the guardianship statutes is the subject of this portion of the chapter, and the fact that the disqualification is incomplete does not diminish the negative aspect of the law.

wholly unrestricted—and wholly unprotected, regarding his person and property. Since very few mentally retarded persons require the total shelter of a full guardian and since a larger number of retarded adults may require some lesser degree of counsel, advice, and protection unavailable to them under existing guardianship laws, these laws do little good.

As a second flaw, traditional guardianship laws assume that, once a guardian is appointed, nothing in the situation of the ward will change. Most statutes do permit a subsequent hearing to determine the continuing need for guardianship, but the ward alone must request the hearing and prove that the guardian is no longer needed. Once a person is placed in a situation of total dependency, such as guardianship, and kept there for a time, the self-advocacy which the statutes require is wholly unrealistic.

Although the basic difficulties remain, law reform efforts have progressed in lessening the impact of these flaws. Statutes in New York and Ohio³ now require multidisciplinary determinations of the need for guardianship, as well as mandatory periodic reviews of its continuing need, and new limited restriction-protection levels of guardianship.

Furthermore, guardianship statutes typically require only the certification by a psychiatrist or other physician of the general clinical statuses listed in the statute, despite the fact that a person's being mentally retarded has nothing in itself to do with the need for guardianship.

In addition, except in the few states which authorize some variety of "agency guardianship," establishing the guardianship relationship depends on the existence of a volunteer guardian. For many mentally retarded citizens, particularly those institutionalized for a long time, no one may be willing to take on this role.

Where is the law headed with respect to guardianship and its numerous failings for mentally retarded persons? Slowly, current trends are indicating four basic shifts in the guardianship laws in several states.⁴

First, the law is dropping the presumption that mental retardation alone requires appointing a guardian. To justify appointing guardians for those few among mentally retarded persons really requiring this extreme protection, the law is now demanding multidisciplinary evaluations. These evaluations will tend to focus on the adaptive behavior of the individual in

³ New York Surrogate's Court Procedure Act, §§ 1750-1754; Ohio Revised Code, sections 5119.85-5119.89.

⁴ Colorado, Massachusetts, Nebraska, New York and Ohio.

the community, rather than on the general medical-clinical categorization. Second, the law is slowly backtracking from the "either-or" character of present appointments and endeavoring to tailor the appointment more to the specific needs of the particular individual requiring guardianship. Third, the institution of guardianship will take on service-procurement and option-creation functions, with "estate preservation," the classical guardianship function, falling far into the background. Last, guardianship will be perceived not as a permanent relationship, but as a protective device brought on by social necessity for limited pre-stated purposes and for limited periods of time. The burden for justifying the continuing need of guardianship will never fall on the mentally retarded person himself, but on the guardian. Further, the decisions of the court and the guardian will be subject to formal periodic review. And most states will no longer authorize certain powers currently exercised or exercisable by guardians. Generally, these limitations will be in areas where vital interests of the ward are put in serious and long-term jeopardy and where objective decision-making on the part of the guardian is most difficult and usually based as much on general social factors as on considerations of the ward's welfare. Areas of traditional guardian-prerogative being curtailed include authorization of medical experimentation, particularly when unrelated to the individual's specific needs, sterilization, abortion, and institutionalization.

IMPLICATIONS FOR THE FUTURE

Based on where the law has been concerning the rights of mentally retarded persons and where it appears to be today, some forecasting of the future situation of the law seems warranted. These forecasts can be framed in terms of broad principles with implications for law reform, for the "helping professions," and for advocacy.

(1) *The Liberty Principle:* Any restriction of the individual is suspect, regardless of the nature, label, or motive of the restriction. Any restriction must be to the minimum degree necessary and for the shortest possible duration. Ultimately, none should be countenanced for any person, let alone any class of persons.

(2) *The Self-Determination Principle:* Advocacy ultimately aims to assist the individual to create and exercise options, within whatever capabilities he possesses.

(3) *The Developmental Principle:* An individual can grow; the function of advocacy should stimulate individual and social change and assist the individual and society in accommodating to this change.

(4) *The Individualization Principle:* All law and social policy is grounded on the individuality and the worth of each human being, regardless of his handicap.

In short, the law seems to be driving toward a goal of broadening the opportunities of every individual, regardless of handicap and allowing him as much responsibility for the course of his life as his inherent and learned capabilities permit. Therefore, advocacy must strive toward the enhancement and full use of this concept, this new right to responsibility.