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Decisions by and for People with Mental Retardation: Balancing Considerations of Autonomy and Protection

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"There's nothing about retarded persons that should lead us to believe that they think less of their freedom than do other people." 1

Major decisions in the lives of people with mental retardation generate substantial dilemmas, of both a personal and public policy nature. On the one hand there is the desire to accommodate the autonomous choices of individuals with disabilities and enhance their ability to make decisions affecting their own lives. On the other hand, there is also a commonly felt need to protect individuals with substantial mental disabilities from the adverse consequences of potentially unwise, ill-informed or incompetently made decisions. Each of these two impulses is a fully understandable and reasonable concern, and yet each may be the source of abuse of persons with disabilities. And of necessity, the implementation of these goals can coexist with one another only in tension.

No simple formula or reductive ideological perspective can resolve these dilemmas in a satisfactory manner. The complex pattern of individual abilities and disabilities, as well as the elements of coerciveness in the structure of the lives of people with mental retardation make any such simplistic paradigm unacceptable. Furthermore, neither of our goals—enhancing autonomy of personal decisionmaking and the improvement of services and life conditions for people with mental retardation—can be pursued single-mindedly at the expense of the other.

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This Article is dedicated to the memory of Tim Cook, who was among the most skilled and thoughtful advocates that people with disabilities have ever possessed. Tim would probably have disagreed with some of the statements in this Article, but it would have benefitted greatly from his invariably wise and generous criticism.

This Article will attempt to analyze some of the considerations that should inform enlightened and compassionate public policy in this area. Section I will describe briefly the definition of mental retardation and common attributes of people who have the disability and the social and political world in which they live within our society. Section II will sketch some of the contexts in which legal issues about decisionmaking arise in the lives of people with mental retardation. Section III will discuss the generic legal doctrines of consent which form the backdrop for legal analysis of these problems, with particular attention to the United States Supreme Court’s 1990 decisions concerning the constitutional aspects of consent law. Section IV will discuss these legal doctrines as they may apply—helpfully or otherwise—in the practical problem situations that people with mental retardation may confront in their lives.

I. MENTAL RETARDATION: DEFINITION AND COMMON CHARACTERISTICS

A. The Previous AAMR Definition

Mental retardation is a substantial handicap affecting the individual’s ability to learn. The universally accepted definition has been the one propounded by the American Association on Mental Retardation (AAMR): “Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.”2 The component parts of this definition are terms of art.

“Significantly subaverage general intellectual functioning” refers to an intellectual disability measurable, and thus defined, by psychometric instruments known as intelligence tests. The phenomenon is therefore quantifiable as an IQ (intelligence quotient) score, and the level of performance on such a test that meets the AAMR definition of mental retardation is at least two standard deviations below the mean for the general population. Expressed in terms of IQ scores, that means that a person with mental retardation must, in ordinary circumstances, score below seventy on such a test (for which the mean score is one hundred). Since the definition is expressed in statistical terms, this means

2. American Ass’n on Mental Deficiency, Classification in Mental Retardation 1 (Herbert J. Grossman ed., 1983) [hereinafter AAMR Classification] (American Association on Mental Deficiency has been renamed American Association on Mental Retardation).
that any person who has mental retardation must be in the lowest two and one-half percent of the population in measured intelligence.\(^3\)

However, for a person to be classified as having mental retardation, it is not enough to have a low IQ score. The AAMR definition also requires that the handicap have some measurable impact on an individual’s ability to function in everyday life. This is defined in terms of “adaptive behavior,” which the AAMR defines as “significant limitations in an individual’s effectiveness in meeting the standards of maturation, learning, personal independence, and/or social responsibility that are expected for his or her age level and cultural group, as determined by clinical assessment and, usually, standardized scales.”\(^4\) The core of this requirement is that a person must have an actual disability that affects everyday life, and not just a lack of test-taking ability.

Finally, the definition requires that this disability have been manifested “during the developmental period,” which means before the age of eighteen. Therefore, the definition includes individuals who were born with an intellectual disability and those who acquired one during childhood or adolescence, but it does not include people whose disability first occurred in adulthood. The excluded group consists primarily of people whose intellectual abilities are substantially impaired as a result of illness or traumatic injury later in life.\(^5\)

B. The Revised AAMR Definition

The American Association on Mental Retardation has recently adopted a revised version of its definition.

*Mental retardation* refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction,

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4. AAMR Classification, *supra* note 2, at 11.
5. Persons whose disabilities occur after the developmental period have some characteristics in common with people who have mental retardation, but there are some functional dissimilarities as well. Whether these individuals should be subject to the same legal rules governing consent as people with mental retardation is beyond the scope of this Article.
health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.\(^6\)

The new definition of mental retardation makes no substantial change in the element of "significantly subaverage intellectual functioning" and the requirement that the disability have manifested itself during the developmental period. The principal change in the definition is the replacement of the global construct of "adaptive behavior" with the more realistic and functional construct of requiring that the intellectual impairment be accompanied by related limitations in particular skill areas.

The revised definition of mental retardation constitutes a valuable refinement of our understanding of the disability. It will focus the attention of educators, clinicians, public policy makers and other users of the definition on the specific areas of disability and service needs of individuals.

These changes will create no substantial change in the size or composition of the group of people classified as having mental retardation. Since the definitional change will not alter the contours of the group defined, it will not have a substantial impact on formulating legal rules governing consent by people within the classification.\(^7\)

\textbf{C. Relevant Characteristics of People with Mental Retardation}

People with mental retardation are individuals. This central truth is sometimes lost in our attempts to classify them and categorize their abilities, needs, and behaviors. Therefore, any generalizations about people with mental retardation (or any other

\^6\textit{American Ass'n on Mental Retardation, Mental Retardation: Definition, Classification, and Systems of Supports} 5 (9th ed. 1992) [hereinafter AAMR 1992 Classification].

\^7\textit{The changes may, however, have an impact on our ability to implement the legal doctrines on an individualized basis. As the definition shifts focus from a construct of adaptive behavior, reducible to a single psychometric scale and a single score, to a more complex and realistic conceptualization of component disabilities and competencies, the consent-seeking and consent-giving or consent-withholding process may be assisted. For a discussion of attempts to formulate a psychometric instrument that would specifically measure the ability of an individual with mental retardation to participate in decisions about services in his or her own life, see Pam Lindsey & Ruth A. Luckasson, Consent Screening Interview for Community Residential Placement: Report on the Initial Pilot Study Data, 29 Mental Retardation 119 (1991). For discussion of a parallel effort regarding competence in the criminal justice system, see Caroline T. Everington, The Competence Assessment for Standing Trial for Defendants with Mental Retardation (CAST-MR): A Validation Study, 17 Crim. Just. & Behav. 147 (1990).
disability) must be undertaken with great caution, and any would-be generalizer must remain mindful that individual differences will create exceptions to almost any description or characterization. But with these caveats duly noted, there are characteristics commonly encountered in people with mental retardation that are either a direct result of their disability or of the way in which they are treated in society, and those characteristics are relevant to assessing their ability to make decisions affecting their lives.8

It is also worth noting the differences between these characteristics and those typically encountered in people with mental illness. The legal doctrines of consent concerning mental disability are most frequently formulated by courts and legislatures with mental illness as the paradigm. In some respects, the disabilities caused by mental illness and mental retardation are sufficiently similar to warrant identical doctrinal approaches. But in other respects, the differences between mental illness and mental retardation should lead to a reexamination of whether the legal approaches are adequately tailored to people with mental retardation.

