

Parental Rights and the Habilitation Decision for Mentally Retarded Children

A child in the United States "is not the mere creature of the State."¹ Rather, his upbringing is entrusted to his parents,² who, unless proven unfit in a formal termination hearing,³ make critical decisions for the child in such areas as educational services, medical treatment, and social development. In a variety of circumstances, the power of parents to make these choices has been granted constitutional protection. In the case of parents whose mentally retarded⁴ child receives residential care⁵ in a state facility, however, parental authority has been curtailed.

Current federal and state statutes limit the ability of parents to make decisions concerning the habilitation that their mentally retarded child re-

1. *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925).

2. The Supreme Court first identified the right of parents to control their child's upbringing in *Meyer v. Nebraska*, 262 U.S. 390 (1923) (state law forbidding teaching of any modern language other than English to elementary school children invades liberty guaranteed by Fourteenth Amendment and exceeds power of state). The *Meyer* Court found that the Fourteenth Amendment's due process guarantee of liberty "denotes not merely freedom from bodily restraint but also the right of the individual to contract, to engage in any of the common occupations of life, to acquire useful knowledge, to marry, establish a home and bring up children . . ." *Id.* at 399 (emphasis added); see also *Pierce v. Society of Sisters*, 268 U.S. at 534-35 (statute requiring all children to attend public schools is unconstitutional interference "with the liberty of parents and guardians to direct the upbringing and education of children under their control"); *infra* notes 83-86 and accompanying text (substantive due process rights of parents in family life).

3. See *Quilloin v. Walcott*, 434 U.S. 246, 255 (1978) (unanimous Court):

We have little doubt that the Due Process Clause would be offended "[i]f a State were to attempt to force the breakup of a natural family, over the objections of the parents and their children, without some showing of unfitness and for the sole reason that to do so was thought to be in the children's best interest."

Id. (quoting *Smith v. Organization of Foster Families for Equality & Reform*, 431 U.S. 816, 862-63 (1977) (Stewart, J., concurring in the judgment)); *Stanley v. Illinois*, 405 U.S. 645, 658 (1972) (all Illinois parents, including unwed fathers, "constitutionally entitled to a hearing on their fitness before their children are removed from their custody" without parental permission). Parental rights termination hearings must meet procedural standards. See *Santosky v. Kramer*, 455 U.S. 745, 768-69 (1982) (Fourteenth Amendment's due process standard requires "clear and convincing evidence" standard of proof before termination of parental rights).

4. The most widely accepted definition of mental retardation is that of the American Association on Mental Deficiency (AAMD): "Mental retardation refers to significantly subaverage general intellectual functioning resulting in or associating with impairments in adaptive behavior and manifested during the developmental period [i.e. prior to age 18]." D. MACMILLAN, MENTAL RETARDATION IN SCHOOL AND SOCIETY 41 (2d ed. 1982). For important criticism of this definition, see *id.* at 44-48 (adaptive behavior cannot be adequately measured at present and AAMD definition said to combine, in confusing way, medical and statistical model). About three to five percent of the children born each year in the United States will be found to be mentally retarded. PRESIDENT'S COMMITTEE ON MENTAL RETARDATION, MENTAL RETARDATION: PREVENTION STRATEGIES THAT WORK 3 (1980). More than six million Americans will be identified as mentally retarded at some point in their lives. PRESIDENT'S COMMITTEE ON MENTAL RETARDATION, MENTAL RETARDATION: PAST AND PRESENT 150-51 (1977) [hereinafter cited as PAST AND PRESENT].

5. Residential care can vary from institutional care in a large facility to deinstitutionalized care in smaller, community-based residences, see *infra* note 18.

ceives when that child is in a state institution. Habilitation consists of education and training for those who are mentally retarded.⁶ This Note argues that habilitation decisions for mentally retarded children in residential care are best made by their parents, and not by public employees, such as mental health workers, as is the current practice. Respecting parental authority in this area will serve the same societal goals as in the traditional areas over which parents retain decisionmaking power in relation to their children. This Note suggests that the current limitations on parental habilitation decisionmaking are unconstitutional. The Note also sets forth a standard, supported by current mental health policy, as well as by current constitutional norms, which ensures that parents have a role in deciding the treatment their institutionalized child will receive. Parental authority can be accorded full effect through incorporation in state statutes of a standard such as the one this Note proposes.