1. Variation

The first item is less a characteristic of individuals with mental retardation than an attribute of the class itself. The severity of intellectual impairment within the class of people we label as having mental retardation varies greatly. It has been observed that within the class of people who have mental retardation, individuals at the highest level of functioning have less in common with those at the lowest level of functioning than they have in common with people who have no intellectual handicap at all.9 For example, at the upper end of the functional spectrum of mental retardation, individuals have both expressive and receptive language abilities, i.e. they can both speak intelligibly and understand the speech of others; at the lowest levels, individuals have neither of these basic communication skills. Similar variation exists in such areas as comprehension and reasoning. These functional differences will also have occasioned dissimilar kinds of life experiences and educational opportunities, and these experiential dissimilarities compound the naturally occurring disparities

8. For a discussion of characteristics relevant to the criminal justice system, see Ellis & Luckasson, supra note 3, at 423-32.

in the level or degree of disability.\textsuperscript{10}

These variations within the classification of mental retardation are indeed wide, but it is important to keep in mind that they are variations within a narrowly defined class. All persons who have mental retardation have a level of intellectual functioning that places them in the lowest two and one-half percent of the population. Therefore, although there is great variation in the level of functioning of people within the classification of mental retardation, the highest functioning individuals in the class have a substantial disability.

2. \textit{Deficits in Basic Knowledge}

A characteristic commonly encountered in people with mental retardation that has direct relevance to shaping the rules of consent is the lack of basic information. These deficits result from both the intellectual impairment itself and the educational opportunities that people with mental retardation are given.\textsuperscript{11} Obviously, the level of knowledge possessed by people with mental retardation varies widely, and is closely correlated to the degree of severity of the individual's disability. But even with rel-

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\item[\textsuperscript{10}] AAMR's previous classification system subdivided the class of people who have mental retardation into four subcategories, designated "mild," "moderate," "severe," and "profound" mental retardation. AAMR \textit{CLASSIFICATION}, \textit{supra} note 2, at 13. Because the statistically defined phenomenon of mental retardation constitutes the "tail" of the bell-shaped curve of normal distribution of intelligence, people with mental retardation are not equally distributed among the four subcategories; approximately 85\% of the people who have mental retardation are classified as having "mild" mental retardation. \textit{AMERICAN PSYCHIATRIC ASSOCIATION, DIAGNOSTIC AND STATISTICAL MANUAL} 32 (3d ed. rev. 1987). The labels "mild" and "moderate" may lead those unfamiliar with the AAMR system to underestimate the level of disability of individuals at those levels. "Judges . . . unfamiliar with this classification scheme may find the labels of 'mild' and 'moderate' to be euphemistic descriptions of individuals at those levels of disability." Ellis & Luckasson, \textit{supra} note 3, at 423.

The new AAMR definition abandons the approach of classifying people with mental retardation according to the level of their intellectual impairment. For a description of the new definition, see \textit{supra} note 6 and accompanying text. As a result, the terms "mild," "moderate," "severe" and "profound" mental retardation will no longer be used. In place of this system, the new classification scheme recognizes differences in the level of support an individual will need in a particular skill area, and classifies the individual's need as "intermittent," "limited," "extensive" or "pervasive." These classifications are no longer directly linked to differences in intellectual functioning (as measured by IQ scores) or overall disability. AAMR 1992 \textit{CLASSIFICATION}, \textit{supra} note 6, at 26. Examples of diagnoses under the new system would be "a person with mental retardation who needs limited supports in communication and social skills" or "a person with mental retardation with extensive supports needed in the areas of social skills and self-direction." \textit{Id.} at 34.

\item[\textsuperscript{11}] See Ellis & Luckasson, \textit{supra} note 3, at 431.
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ventionally modest impairment within the classification of mental retardation, individuals may not know factual information that mentally typical people are likely to know.

3. Communication

Mental retardation is generally accompanied by some level of disability in the area of communication. The disabled individual may be limited in receptive communication, expressive communication, or both. The impairment of the individual's communication skills is generally correlated to the level of disability.

4. Denial of Disability

Less widely recognized by the general public than deficits in knowledge, reasoning or communication skills is the tendency of many people with mental retardation to seek to conceal the fact of their disability. Because of the stigma that they perceive as accompanying the label of mental retardation, often people with the disability will go to great lengths to prevent others from discovering their handicap. This often precludes them from seeking assistance with matters they do not comprehend, and prevents others from taking the limitations of their disability into account in their dealings with people with mental retardation.

5. Reduced Ability To Make Decisions

Some limitations on the ability of people with mental retardation to make decisions regarding their own lives are an inevitable consequence of the disability. For example, a person with a severe receptive communication disability or one whose intellectual limitation prevents them from understanding a particular proposal may be unable to formulate and communicate a reasoned choice.

But in addition to these naturally occurring limitations in the

12. For a discussion of communication issues in the criminal justice system, see Ellis & Luckasson, supra note 3, at 428-29.


lives of some individuals, there is often a reduced ability to make decisions which is caused by the circumstances under which the individual has lived. Even for individuals whose natural abilities to comprehend and communicate would otherwise allow them to make their own decisions, prolonged and extensive denial of the opportunity to make such decisions in the past may prevent actual effective decisionmaking. It may be that the ability to make such decisions has never been mastered, or that a previous ability has atrophied over time. This phenomenon is often observed in individuals who have been confined for a significant period of time in large congregate care facilities, but may also be found in individuals who have lived in their communities under extremely restrictive or over-protective circumstances.

The combination of naturally occurring and societally created limitations inherent in an individual’s ability to make his or her own decisions will have some correlation with general intellectual functioning, but cannot be determined with sufficient accuracy merely by referring to an individual’s IQ score. An assessment must be made which considers an individual’s particular abilities and limitations, the subject matter of the decision proposed, and the context in which the decision is sought.

6. Settings in Which People with Mental Retardation Are Asked To Make Decisions

The residential, familial, legal and socioeconomic contexts in which people with mental retardation live vary widely. Each of these factors may influence the amount of perceived coercion in a particular decisional context. It has been widely recognized that the coerciveness of an individual’s setting may be a determinative

17. For example, a person previously classified as having severe mental retardation would be much more likely to have a substantially impaired ability to make decisions than a person classified as having mild mental retardation. Classification under the new AAMR system would focus on the difference more precisely, by referring, for example, to the more substantially disabled individual as needing extensive or pervasive supports in such specific areas as communication.
18. See Lindsey & Luckasson, supra note 7.
factor in the legal adequacy of choices he or she may make.\textsuperscript{20}

A considerable number of people who have mental retardation continue to live in large institutional settings. Such congregate care facilities create the most obvious and severe problems of coerciveness. But an increasing number of people with mental retardation live in an increasingly complex array of structured community living arrangements.\textsuperscript{21} Those arrangements vary greatly in the degree of restrictiveness that their residents experience. Even within a particular category, such as group homes, there are substantial variations in style and atmosphere that influence the validity of an individual’s consent or refusal.\textsuperscript{22} Other individuals with mental retardation reside outside any structured environment, but may work or pursue other activities in settings in which they experience varying degrees of restriction and coerciveness.\textsuperscript{23}

7. Permanence

Mental illness is, for many individuals, a sporadic, episodic, or temporary phenomenon. The same cannot be said about mental retardation. Intellectual impairment at the level that constitutes mental retardation is not “curable” or “changeable” in the ordinary sense of those terms. Nevertheless, significant changes may occur over the life span of a person with mental retardation that are relevant to questions of consent. Adaptive skills and service needs may change with the changing circumstances of an individual’s life, and the result may be that although the intellectual impairment is the same as it was in an earlier pe-

\textsuperscript{20} See, e.g., id.; \textsc{Michael L. Perlin}, \textit{2 Mental Disability Law: Civil and Criminal} 244-51 (1989) [hereinafter \textit{Mental Disability Law}] (discussing legal and behavioral theories upon which right to refuse treatment may be premised); \textsc{Fay Rozovksy}, \textit{Consent to Treatment: A Practical Guide} 12-17 (2d ed. 1990) (discussing capacity of individuals with mental retardation to consent to medical treatment and also discussing their guardians’ authority to consent to such treatment).

The extent to which coercion bears upon an individual’s capacity to consent has been explored in case law as well. The leading case is \textit{Kaimowitz v. Michigan Dep’t of Mental Health, Civ. No. 73-19434-A.W.} (Mich. Cir. Ct., Wayne Cty. July 10, 1973) (holding that involuntarily detained mental patient cannot consent to experimental psychosurgery), reprinted in \textit{2 Prison L. Rptr.} 433 (1973).

\textsuperscript{21} See \textsc{Bradley K. Hill & K. Charlie Lakin}, \textit{Classification of Residential Facilities for Individuals with Mental Retardation}, \textit{24 Mental Retardation} 107 (1986).

\textsuperscript{22} See generally \textsc{Mary F. Hayden et al.}, \textit{Placement Practices in Specialized Foster Homes and Small Group Homes for Persons with Mental Retardation}, \textit{30 Mental Retardation} 53 (1992).

\textsuperscript{23} For a discussion of such settings from an anthropological perspective, see \textit{Lives in Process}, supra note 13.
period, the person no longer falls within the definition of mental retardation because the impact on daily functioning is reduced. It is in this sense (and only this sense) that the AAMR’s new classification manual states that “[m]ental retardation begins prior to age 18 but may not be of lifelong duration.”

Far more numerous than the persons who no longer fall within the definition of mental retardation are the individuals who continue to have mental retardation but whose functional impairment differs significantly over time. For example, an individual in a successful special education program may be able to understand and make choices about things that were beyond his or her ability in an earlier period of life. This is particularly true if the educational or habilitation program is specifically targeted to teaching that individual the skills or concepts that are directly relevant to that choice.

In addition, environmental changes in an individual’s life may have relevance to the ability to give or withhold consent. An individual whose decisional abilities were previously impaired because of the coerciveness of the environment in which he or she lived may find those abilities improved with change to a new and freer environment. But typically, a “change of scene” alone will not be sufficient to improve these skills. Often an individual will need special educational or habilitative assistance to learn how to function effectively in the less restrictive environment.

With this brief sketch of common characteristics in mind, we turn to the legal contexts in which consent issues arise in the lives of people with mental retardation.

II. Consent Issues in the Lives of People with Mental Retardation

A. Analogies to Minors and to Adults with Mental Illness

The legal doctrine of consent has developed in general medical cases, and the variations of that doctrine involving mental disability have often involved minors or people with mental illness. The particular nature of mental retardation, and the consent issues that arise in the lives of people with that disability, require a reconsideration of the applicability of rules developed in different settings.

The general rules of tort law have typically involved the con-

24. AAMR 1992 Classification, supra note 6, at 18.
sought the patient as an asserted defense in a battery action against the physician, most frequently, a surgeon. These are cases in which the courts typically can assume that the patient was mentally capable of making decisions regarding medical care, and was free of extraordinary coercion or duress in the making of that decision. This has meant that the cases focus most extensively on the level of information that the physician must provide to the patient. This emphasis is reflected in the common reference in medical circles to “informed consent.”

Variations from this model of legal consent have most frequently involved minors and persons with mental illness. Many of the leading cases involving the possible lack of mental capacity to make medical decisions have involved children. Some of these cases have decided when the consent of a parent is required, while others have dealt with the standard to be employed by adult substitute decisionmakers on behalf of children. The other leading cases that vary from the surgery patient model involve adults with mental illness. These cases most frequently involve mental patients who attempt to refuse consent to some form of treatment.

Although there are some useful parallels between adults with mental illness and children on the one hand and people with mental retardation on the other, there are limitations to the analogies as well. For example, the cases involving children often presuppose the minor’s incapacity to give or withhold consent based on age alone, rather than requiring an inquiry into individual ability. By contrast, it is not possible to determine whether

25. See, e.g., Mohr v. Williams, 104 N.W. 12 (Minn. 1905).
26. A leading text, for example, asserts that “[r]elatively few cases have dealt with the problem of consent given under duress. Duress is an important defense in the criminal law, and will justify rescission of a contract or other transaction, with restitution, but there has been no discussion of its place in the law of torts.” W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS 121 (5th ed. 1984) [hereinafter PROSSER & KEETON].
27. See, e.g., Rozovsky, supra note 20, at 44-64 and cases cited therein.
30. See, e.g., Bonner v. Moran, 126 F.2d 121 (D.C. Cir. 1941) (holding surgeon liable for battery where he operated on minor without parent’s consent).
an individual is capable of giving or withholding consent based solely on whether or not the person has mental retardation, or by considering an IQ score. Additionally, almost all minors have parents who are available to serve as substitute decisionmakers. Most adults with mental retardation do not have guardians appointed for them, and unless they are appointed as guardians, their parents have no legal authority to make decisions on their behalf.

Relevant differences also exist between mental retardation and mental illness. Since mental illness is often episodic or cyclical in its manifestations, it may be possible to seek guidance from an individual's previous preferences in determining what he or she would do during a period of competence. Although people with mental retardation are capable of gaining (or losing) skills over time, the level of an individual's underlying intellectual impairment does not change appreciably. As a result, it will seldom be possible to refer to an individual's preferences as expressed during a previous period of greater decisional capacity.

More significantly, consent cases involving mental illness most frequently focus on an individual who actively opposes a proposed course of treatment. As a result, the legal dispute centers around whether there is a sufficient justification for overriding the patient's articulated preferences. Such cases also arise that involve people with mental retardation, but more frequently in mental retardation cases, the preference of the disabled individual is not known, and often has not been sought. As a result,

Baird, 443 U.S. 622 (requiring individualized assessment of minor's ability to consent to abortion), reh'g denied, 444 U.S. 887 (1979).

34. See Lindsey & Luckasson, supra note 7.


36. See generally Lane v. Candura, 376 N.E.2d 1232, 1236 (Mass. App. Ct. 1978). Incapacity caused by injury or trauma to a previously competent person may also permit inquiry into the individual's past preferences or statements of intent. See, e.g., Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 284 (1990) (concluding that state may require clear and convincing evidence of incompetents's previous wishes concerning withdrawal of life support treatment); In re Quinlan, 355 A.2d 647, 664 (N.J.) (holding individual's past preferences are controlling if sufficiently probative; affirming individual's rights to choice and privacy), cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976).