I. CURRENT STATE OF HABILITATION DECISIONMAKING

Legally and medically, habilitation has been broadly defined. Habilitation is the application of professional services to help a mentally retarded person make maximal use of his capacities so he will function more effectively.⁷ Retarded persons have a constitutional right to an amount of habilitation which requires "the State to provide minimally adequate or reasonable training to ensure safety and freedom from undue restraint."⁸ Habilitation can include choices among educational options;⁹ medical treatments, such as psychotropic drugs;¹⁰ and various kinds of behavior

6. For a full definition of habilitation, see *infra* note 7 and accompanying text.

7. P. ROSEN, M. CLARK & S. KIVITZ, *HABILITATION OF THE HANDICAPPED* 3 (1977); see also Katz-Garris, *Litigation and Legislative Regulations Impacting on the Treatment of the Developmentally Disabled*, in *TREATMENT ISSUES AND INNOVATIONS IN MENTAL RETARDATION* 104 (J. Matson & F. Andrasik eds. 1983) (habilitation "not only. . . a skills acquisition or maintenance function but also. . . a remedial process") [hereinafter cited as *TREATMENT ISSUES*].

For legal discussions of habilitation, see *Youngberg v. Romeo*, 457 U.S. 307, 309 n.1 (1982) (habilitation's principal focus is on training and development of needed skills); *Pennhurst State School & Hosp. v. Halderman*, 451 U.S. 1, 7 n.2 (1981) (habilitation consists of "education and training for those, such as the mentally retarded, who are not ill"). Lower federal courts have more closely followed the medical definition, which emphasizes the maximization of the retarded person's capabilities. See, e.g., *Halderman v. Pennhurst State School & Hosp.*, 446 F. Supp. 1295, 1299 (E.D. Pa. 1978) ("'Habilitation' is the term of art used to refer to that education, training and care required by retarded individuals to reach their maximal development."), *aff'd and modified*, 612 F.2d 84 (3d Cir. 1979), *rev'd*, 451 U.S. 1 (1981).

8. *Youngberg v. Romeo*, 457 U.S. 307, 319 (1982).

9. An important educational option relates to language development because a retarded person's progress towards independence is greatly affected by his ability to communicate. Bennett, *Reviewing an Individual Habilitation Plan: A Lawyer's Guide*, 4 U. ARK. LITTLE ROCK L.J. 467, 480 (1981). Decisions relating to language development include whether a retarded child should be taught to speak or should be trained in alternative methods of communication, such as a language board. *Id.*

10. Psychotropic drugs are substances used for the express purpose of producing behavioral, emotional, or cognitive changes. Aman, *Psychoactive Drugs in Mental Retardation*, in *TREATMENT ISSUES*, *supra* note 7, at 455. Pharmacotherapy is employed with the retarded in the hopes of both

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modification programs.¹¹ Elements used in habilitation can be highly controversial. For example, "response contingent electrical stimulation," a type of behavior modification, involves the brief application of an electrical shock after undesirable behavior.¹² "Overcorrection,"¹³ another type of behavior modification used in habilitation plans, uses "punishment"¹⁴ to change unwanted behavior.¹⁵

diminishing "pathological behavior" and encouraging "adaptive behavior." *Id.* at 456. But psychotropic drugs can provide no qualities that a person does not already possess. *See* Hollis & St. Olmer, *Direct Measurement of Psychopharmacologic Responses*, 76 AM. J. MENTAL DEFICIENCY 397, 403 (1972) (drugs merely accelerate or decelerate behavior already in subject's repertoire or change probability of its occurrence).

11. Behavior modification refers to a group of techniques "derived from the models of classical conditioning, social learning, and operant conditioning, with heavy emphasis on the last." McCarver & Cavalier, *Philosophical Concepts and Attitudes Underlying Programming for the Mentally Retarded*, in *TREATMENT ISSUES*, *supra* note 7, at 8. Like any other element of a habilitation program, behavior modification attempts to maximize the potential of the retarded individual. *See* Bigelow, *The Behavioral Approach to Retardation*, in *BEHAVIOR MODIFICATION OF THE MENTALLY RETARDED* 17-18 (T. Thompson & J. Grabowski eds. 1977) [hereinafter cited as *BEHAVIOR MODIFICATION*] ("Behavior modification attempts to teach individuals the specific skills they have failed to learn earlier—skills which help them to function more effectively, enjoy wider experiences, and put them in a position to continue learning other valuable skills."). *But see* P. ROSEN, M. CLARK & S. KIVITZ, *supra* note 7, at 24 ("[B]ehavior modification techniques often represent radical departures from traditional habilitation efforts, although the same habilitative goals certainly apply.").