37. See, e.g., Superintendent of Belchertown v. Saikewicz, 370 N.E.2d 417 (Mass. 1977) (speculating as to what individual with profound mental retardation would prefer if competent and capable of considering effect of his incompetence).

38. For a discussion of cases involving mentally ill individuals who have refused consent to treatment, see infra notes 45-47.
mental retardation cases have more frequently involved balancing what is perceived by others to be the individual's stake in the outcome against the state's interest, rather than considering the individual's interest in making his or her own choice.39

B. Consent Issues in the Lives of People with Mental Retardation

The nature of mental retardation as a disability and the status of adults with mental retardation in society combine to shape consent issues in a unique way. Unlike mentally typical adults, it cannot be assumed that mentally retarded adults understand the standard explanations of ordinary procedures or activities, nor can it be assumed that they have chosen to acquiesce in a proposals merely because they do not voice an objection.40 Unlike minors, adults with mental retardation cannot be assumed, because of their status, automatically to be incompetent (or competent) to make their own decisions. If there is doubt about particular individuals' capacity to consent, they cannot be presumed to have a legally authorized surrogate decisionmaker in place. Nor can it be assumed that adults with mental retardation will eventually become competent through the passage of time, thus allowing postponement of some decisions for the duration of their incompetence.

There are also relevant differences between mental illness and mental retardation. Unlike adults with mental illness, any possible legal impairment of decisionmaking capacity in individuals with mental retardation is likely to result from failure to comprehend what is proposed or inability to communicate a choice.41

39. See, e.g., Youngberg v. Romeo, 457 U.S. 307 (1983) (failing to discuss what Nicholas Romeo's preferences might have been with respect to conditions of his involuntary confinement in Pennsylvania mental institution); see also Buck v. Bell, 274 U.S. 200 (1927).

40. As a practical matter, the degree of formality in assuring consent from mentally typical adults varies with the complexity and severity of the procedure. For example, medical care providers would certainly document their efforts to assure adequate consent before performing major surgery, but would be unlikely to do so before applying a Band-Aid. Omission of the formalities of consent in the latter case reflects both the minimal level of risk (both medical and legal) and the assumption that the individual's "consent" is sufficiently indicated by his or her failure to object.

41. In a smaller percentage of cases, the incapacity of a person with mental illness may similarly derive from failure to understand or inability to articulate a choice. See, e.g., Zinermon v. Burch, 494 U.S. 113, 132-33 (1990) (holding that individual who was unable to give express consent was legally unable to agree to voluntary confinement). It should also be noted that mental illness and mental retardation are not mutually exclusive conditions; some individuals may have both disabilities. See generally Jack A. Stark et al., Mental Retardation and
rather than society’s concern that their disability might lead them to irrational choices.

The potential incompetence of particular individuals with mental retardation to make decisions is also more likely to be disguised than in cases of mental illness. Individuals who have mental retardation often attempt to mask their disability and “pass” as mentally typical. The phenomenon of denial of disability is likely to matter in cases of the provision of generic services, where most clients are mentally typical (such as those who visit a dentist), and not in cases where the service delivery system is directed toward people with disabilities (such as a group home).

C. Settings in Which Consent Issues Arise for People with Mental Retardation

For people with mental illness, the vast majority of consent cases involve attempts to refuse treatments designed to address direct consequences of their mental illness. Most prominent among these are possible refusal of consent to psychosurgery, electroconvulsive therapy and psychotropic medications. Also within this category, although typically addressed in different


42. Some forms of mental retardation, of course, involve distinctive visible physical characteristics. A well known example is Down’s Syndrome. But more frequently, mental retardation is unaccompanied by any identifiable physical attributes.

43. For a discussion of this phenomenon, see supra notes 13-14 and accompanying text.

44. See Perlin, supra note 20, at 217-438.


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terms, are civil commitment and voluntary admission to resid-
tential treatment facilities.48 Much less frequent are litigated cases in
which mental illness is considered in the context of nonpsychia-
tric treatments or other activities.49

Individuals with mental retardation present consent issues in
a wide variety of settings. Almost any residential setting raises
questions of the adequacy of, or alternatives to, an individual's
consent. Most obvious are commitment or admission to large
congregate facilities often described as institutions.50 Less obvi-
ous are placements in group homes and other community resi-
dential programs.51 Although these settings do not involve the
"massive curtailment of liberty"52 of total institutions, they affect
significant liberty interests nonetheless.53 Decisions about where
a person will live, and with whom, involve a degree of coercion
and intrusiveness that have no parallels in the lives of nondis-

48. Civil commitment can be thought of as surrogate decisionmaking by the
judge without inquiry into the individual's capacity to make decisions, unless
incompetence is part of the substantive criteria for commitment in a particular
state. Voluntary admission clearly involves the full range of consent issues, but
is seldom litigated because of the tendency of mental health facilities and profes-
sionals to accept any apparent acquiescence in institutionalization. See Grace
Olin & Harry Olin, Informed Consent in Voluntary Mental Hospital Admissions, 132
AM. J. PSYCHIATRY 938 (1975) (noting that few "voluntary" patients possessed
adequate information); Howard Owens, When is Voluntary Commitment Really Vol-
untary?, 47 AM. J. ORTHOPSYCHIATRY 104 (1977) (indicating that many "volun-
tary" admission forms that had been accepted as legally adequate were
inconsistent with either understanding or acquiescence). See generally 1 MENTAL
DISABILITY LAW, supra note 20, at 407-13. Janet Gilboy & John Schmidt, "Volun-

49. See, e.g., In re Milton, 505 N.E.2d 261 (Ohio 1987) (holding that state
could not compel legally competent individual to undergo medical treatment
even though she suffered from long-standing religious delusions). See generally
ROZOFSKY, supra note 20, at 430-36 (discussing right to refuse treatment in emer-
gency situations).

50. See, e.g., People v. Reliford, 382 N.E.2d 72 (Ill. App. Ct. 1978); In re
Harhut, 385 N.W.2d 305 (Minn. 1986). See generally Gunnar Dybwad & Stanley
S. Herr, Unnecessary Coercion: An End to Involuntary Civil Commitment of Retarded

51. For a discussion of how the judiciary monitors the residential placement
of mentally retarded individuals in the District of Columbia, see J. Dennis Doyle,
Court Procedures for Placements in Community Living Facilities, 24 MENTAL RETARDA-
TION 311 (1986).


53. See James W. Ellis, Right to Developmental Disabilities Services Act, in DIS-
ABLED PERSONS AND THE LAW: STATE LEGISLATIVE ISSUES 409, 440 (Bruce Sales et
al. eds., 1982) [hereinafter Ellis, Services Act] (requiring more formalized proce-
dure for residential services because such services involve greater loss of liberty).
abled individuals who are not incarcerated. 54

Nonresidential programs also involve choices that require attention to the adequacy of consent. 55 Whether they take the form of participation in an adult habilitation program, enrollment as a worker or trainee in a sheltered workshop, or some other program, the individual faces a choice with significant potential advantages and drawbacks to be considered. Similarly, provision of medical services unrelated to the individual’s disability require consent by the individual or someone who is authorized to make decisions on his or her behalf. For example, although psychotropic medications do not address the disabilities caused by mental retardation, many individuals who have mental retardation are given these medications, either for administrative convenience or to address an individual’s coexisting mental illness. 56 In addition, people with mental retardation may be sought as subjects in programs of behavior modification or experimentation. 57

Substantial attention has been directed to consent issues that involve procedures related to sexuality and procreation on the part of people with mental retardation. 58 The most prominent issue, especially in the first half of this century, has been involuntary sterilization. 59 Increasing attention has also been directed to

54. For a striking example of coercion and intrusion into the lives of persons with mental retardation, see infra notes 94-95 and accompanying text.
55. Ellis, Services Act, supra note 53, at 438-40.
57. See NATIONAL COMM’N FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, REPORT AND RECOMMENDATIONS: RESEARCH INVOLVING THOSE INSTITUTIONALIZED AS MENTALLY INFIRM (1978) (reporting results of comprehensive study on consent procedure applicable to mentally retarded individuals in various institutions); Paul R. Friedman, Legal Regulation of Applied Behavior Analysis in Mental Institutions and Prisons, 17 ARIZ. L. REV. 39 (1975).
59. The case which authorized the epidemic of involuntary sterilization of mentally retarded persons in the first half of this century was Buck v. Bell, 274 U.S. 200 (1927). More recent cases have made involuntary sterilizations more difficult to obtain. See, e.g., North Carolina Ass’n for Retarded Children v. North Carolina, 420 F. Supp. 451 (M.D.N.C. 1976) (requiring that court order be obtained before parents could have child involuntarily sterilized and concluding that parents must demonstrate clear and convincing need for such procedures); In re A.W., 637 P.2d 366 (Colo. 1981) (holding that parents must obtain court order and further holding that sterilization of minor may be performed only when “medically essential”); In re Grady, 426 A.2d 467 (N.J. 1981) (holding it appropriate for court to decide whether parents can have daughter involuntarily sterilized in her best interests given that daughter had Down’s Syndrome); In re Hayes, 608 P.2d 635 (Wash. 1980) (holding that minor’s parents need court’s
the issue of abortion of the pregnancies of women with mental retardation. Similarly complex questions surround the prescription of contraceptives for individuals with mental retardation who may lack the capacity to give or withhold consent.

A growing number of cases have begun to address the issue of withholding life-saving or life-sustaining treatment from individuals with mental retardation who may be terminally ill. The United States Supreme Court has recognized a liberty interest in being free from unwanted treatment, and courts will have to address how this right is to be implemented for individuals with mental retardation.

In each of these varied situations, similar consent questions must be addressed. At the outset, it must be determined whether the individual with mental retardation possesses the ability to make the decision. If the person lacks that capacity, the issue becomes who will make the decision on that person's behalf, and what standard the decisionmaker will be asked to employ.

III. GENERAL DOCTRINES OF CONSENT

A. Tort Law

The structure of the law of consent begins from the framework that consent forms a defense to the tort of battery. A physician (or anyone else) who is guilty of an offensive touching has

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63. Although Cruzan involved a person who had become incompetent because of degeneration into a persistent vegetative state, the focus was on the adequacy of the evidence of what Ms. Cruzan had indicated about her preferences while she was still competent. As a result, the Supreme Court's decision does not resolve the issue of an individual who may never have been competent to make his or her own decisions.

64. Some decisions, because of their uniquely personal character, will not be amenable to decisions by surrogates if the individuals with mental retardation lack the capacity to choose for themselves. For example, it is intuitively obvious that a guardian (or a court) will not be authorized to select a marriage partner for an incompetent person. Similarly, all would agree that a guardian is not authorized to vote on behalf of his ward in a public election.
committed a tortious battery, but when that touching is at the pa-
tient's request, or with his or her acquiescence, no tort has been
committed. 65 As the Supreme Court has noted, "[t]he informed
consent doctrine has become firmly entrenched in American tort
law." 66

The general rules of consent require that an individual be
competent to give or withhold assent to a particular proposal.
This requirement of competence is an attempt to assure that
treatment providers and others do not take advantage of individu-
als who lack the requisite level of capacity. The essence of the
rule is to respect the autonomy of those deemed competent by
allowing them to make their own choices, while protecting incom-
petent persons from decisions that are actually made by others
that may not be in the individual's best interest.

The tort law definition of competence reflects these pur-
poses. Traditionally, competence has been recognized as requir-
ing three elements: capacity, information and voluntariness. 67
Thus, legally adequate consent requires that the individual be
able to understand what is proposed, have sufficient knowledge
about the proposal and its alternatives, and be able to make a free
choice. Each of these elements is designed to promote the policy
goals of protecting individuals who cannot make their own
choices.

The requirement of capacity is central to the definition; it re-
quires that an individual have the mental capacity to process the
information involved in making a choice. If a proposal is beyond
an individual's ability to comprehend, any assertion of acquies-
cence will be treated as a nullity. Similarly, if a person who does
not understand what is proposed purports to object to it, the law
has traditionally disregarded the refusal.

The information component of the definition reflects the

65. Some authorities view consent as negating an element of the tort,
rather than constituting a defense. The formulation of this view would treat
battery as an unconsented touching. See Prosser & Keeton, supra note 26, at
112. These two formulations of the role of consent have no practical conse-
quences for the resolution of consent cases discussed in this Article.

The issue before the Court in Cruzan was whether the guardians of a patient,
who was in a persistent vegetative state, had the right to terminate life support.
The Court recognized that the notion of bodily integrity has become firmly en-
trenched in consent law and concluded that "[e]very human being of adult years
and sound mind has a right to determine what shall be done with his [or her]
own body .... " Id. (quoting Schloendorff v. Society of New York Hosp., 105
N.E. 92 (N.Y. 1914)).

judgment that a theoretical ability to understand a proposal is insufficient. Actual understanding requires a mastery of the facts relevant to making a rational choice. For example, a patient who is capable of understanding a proposed operation, but who has not been informed that there are chances of adverse consequences will not be held to have given adequate consent. There has been substantial debate in recent years about how much information must be provided, and whether the measure of adequacy is what a reasonable doctor would disclose or what a reasonable patient would want to know. But all parties to this debate agree that a person who is uninformed—by whatever definition is adopted—cannot be said to have given legally adequate consent.

The third element of consent requires that the purported agreement of the individual actually reflect his or her own choice and will. This insistence on the individual’s volition may be thought of as analogous to the criminal law’s defense of duress: the law will not attribute to a person actions that the person did not voluntarily choose to take. In the context of consent, the issue most frequently involves the possibility of excessive influence rather than direct threats or physical coercion.

B. Constitutional Doctrine.

For years, courts and commentators have explored the contention that the common law doctrine of consent has constitutional proportions when state action is involved. Despite earlier opportunities, the United States Supreme Court did not directly


70. For discussion of the initial cases in this area, see Friedman, supra note 57, at 56-75.

71. For example, the Supreme Court could have addressed the constitutional implications of consent law in Mills v. Rogers, 457 U.S. 291 (1982). In Mills, the Court addressed claims brought by six individuals who were forced to take anti-psychotic drugs while in mental institutions. Id. at 305. The Court refrained from reaching the constitutional questions. Id.
address the possibility of a constitutional dimension to consent law until three cases decided in 1990.