12. Richmond & Martin, *Punishment as a Therapeutic Method with Institutionalized Retarded Persons*, in *BEHAVIOR MODIFICATION*, *supra* note 11, at 467, 485. Richmond and Martin note a number of significant problems with response-contingent electrical stimulation: (1) the use of "punishing electrical stimulus can be dangerous if administered carelessly"; (2) if used inappropriately, the technique can generate undesirable results; (3) "the need for long-term follow up requires that the equipment be set aside for a specific resident for months, or even years." *Id.* at 485-86, 491.

13. Overcorrection "incorporates several basic learning principles: extinction (immediate termination of the inappropriate behavior and its accompanying reinforcement), timeout (removal of general reinforcement for a period of at least several minutes), and punishment (instruction and guided practice in a restitutional or related activity requiring some physical effort)." Roberts, Iwata, McSween & Desmond, Jr., *An Analysis of Overcorrection Movements*, 83 AM. J. MENTAL DEFICIENCY 588 (1979).

Overcorrection, like behavior modification, is controversial. *See* Foxx, *Attention Training: The Use of Overcorrection Avoidance to Increase the Eye Contact of Autistic and Retarded Children*, 10 J. OF APPLIED BEHAVIORAL ANALYSIS 489, 498 (1977) (ethical considerations arise in studies that use intrusive procedures such as overcorrection where only aversive consequences are available and no positive consequences for appropriate behaviors); Matson, Stephens & Smith, *Treatment of Self-Injudicious Behavior with Overcorrection*, 22 J. MENTAL DEFICIENCY RESEARCH 175-78 (1978) (use of overcorrection therapy required profoundly retarded woman to brush her teeth with mixture of lemon juice and hot sauce because she drank prescribed mouthwash during pretreatment sessions); Richmond & Martin, *supra* note 12, at 485 ("severe abuses of overcorrection occur all too often" as result of "the vague nature of the procedure" and tendency of some staff members to use "excessive coercive force").

14. In behavior modification, "punishment" is generally defined as an event following a maladaptive behavior which will lead to a rapid reduction of the behavior in question. Azrin & Holtz, *Punishment*, in *OPERANT BEHAVIOR* 234 (W. Honig ed. 1966). The punishment element of overcorrection is also termed "aversive consequences." Ferretti & Cavalier, *A Critical Assessment of Overcorrection Procedures with Mentally Retarded Persons*, in *TREATMENT ISSUES*, *supra* note 7, at 241, 243.

15. Richmond & Martin, *supra* note 12, at 481.

A. *The Problem: Excluding Parents*

The extent and seriousness of parent's lack of control over habilitation decisions are manifest in litigation seeking to deinstitutionalize or improve the treatment of retarded individuals who receive residential care. The plaintiffs in these cases have complained at length about the lack of institutional response to parental requests for modifications in the treatments of patients.¹⁶ The lack of institutional response has sometimes led to tragic results.¹⁷

This absence of parental control is not remedied by the current deinstitutionalization movement.¹⁸ Although deinstitutionalization has helped retarded persons,¹⁹ it alone will not solve all the problems associated with the treatment of retarded children, and parents of a retarded child may still be denied the power to make habilitation decisions when the child is placed in a small residential setting rather than a larger institution.²⁰ In-

16. See, e.g., Brief for Respondent at 5-6, *Youngberg v. Romeo*, 457 U.S. 307 (1982) (mother repeatedly attempts to influence son's treatment program without avail before seeking to improve his care by filing civil rights suit against officials of institution); *Garrity v. Gallen*, 522 F. Supp. 171 (D.N.H. 1981) (parents of retarded children institutionalized in state school sue school because of deficiencies in school's education and training and its lack of habilitation plans); *Philipp v. Carey*, 517 F. Supp. 513 (1981) (parents and relatives of mentally retarded citizens confined at state-owned facility in Syracuse, N.Y. contest inappropriate programs and services); Complaint at 4, *Connecticut Ass'n for Retarded Citizens v. Mansfield Training School*, Civ. No. H78-653 (D. Conn. Dec. 12, 1983) (parent's protest over lack of programs or therapy for institutionalized child said to lead to physical abuse of child by staff); see also D. ROTHMAN & S. ROTHMAN, *THE WILLOWBROOK WARS* 42-43 (1984) (parents protest conditions at New York institution for mentally retarded individuals, paraphrase Robert Kennedy's comment about institution: "[A]nimals in the Staten Island Zoo have more space and get better care than the children at Willowbrook").