In *Cruzan v. Director, Missouri Department of Health*,\(^\text{72}\) the Court decided that under the Due Process Clauses, "a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment."\(^\text{73}\) But the *Cruzan* case involved a proposal to withdraw life-sustaining nutrition and hydration from an individual who was in a persistent vegetative state, and thus, by any definition, incompetent to make her own decisions. The party seeking to have the treatment withheld argued that the right of incompetent persons should be held parallel to those of competent individuals who can make their own decisions. The majority rejected the contention that this conclusion was compelled by its previous decisions in *Parham v. J.R.*\(^\text{74}\) and *Youngberg v. Romeo*,\(^\text{75}\) but declined to rule directly on what the scope of an incompetent person's consent rights might be.\(^\text{76}\)

In *Washington v. Harper*,\(^\text{77}\) the Justices confronted the issue of the right of prisoners to refuse unwanted psychotropic medication. After noting that state law had conferred on the prisoner "a right to be free from the arbitrary administration of antipsychotic medication,"\(^\text{78}\) the Court concluded that even in the absence of that state-created right, Harper would have "a significant liberty interest in avoiding the unwanted administration of antipsychotic drugs under the Due Process Clause of the Fourteenth Amendment."\(^\text{79}\) The Justices then proceeded to uphold the Washington regulation against both substantive and procedural due process challenges.

On the substantive due process issue, the *Harper* Court held that state authorities could medicate a prisoner without his con-

\(^{72}\). *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990).

\(^{73}\). *Id.*

\(^{74}\). 442 U.S. 584, 606 (1979). In *Parham*, the Court held that Georgia's procedures for admitting children to state mental hospitals were constitutional because the procedures neither unduly burdened the state nor unduly inhibited parental consent. *Id.* The Court also recognized that "a child ... has a substantial liberty interest in not being confined unnecessarily for medical treatment." *Id.* at 600.


\(^{76}\). *Cruzan*, 497 U.S. at 279-80; see also *id.* at 289 (O'Connor, J., concurring) ("I also write separately to emphasize that the Court does not today decide the issue whether a State must also give effect to the decisions of a surrogate decisionmaker.").


\(^{78}\). *Id.* at 221.

\(^{79}\). *Id.*
sent if it were determined that he had “a serious mental illness” and that the inmate was “dangerous to himself or others and the treatment [was] in the inmate’s medical interest.”

Addressing the procedural due process issues, the majority approved adjudication by an “independent” decisionmaker who was not a judge, and denied a claim that the decisionmaker was obligated to employ a standard of proof higher than preponderance of the evidence.

The applicability of the Harper holding in contexts and settings other than prisons is unclear, since the Court emphasized “the legitimacy, and the necessity of considering the State’s interests in prison safety and security.” Caution about extending the Court’s ruling to non-prison settings is also emphasized by the majority’s citation to other prison cases, such as Turner v. Safley and O’Lone v. Estate of Shabazz. As the Court noted, “the extent of a prisoner’s right under the [Due Process] Clause to avoid the unwanted administration of antipsychotic drugs must be defined in the context of the inmate’s confinement.” This limitation is particularly significant with regard to the Court’s rejection in Harper of the claim that the state should have to demonstrate that the forced medication was consistent with the least-drastic-means principle. Both Turner and Estate of Shabazz involved rights (correspondence and free exercise of religion, respectively) that would have triggered strict scrutiny and the least-drastic-means test had they arisen in a non-prison setting.

The third relevant decision in 1990 was Zinermon v. Burch, in which the Court held that it was sufficient to state a claim under 42 U.S.C. § 1983 for a patient to allege that the state had admitted him as a “voluntary” patient in a mental hospital when they had reason to know that he was not mentally competent to make a voluntary decision to enter the facility. The Court explicitly de-

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80. Id. at 227.
81. Id. at 228-36.
82. Id. at 233.
86. Id. at 224-25. In Harper, the Court concluded that an absence of alternatives constitutes evidence of a regulation’s reasonableness. However, the Court stated that “[t]his does not mean that prison officials ‘have to set up and then shoot down every conceivable alternative method of accommodating the claimant’s constitutional complaint.’ ” Id. (quoting Turner, 482 U.S. at 90-91).
88. Id. at 137-39.
clined to rule on whether Burch could raise a substantive due process claim of unlawful detention. Instead, the majority limited its examination to the procedural due process claim and concluded that an individual who lacked the capacity to consent could not be deprived of a hearing on the issue of whether he should be confined in a mental institution.

The *Zinermon* decision contains commentary on the special consent issues presented by people with substantial mental illness. Justice Blackmun's majority opinion observed:

Indeed, the very nature of mental illness makes it foreseeable that a person needing mental health care will be unable to understand any proffered "explanation and disclosure of the subject matter" of the forms that person is asked to sign, and will be unable "to make a knowing and willful decision" whether to consent to admission.

The Court elaborated on this point in a footnote:

The characteristics of mental illness thus create special problems regarding informed consent. Even if the State usually might be justified in taking at face value a person's request for admission to a hospital for medical treatment, it may not be justified in doing so, without further inquiry, as to a mentally ill person's request for admission and treatment at a mental hospital.

Thus the Court refused to allow a state to accept as valid a consent document signed by an individual known or strongly suspected to be incompetent.

89. *Id.* at 126-27 (noting that substantive due process issue was not raised in petition for certiorari). However, the *Zinermon* Court did hold that Burch's complaint stated a claim under 42 U.S.C. § 1983 (1988). *Id.* at 139. Section 1983 provides:

Every person who, under the color of any statute, ordinance, regulation, custom, or usage of any State . . . subjects, or causes to be subjected, any citizen of the United States . . . to the deprivation of any rights, privileges or immunities secured by the Constitution and laws, shall be liable to the party injured in an action at law . . . .


91. *Id.* at 133 n.18.

92. *Id.* The Court also rejected the possibility that failure to obtain legally adequate consent would be the equivalent of "harmless error" on the theory that such a person would certainly have been confined if involuntary commitment had been sought. The Court stated:
Taken together, these three decisions resolve some constitutional questions about consent and leave others unanswered. *Cruzan* makes clear that the common law doctrine of consent has constitutional proportions, and that competent individuals have a substantive due process right to be free from at least some forms of unwanted treatment. *Harper* teaches that individuals have a liberty interest in being free from unwanted psychotropic medications, but that under some circumstances the state may have a sufficient interest in medicating the individual over his objections. *Zinermon* warns that imposing treatment on an individual under the guise of accepting his consent will raise due process concerns when there was reason to anticipate that his mental condition rendered him incapable of making his own legally valid choice.

There are also important constitutional questions that remain unresolved. The Court has not specified the level or “tier” of substantive due process analysis to be employed in deciding when the state may overcome a competent patient’s objections to treatment outside a prison setting. Thus it remains uncertain whether the state must demonstrate a compelling interest in overcoming a patient’s choice to decline treatment, and whether the state must demonstrate that it had no less drastic means available to accomplish its purpose. Similarly, the Court has not provided a constitutional definition of when an individual is incapable of making his or her own decisions about treatment, nor has it announced what kind of hearing is required to determine incompetence or overcome the objections of a competent person. The Court has also declined to decide under what circumstances providing treatment without obtaining adequate consent will constitute a violation of substantive due process. 93

Persons who are mentally ill and incapable of giving informed consent to admission would not necessarily meet the statutory standard for involuntary placement, which requires either that they are likely to injure themselves or others, or that their neglect or refusal to care for themselves threatens their well-being. . . . The involuntary placement process serves to guard against the confinement of a person who, though mentally ill, is harmless and can survive safely outside an institution. Confinement of such a person not only violates Florida law, but also is unconstitutional.

*Id.* (quoting *O'Connor v. Donaldson*, 422 U.S. 563, 575 (1975)).

93. This inquiry is analogous, however, to the Court’s inquiry in *O'Connor v. Donaldson*, 422 U.S. 563 (1975). In *O'Connor*, the Court held that confining a nondangerous individual in custodial confinement that provided no treatment deprived him of liberty in violation of the substantive meaning of the due process clause. *Id.* at 575.
IV. APPLYING CONSENT DOCTRINES TO MENTAL RETARDATION ISSUES

A. The Context

As noted earlier, consent issues in the lives of people with mental retardation will be shaped largely by cases that involved individuals with other kinds of disabilities or no disability at all. Yet these decisions, for the most part, provide useful guidance for the resolution of mental retardation cases.

It is well established that some individuals with mental retardation will be competent to make important decisions concerning their lives and that others will not. It is also clear that for a particular individual, some proposed treatments or activities will be within his or her capacity to give or withhold consent and that others will not. Although we know that these variations in decisional capacity exist among the population of people who have mental retardation, in many cases it will not be clear whether a particular individual is capable of making a particular decision.

To understand how these varying capacities work in the lives of people with mental retardation, it is essential to understand how coercive the atmosphere is in which many, if not most, of them live. The most obvious element of this phenomenon is authorized, official coercion, such as the powers of a court-appointed guardian or the authority of a facility’s staff over civilly committed individuals. But the reality of the lives of people with mental retardation involves a more pervasive coerciveness. A wide variety of nondisabled individuals, including social workers, therapists, operators of sheltered workshops and group homes, and others will often assume and exercise decisionmaking authority over people with mental retardation in ways that are not described in, or authorized by the law. People with mental retardation often believe, accurately for the most part, that, as a practical matter, they must obtain “permission” from nondisabled individuals to do things that no other adults in society must obtain permission to do. Both people with mental retardation and nondisabled individuals who deal with them on a regular basis assume that such authority is natural, necessary and appropriate.

An example that suggests the nature of this reality in the lives of people with mental retardation is in which many, if not most, of them live. The most obvious element of this phenomenon is authorized, official coercion, such as the powers of a court-appointed guardian or the authority of a facility’s staff over civilly committed individuals. But the reality of the lives of people with mental retardation involves a more pervasive coerciveness. A wide variety of nondisabled individuals, including social workers, therapists, operators of sheltered workshops and group homes, and others will often assume and exercise decisionmaking authority over people with mental retardation in ways that are not described in, or authorized by the law. People with mental retardation often believe, accurately for the most part, that, as a practical matter, they must obtain “permission” from nondisabled individuals to do things that no other adults in society must obtain permission to do. Both people with mental retardation and nondisabled individuals who deal with them on a regular basis assume that such authority is natural, necessary and appropriate.

94. The rarity of such coerciveness in the lives of nondisabled individuals and its pervasiveness in the lives of people with mental disabilities may be suggested by contemplating the type of control that a parole officer exercises over criminal parolees.
of people with mental retardation can be found in a memo issued in 1967 to individuals who were about to be released from a state mental retardation institution:

We congratulate you on being given this chance to take your place in society. During this period you will be on probation and you must not only obey all of the laws of your community, but also the following rules of our School:

1. You must not leave your present place without first notifying us.
2. You must not drive or own a car.
3. You must not drink alcoholic beverages or enter any tavern.
4. You must not get married.
5. You must not get engaged, go steady, or date.
6. You must not make any written contract in regard to purchase of articles on time payments without first talking to your social worker. See worker before using "lay-a-way" plan.
7. You must be home by 12:00 A.M., earlier if requested by employer or other person in charge.
8. You must not leave the state.

Carry this reminder with you at all times and read it frequently. Violation of any one of the above rules may result in your return to the school.

Superintendent, Lincoln State School

The range of intentionally chilling effects on the financial, familial, social, mobility and almost every other aspect of an individual’s life and liberty is truly Orwellian. The authors who uncovered this haunting example of pervasive intrusiveness and coercion also ask us to speculate whether there are still individuals with mental retardation released in 1967 who are still carrying around this “reminder” and still “reading it frequently” a quarter of a century later.96

96. Id. at 64. Although the specificity of this memo is startling, there is reason to believe that, in a way, its explicit warnings may be superfluous. The pervasiveness of informal (and essentially lawless) controls, the necessity of obtaining permission from officials such as social workers for everyday activities, and the ubiquitous threat of being “sent back” are unambiguously perceived by many individuals living in the community.
Thus in shaping the consent rules to be applied in cases involving mental retardation, we have the confluence of three significant phenomena: substantial mental and communication disabilities that may not be apparent to outsiders, a uniquely coercive environment in the lives of many of these individuals, and the fact that many of the decisions involve possible deprivation of fundamental rights. It is against this background that the constitutional and common law doctrines must be analyzed.

A principal problem in the lives of people with mental retardation is the extent to which they have been denied the right to make important decisions affecting their own lives. In some circumstances, the law has allowed others to make these decisions for them. But in many other cases, authorizing others to make the decisions has reflected a desire to shape their lives in ways that are convenient to society. In reshaping the doctrine of consent for people with mental retardation, it is essential to permit individuals who can make their own decisions to do so. An equally important goal must be to protect those individuals who cannot make their own decisions from unwarranted deprivation of their substantive liberties.

B. Autonomous Decisions

The implementation of the rules of consent for people with mental retardation must first reflect the importance of letting individuals make as many decisions about their own lives as possible. There are several practical ways of pursuing this goal.

The first is to recognize that people with mental retardation have substantial liberty interests that merit full legal protection. In the terminology of constitutional law, this involves both substantive and procedural due process. For example, in contexts other than mental retardation, the United States Supreme Court has recognized procreation, contraception, and freedom from

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98. See Skinner v. Oklahoma ex rel. Williamson, 316 U.S. 535, 537 (1942) (reasoning that Oklahoma statute deprived claimant of fundamental right and invalidating statute where such statute permitted court ordered sterilization of "habitual criminal").

physical confinement\textsuperscript{100} as fundamental rights. Under the substantive meaning of due process, to deprive an individual of these rights, the government must demonstrate a compelling interest and prove that no alternative means were available that involved less deprivation of liberty. Similarly, the Supreme Court has recognized substantial liberty interests in being free from unwanted medical treatment,\textsuperscript{101} and to custody and control of the upbringing of one’s children.\textsuperscript{102} Too frequently in mental disability cases, the tendency has been to exaggerate the state’s interest or to minimize the liberty interest of the individual.\textsuperscript{103}

Second, it is equally important to enhance the ability of individuals with mental retardation to make their own decisions. This effort must take several forms. One is to make decisionmaking a major element in special education curricula.\textsuperscript{104} Another is to implement habilitation programs for adults that identify difficulties in making decisions and that seek to address and remedy those problems.\textsuperscript{105} A substantial argument can be made that in some settings, such habilitation is constitutionally mandated under substantive due process doctrine through its connection to other important constitutional rights.\textsuperscript{106}

A third approach would be to implement the recognition that competence to make decisions is not an all-or-nothing phenomen-
non, but rather varies with the complexity and importance of the subject matter of the proposed decision. The need for limited purpose guardianships has been recognized for a quarter of a century, but states have been painfully slow in implementing this principle. It may be necessary to pursue the possibility of constitutional litigation against the practice of automatically ordering plenary guardianships in all cases in a particular jurisdiction.