17. See, e.g., *Naughton v. Bevilacqua*, 458 F. Supp. 610, 613-14 (D.R.I. 1978), *aff'd*, 605 F.2d 586 (1st Cir. 1979) (parents of retarded child communicated child's sensitivity to phenothiazane, a major tranquilizer, but drug was administered anyway, possibly in "a calculated effort" to control behavior of child, causing convulsive spasms and hemorrhaging).

18. Deinstitutionalization is the important trend away from placing or maintaining retarded persons in large institutions in favor of a multi-faceted community-based system, which allows retarded persons to be served by programs and in residences in as normal a way as possible. V. BRADLEY, *DEINSTITUTIONALIZATION OF DEVELOPMENTALLY DISABLED PERSONS* 5 (1978). This trend began in the late 1960's. Butterfield, *Some Basic Changes in Residential Facilities*, in *CHANGING PATTERNS IN RESIDENTIAL SERVICES FOR THE MENTALLY RETARDED* 15 (R. Kugel & A. Shearer eds. 1976) [hereinafter cited as *CHANGING PATTERNS*].

Deinstitutionalized residential care is commonly provided in various kinds of community-based arrangements, which include community residences and intermediate care facilities. *Society for Good Will to Retarded Children v. Cuomo*, 572 F. Supp. 1300, 1338 (E.D.N.Y. 1983). In a community residence, which is often a single family dwelling with four to fourteen clients, clients are supervised either by live-in house parents or by a rotating staff. *Id.* The intermediate care facility is similar to a community residence, but provides greater supervision for clients with more substantial medical and behavioral needs. *Id.*

19. See PAST AND PRESENT, *supra* note 4, at 130 (main thrust of deinstitutionalization not just to move retarded people out of institutions but to provide quality alternatives to institutions). Deinstitutionalization may also help minimize the problems of stigma and isolation faced by mentally retarded persons. V. BRADLEY, *supra* note 18, at 5.

20. A survey of group homes of varying sizes found that "institution-oriented management patterns prevailed. . . regardless of the size of the facility." S. BERCOVICI, *BARRIERS TO NORMALIZATION: THE RESTRICTIVE MANAGEMENT OF RETARDED PERSONS* 141 (1983). Other problems were

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deed, deinstitutionalization may create some new difficulties and dangers²¹ that make necessary continuing parental decisionmaking.

B. *Current Law Regarding Habilitation Decisions*

Federal and state laws currently employ a variety of legal standards, some of which are not entirely clear in intent or meaning, to assign decisionmaking power over the habilitation of retarded children in state institutions.

1. *Federal Law: The DDA*

Many of the federal statutes that help handicapped persons also assist the mentally retarded.²² Of these, one suggests the imposition of a legal burden on states to consult with parents in making habilitation decisions: The Developmentally Disabled Assistance and Bill of Rights Act (DDA).²³ State facilities accepting financial allocations under the DDA must meet its standards relating to the services that people with developmental disabilities receive.²⁴

The DDA gives parents "where appropriate" a role in developing the individual habilitation plan (IHP), which is required for each mentally retarded individual in a state facility.²⁵ The legislative history of the DDA

found in the group homes included in this survey: (1) small group homes, despite prior expectations, were more custodial in some ways than the larger facilities; (2) certain features of the group homes "reinforce thinking and behavior on the part of the retarded individual that are not adaptive when the individual is in noninstitutional settings"; (3) the general quality of the environment at the facilities varied widely; (4) the program goals and methods of the majority of the facilities "could only be seen as adhering to an implicit corrective-detentive model which, by its nature, is non-normalizing"; (5) an "institution-oriented practice of depersonalization" occurred to some degree at all the facilities. *Id.* at 141-45.

21. See V. BRADLEY, *supra* note 18, at 10 ("In their haste to decentralize the system of care for developmentally disabled persons by shifting the emphasis away from large, state-run programs, some states have lost their ability to ensure adequate accountability for the well-being of those receiving care."); cf. Cruickshank, *Foreword*, in DEINSTITUTIONALIZATION vii (J. Paul, D. Stedman & G. Neufeld eds. 1977) ("No social movement has been initiated with such abruptness or so little planning as has been deinstitutionalization.").

22. For example, 400,000 retarded people receive Supplemental Security Income and 250,000 receive Social Security payments under 42 U.S.C. §§ 402(d), 403 (1982). Turnbull, *Rights for Developmentally Disabled Citizens*, 4 U. ARK. LITTLE ROCK L.J. 400, 414 n.54 (1981). Between 1979 and 1981, approximately 1,250 retarded people received Department of Housing and Urban Development loans to help them live in group homes or small apartment complexes. *Id.* at 414.