Finally, governments must work to eliminate the problem of false alternatives. By declining to create alternatives to institutional placements in sufficient numbers, states have created an artificial scarcity of the kind of environments most likely to enhance the full enjoyment of liberty by individuals with mental retardation. This scarcity creates a “take it or leave it” environment that pushes many individuals into settings more restrictive than their habilitation needs require. Addressing this problem will involve reforming the formula by which the Federal government reimburses states for expenditures under the Medicaid program. It may also be possible to provide some relief through constitutional litigation implementing the Supreme Court’s decision in *Romeo*.

But any attempted constitutional remedy to consent issues involving people with mental retardation will be limited in its effectiveness if courts contrive excuses for deferring to state government officials. In *Romeo*, this deferral was described in terms

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110. An increasing portion of the cost of state institutions is being paid by the federal government. In 1988, more than half the states relied on federal funding to pay at least 50% of the costs of running their mental retardation institutions, and all but two states used federal funding to pay for at least 25% of the cost. Braddock et al., supra note 109, at 10.

of deference to professional expertise, and two justifications were offered. The first was judicial agnosticism—the assertion that courts are no “better qualified than appropriate professionals in making such decisions.” But courts are not required—or indeed permitted—to select and implement the professional opinion that represents the consensus within the relevant profession. Instead, the courts are required to defer to the judgment of the state official unless it “is such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment.” Thus the reason for the deference is not because the judgment is made by a professional, but rather is because it is made by a professional chosen by the state—a state official.

This reading of *Romeo* is consistent with the opinion’s other rationale for deference—that courts should allow state officials to shape services in the way they choose. “By so limiting judicial review of challenges to conditions in state institutions, interference by the federal judiciary with the internal operations of these institutions should be minimized.” Similar justifications for judicial abdication to the decisions of state officials in the consent context can be found in Justice Kennedy’s opinion for the Court in *Harper*, referring to “the recognition that prison authorities are best equipped to make difficult decisions regarding prison administration.”

The Court’s interest in judicial deference is clear, but it is not certain whether consent issues outside a prison setting would be evaluated under *Romeo*’s professional judgment standard or the more extreme prison test in *Harper*, which subjects even deprivations of fundamental rights to evaluation under the test of “reasonableness.” The setting in which consent issues arise may influence the courts’ approach to people with mental retardation in group homes, or large institutions, or who are living independently in the community.

112. Youngberg v. Romeo, 457 U.S. 307, 322-23 (1982). In *Romeo*, the Court concluded that the minimally adequate training that is required by the Constitution must be reasonable in light of the disabled person’s liberty interests. *Id.* The Court emphasized that, in the future, courts must defer to professional judgments on the issue of reasonableness. *Id.*

113. *Id.* (concluding that professional decisions are presumptively valid).

114. *Id.*


116. *Id.* at 224-25.

117. It seems likely that the Court views prisons as *sui generis*, whose officials
C. Protection from Coercion

Just as respect for the choices made by competent individuals with mental retardation is essential for the protection of their autonomy, preventing the state from accepting fictitious "consent" from incompetent persons protects them from unwarranted deprivations of their liberty. The constitutional dimensions of this concern can be found in the Court's opinion in *Zinermon*.

The concern has special importance for people with mental retardation. In many service settings, all individuals who have mental retardation are treated as "voluntary" clients, whose "consent" is "inferred" from their failure to object. This situation is closely analogous to the facts of *Zinermon*, where an individual with mental illness was admitted to a mental hospital despite the fact that he had appeared "disoriented, semi-mute, confused and bizarre in appearance and thought" and "appeared to be paranoid and hallucinating." Confining such an incompetent person without a hearing or proof of dangerousness to himself or to others might give rise to claims under both the substantive and procedural meanings of the due process clause, but the Supreme Court addressed only the procedural aspects.

The *Zinermon* Court's recognition of the relationship between mental disability and incompetence has been criticized as imperiling the current system of voluntary admission to mental hospitals. Whatever validity this criticism may have regarding public policy for individuals with mental illness, the Court's approach may prove beneficial in cases involving mental retardation.

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120. *Id.* at 126-27. For a discussion of substantive and procedural due process issues that arise in the consent setting, see *supra* text accompanying notes 87-92.

It appears that a majority of persons with mental retardation who are confined to large residential institutions are there as "voluntary patients," and indeed some states regard the presence of all persons in those institutions as "voluntary." Yet in all states that still have such institutions, the majority of the institutional population consists of individuals who have severe and profound mental retardation. It is certain that a large percentage of these individuals have not validly "consented" to their placement by any process that will bear inspection. In reality, the states are using the fiction of "voluntariness" for most institutionalized persons with mental retardation to avoid judicial scrutiny of individual placement decisions. The possibility of liability under Zinermon may finally assure that such individuals are no longer warehoused in facilities they have not chosen, with restrictions on their liberty that their disability does not require.

V. Conclusion

People who have mental retardation present unique problems in the area of consent. Their interest in autonomous decisionmaking in important areas of their own lives demands greater respect than the law and service delivery system now offer. Yet at the same time, individuals with mental retardation need to be protected from deprivations of liberty accomplished under the ruse of consent, when knowing, voluntary assent was not truly given, and often was not even sought. True autonomy is not promoted by pretending that an individual is competent to make choices that he or she cannot in fact understand.


123. New Hampshire and the District of Columbia have closed their institutions and replaced them with community living arrangements. The trend toward institutional closure is also advancing in other states. See generally BRADDOCK ET AL., supra note 109, at 14-15.

124. A case that illustrates the way people get "lost" and forgotten in mental retardation institutions is Clark v. Cohen, 794 F.2d 79 (3d Cir. 1986), cert. denied, 409 U.S. 962 (1986). Ms. Clark was involuntarily committed as a minor when she was 15 years old. When she reached the age of majority, her commitment was not reviewed or reexamined. Despite the fact that the law under which she had been committed had been repealed years earlier, and the fact that she was not recommitted under the newly enacted statute, her constant protests that she should be released were ignored for nearly 30 years. The trial court concluded that the reasons she had been confined for so long, despite professional judgment that she should be released, were "bureaucratic ineptitude and insufficient allocations of funds to community residence programs." Id. at 86 (quoting Clark v. Cohen, 613 F. Supp. 684, 689 (E.D. Pa. 1985)).