23. Developmentally Disabled Assistance and Bill of Rights Act of 1975, Pub. L. No. 95-602, 92 Stat. 3004 (codified as amended at 42 U.S.C. §§ 6000-6081 (1982)); see also *infra* note 52 (discussing Education for Handicapped Children Act).

24. See, e.g., 42 U.S.C. § 6012(a) (for state to receive federal allotment under DDA, it must have in place "a system to protect and advocate the rights of persons with developmental disabilities"); 42 U.S.C. § 6063 (any state desiring to take advantage of funds available under DDA must have detailed state plan providing for fiscal administrative procedures approved by Secretary of Health and Human Services).

25. 42 U.S.C. § 6011(b) (1982) states:

A habilitation plan for a person with developmental disabilities shall meet the following

is silent as to the extent to which it is "appropriate" for states to give parents this role,²⁶ and no cases have examined the language of this section of the Act.²⁷ The DDA's failure to specify the weight that is to be assigned to parental wishes is matched by its neglect to establish procedures for appealing habilitation decisions.²⁸ The language of the DDA is vague enough to leave parental involvement entirely to a state's discretion.²⁹ The language is also broad enough, however, to be consistent with the standard advocated in this Note.³⁰

2. State Law

State statutes do not permit adequate parental involvement in the determination of their institutionalized child's habilitation. The largest group of state statutes fail to require any habilitation plan for the mentally retarded clients of their institutions.³¹ The next largest group of states,

requirements:

(1) The plan shall be in writing.

(2) The plan shall be developed jointly by (A) a representative or representatives of the program primarily responsible for delivering or coordinating the delivery of services to the person for whom the plan is established, (B) such person, and (c) [sic] *where appropriate, such person's parents or guardian or other representative.*

(emphasis added). Regulations issued by the Office of Human Development, Department of Health and Human Services, require that each state receiving funds under the DDA meet "the requirements regarding individual habilitation plans" set forth in 42 U.S.C. 6011. 45 C.F.R. § 1386 (1984).

26. See H.R. REP. NO. 1149, 95th Cong., 2d Sess. 1-44, H.R. REP. NO. 1188, 95th Cong., 2d Sess. 1-113, *reprinted in* 1978 U.S. CODE CONG. & AD. NEWS 7312-24; H.R. REP. NO. 58, 94th Cong., 1st Sess. 1-44, *reprinted in* 1975 U.S. CODE CONG. & AD. NEWS 919-64.

27. While no cases give a substantive dimension to this role, there have been important judicial decisions relating to the DDA. In *Pennhurst State School & Hosp. v. Halderman*, 451 U.S. 1 (1981), the Supreme Court examined the bill of rights provision of the DDA, 42 U.S.C. § 6010 (1982), and concluded that nothing in the Act or its legislative history suggested that Congress intended to require the states to provide "appropriate treatment" for mentally retarded citizens in the "least restrictive environment." The Court contrasted the Bill of Rights section, which expressed congressional preference, with sections that were conditions for the receipt of federal funding, such as § 6011. *Id.* at 13. See *Garrity v. Gallen*, 522 F. Supp. 171, 195-205 (D.N.H. 1981) (DDA grants to residents of state school limited private right of action against Secretary of Health and Human Health Services to force performance of duties imposed by this Act); *Developmental Disabilities Advocacy Center v. Melton*, 521 F. Supp. 365, 369 (D.N.H. 1981) (legal services organization established pursuant to DDA, 42 U.S.C. § 6012, and counsel who purported to represent mentally retarded residents of state school lacked standing to challenge visitation regulations).

28. 42 U.S.C. § 6011 (1982).

29. All a state has to do is decide that it is not "appropriate" to involve parents in the development of their child's IHP.

30. See *infra* Part IV.

31. See ALA. CODE §§ 22-52-50 to -52-58 (1975); ARK. STAT. ANN. §§ 59-1002.1 to -1009 (1983); DEL. CODE ANN. tit. 16, § 5501 (1974); D.C. CODE ANN. § 21-11-1 (1981); HAWAII REV. STAT. § 33(E) (1980 Supp. & 1976); IOWA CODE ANN. § 222 (West 1967); KAN. STAT. ANN. §§ 65-4401 to 4408 (1980); LA. REV. STAT. ANN. § 28:380 (West Supp. 1984); MASS. ANN. LAWS ch. 111, § 70(E) (Michie/Law. Co-op. 1983); MISS. CODE ANN. § 41-21-9 (1983 Supp. & 1981); MO. ANN. STAT. §§ 633.025, .130 (Vernon Supp. 1984); N.C. GEN. STAT. §§ 35-2, 168-8 (1976); NEV. REV. STAT. § 435 (1981); N.M. STAT. ANN. § 23-6-1 (1978); PA. STAT. ANN. tit. 50, § 4423 (Purdon 1966); R.I. GEN. LAWS § 40.1-22-2 (1981); S.C. CODE ANN. § 44-21-10 (Law. Co-op. 1976); UTAH CODE ANN. § 64-8-13 (1953); VA. CODE § 37.1-84.1 (1984); WASH. REV. CODE ANN.

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while requiring habilitation plans, fail to specify any need for a parental role in their development.³² State statutes that do mention a general need for consulting with parents,³³ or for giving them some kind of opportunity

§ 71.20 (1975); WISC. STAT. ANN. § 51.47 (West Supp. 1984-1985).

32. See COLO. REV. STAT. § 27.10.5-113(1) (1982) ("Each resident shall have an individualized treatment plan formulated" and "reviewed semiannually" by "professional persons."); GA. CODE ANN. §§ 37-4-2(9), -4-20, -4-122 (1982) (parent of minor child may apply to have child examined by "comprehensive evaluation team," and if majority of team concludes child needs "specialized services other than that which he is then receiving," team will recommend individual program plan for child); IND. CODE ANN. § 16-14-1.6-7 (Burns 1983) ("All patients or clients are entitled to be informed of the nature of the treatment or habilitation program proposed"; adult clients may refuse to submit to program and involuntary patient may petition court or hearing officer for consideration of program; "In the absence of such petition, the service provider may proceed with the proposed treatment or habilitation program."); ME. REV. STAT. ANN. tit. 34, § 2147(2)(A) (1978) (every client served by department of mental retardation shall have "habilitation program"); MD. HEALTH CODE ANN. § 7-605 (1982) ("The professional and supportive staff of a residential State facility shall make a written plan of treatment . . ."); MICH. COMP. LAWS ANN. § 330.1712 (West 1980) ("An individualized written plan of services shall be developed for each resident and shall be kept current and shall be modified when indicated."); MINN. STAT. ANN. § 253 B.03(7) (West 1982) ("The treatment facility shall devise a written program plan for each person which describes in behavioral terms the case problems, the precise goals, including the expected period of time for treatment, and the specific measures to be employed" and which "shall be devised and reviewed with the designated agency and the patient"); MONT. CODE ANN. § 53-20-148(4) (1983) ("Each resident has a right to a habilitation program . . ."); N.D. CENT. CODE § 25.01.2-14 (1983 Supp.) ("Any institution, facility, agency or organization that provides services for developmentally disabled persons shall have a written, individual habilitation plan developed and put into effect for each person . . ."); N.H. REV. STAT. ANN. § 171-A:12 (1977 & Supp. 1983) ("There shall be an individual service plan for every client in the service delivery system" which shall be developed under "the supervision of the administrator" and reviewed continually); OHIO REV. CODE ANN. § 5123.85(B) (Page 1981) ("All . . . residents shall have a written habilitation plan . . ."); OKLA. STAT., ANN. tit. 43A, § 622 (West Supp. 1984)("[A]n individualized treatment plan . . . shall be specifically tailored to [each] person's treatment needs."); OR. REV. STAT. § 427.020 (1981) (each resident of state training center for mentally retarded persons required to have "plan of care" that includes "current diagnosis . . . ; [c]urrent habilitation and health programs in which the resident is participating . . . ; [s]tatement of long-term and short-term goals for the resident . . ."); S.D. CODIFIED LAWS ANN. §§ 27B-8-10, -11 (1984)("[Q]ualified developmental disabilities professional" shall "[f]ormulate an individual habilitation plan" for each resident); TENN. CODE ANN. §§ 33-520, -521 (1977) ("From the time a mentally retarded person or delinquent is received in a program . . . he shall be under the exclusive care, custody, and control of the director," and shall receive "an individualized program of training."); VT. STAT. ANN. tit. 18, § 8835 (1984) ("[F]or each mentally retarded person placed in a residential facility established by the commissioner, . . . a current individual program plan" will be maintained); W. VA. CODE § 27-5-9 (1980) ("The chief medical officer shall cause to be developed within the clinical record of each patient a written treatment plan . . ."); WYO. STAT. §§ 25-5-102, -116 (1982) ("Each resident . . . shall have on file . . . an individual program plan" that will be reviewed at least annually by an interdisciplinary team of which parent is member).

33. FLA. STAT. ANN. § 393.065(2) (West 1983) ("The parent or guardian of the client . . . shall be consulted in the development of the plan" and in annual revision of plan); N.J. STAT. ANN. § 30:6D-10 (West 1981) (individualized habilitation plan "shall be developed and may be revised from time to time . . . in consultation" with client and parents).

for participation,³⁴ leave it to state employees to decide when and how parents should be involved.³⁵

The Connecticut statute, for example, contains broad language that requires the attending physician of any institutionalized child to obtain "informed consent" from the parents of any unemancipated resident under eighteen years of age before "any medical treatment."³⁶ The practice in this state, however, is to obtain parental consent only when life-threatening medical treatments are to be performed on institutionalized children.³⁷ Thus, in Connecticut as in other states, the extent of a parent's right to control treatment decisions is limited.³⁸ Under state law, a par-

34. ARIZ. REV. STAT. ANN. § 36.551.01(J) (1983) ("Each client who has been accepted to receive developmental disability services shall have the right to receive a written individual program plan" that "shall be developed by appropriate department personnel with the participation of the client, his parents, and his guardian, if any . . ."); CAL. WELF. & INST. CODE § 4646 (West 1984) (The "individual program plan" that "may be developed for any person who . . . is found to be eligible for, and in need of, such plan" is to be "prepared jointly by one or more representatives of the regional center, the developmentally disabled person, and where appropriate, the person's parents . . ."); IDAHO CODE § 66-431(2) (1983) ("Each facility shall take reasonable efforts to include the resident or client and parents of minor residents or clients . . . in the development of the [individual treatment] plan."); ILL. REV. STAT. ch. 91½, § 4-309, Mental Health & Dev. Disab. Code § 4-309 (1982) ("Every reasonable effort shall be made to involve the client and his family in the preparation and implementation of the [habilitation] plan."); KY. REV. STAT. § 202B.060(1), (2) (1982) (mentally retarded residents and their families have right to be "adequately informed as to the individual treatment program of the resident" and "to assist" in its planning); NEB. REV. STAT. § 43-661 (1984) (habilitation plan not required, but parents given right "to initiate a hearing on matters relating to the initiation, change, or termination or the refusal to initiate, change, or terminate the identification, evaluation, or educational placement of a [handicapped] child"); N.Y. MENTAL HYG. LAW § 29.13(b) (1979) (In causing "written treatment plan" to be prepared or revised, "the patient or an authorized representative, to include the parent or parents if the patient is a minor, shall be interviewed and provided an opportunity to actively participate in such preparation or revision.").

35. The language of the statutes that do specify a need for some kind of parental involvement provide an easy escape for the state official who does not want to involve any given parent—he need only decide that it is not "appropriate" to involve them or that he can not do so with any "reasonable effort." And, of course, these statutes leave the *extent* of participation by parents to the discretion of the official. Cf. *Developmental Disabilities Advocacy Center v. Melton*, 521 F. Supp. 365, 368 n.3 (D.N.H. 1981) (staff members who feel "best interests" of resident warrant overturning of guardian's refusal to agree to placement decision do so).

36. CONN. GEN. STAT. §19(a)-469(f) (1983) states:

The commissioner of mental retardation shall require the attending physician of any person placed or treated under his direction to obtain informed written consent from the following persons prior to authorizing any surgical procedure or any medical treatment, excluding routine medical treatment which is necessary to maintain the general health of a resident or to prevent the spread of any communicable disease: (1) The resident if he is eighteen years of age or over or is legally emancipated and competent to give such consent; (2) the parent of a resident under eighteen years of age who is not legally emancipated; or (3) the legal guardian or conservator of a resident of any age who is adjudicated unable to make informed decisions about matters relating to his medical care.

37. Conversation with George Doyle, Director of Social Services, New Haven Regional Center, Department of Mental Retardation for the State of Conn., Apr. 12, 1984. Connecticut has, however, granted the parents of mentally retarded residents of the Mansfield Training School, a large institution for the mentally retarded, "a primary role" in the placement decisionmaking process following a consent decree to reduce the population of the clients at this school. *Consent Decree, Connecticut Ass'n for Retarded Citizens v. Thorne*, Civil No. H-78-6534 (D. Conn. Nov. 7, 1983).

38. The exception to this general pattern may be Texas. See TEX. STAT. ANN. art. 5547-300 (§ 18) (Vernon 1982) ("Whenever possible, the client or the parent of a minor . . . shall be given

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ent's wishes for his child have less weight than those of the state employees who are assigned to the child's treatment team. These employees, by having the discretion to decide the scope of parental involvement, have the power to decide the habilitation that an institutionalized mentally retarded child will receive.

C. *A Narrower Definition of Habilitation*

In order to set clear limits on the scope of authority of both the state and the parents, this Note narrows the general definition of habilitation. The proposed definition sets an age limit for those on whose behalf habilitation decisions are made and excludes certain kinds of decisions from the ambit of habilitation plans, which set long-term goals and short-term objectives for the child.³⁹

Parental habilitation power should be restricted to choices made on behalf of children who are legal minors. When a mentally retarded individual reaches the age of majority, there should be a hearing at which parents, if they choose, can petition to continue as their son's or daughter's legal guardian.⁴⁰

Although "health" is an "ambiguous state about which doctors and patients may have conflicting expectations,"⁴¹ routine minor health care demands no more than those noncontroversial procedures performed routinely to maintain a general level of physical well-being.⁴² A decision to treat a minor cut with antiseptic and an adhesive bandage, for example, does not belong within the scope of an individual habilitation plan. At the other extreme, but also excluded by this narrowing of habilitation, are emergency situations involving non-terminally ill children.⁴³ In this type of situation, when obtaining parental permission would take time during which the child's life might be seriously impaired, on-the-spot medical

the opportunity to decide among several appropriate alternative services available to the client . . ."). But see *Lelsz v. Kavanagh*, 98 F.R.D. 11, 12 (E.D. Tex. 1982), *appeal dismissed*, 710 F.2d 1040 (5th Cir. 1983) (class action suit challenges adequacy of conditions, care, and habilitation at Texas institutions for mentally retarded individuals).

39. See 42 U.S.C. § 6011(b)(3) (1982) ("The plan shall contain a statement of the long-term habilitation goals for the person and the intermediate habilitation objectives relating to the attainment of such goals.").

40. Applicable guardianship provisions are already found in state codes, see, e.g., IOWA CODE ANN. §§ 639.634 to .682 (West 1950).

41. J. KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 98 (1984).

42. These routine procedures carry no more than minor risks which, "if they materialize will not cause the patient substantial harm, pain, or discomfort." Meisel & Kabnick, *Informed Consent to Medical Decisionmaking: An Analysis of Recent Legislation*, 41 U. PITT. L. REV. 407, 432 (1980).

43. An emergency exception applies when immediate treatment is needed to preserve life or prevent a serious impairment to health, and consent cannot be obtained from the parent. See Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WISC. L. REV. 413 (defining emergency exception to informed consent doctrine).

personnel need the authority to act promptly.⁴⁴ Habilitation decisions should also be defined so as to disallow the choice of procedures that are not generally accepted medically.⁴⁵ The state, while sometimes unable to interfere with these procedures in other circumstances,⁴⁶ is not obliged to be the instrument by which they are delivered.

Finally, parental control over non-emergency life and death decisions raises different questions than parental control over a habilitation plan.⁴⁷ As such, these decisions require a different framework than does habilitation.⁴⁸

II. HABILITATION DECISIONMAKING BY PARENTS

Habilitation decisionmaking includes choices in three areas over which parents are normally granted control: a child's education,⁴⁹ medical treatment,⁵⁰ and social development.⁵¹ Habilitation decisions have educational

44. For example, cardiac arrest usually has a fatal outcome for an injured child. Morse, *Evaluation and Initial Management*, in *PEDIATRIC TRAUMA* 30 (R. Touloukian ed. 1978).

45. See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *MAKING HEALTH CARE DECISIONS: REPORT 3* (1982) (hereinafter cited as PRESIDENT'S COMMISSION FOR ETHICAL PROBLEMS IN MEDICINE) ("Patients are not entitled to insist that health care practitioners furnish them services when to do so would violate . . . the bounds of acceptable practice.").

46. See, e.g., *Founding Church of Scientology v. United States*, 409 F.2d 1146 (D.C. Cir. 1969) (simple electrical instruments, dubbed E-meters or Hubbard Electrometers, used in process said to improve spiritual and bodily condition cannot be banned by government because of unopposed case that religious belief involved); *People v. Woody*, 61 Cal. 2d 716, 394 P.2d 813, 40 Cal. Rptr. 69 (1964) (native Americans' use of peyote in mystical religious ceremony can not be banned by state statute).

47. Gaylin, *Who Speaks for the Child?*, in *WHO SPEAKS FOR THE CHILD* 5 (W. Gaylin and R. Macklin eds. 1982) ("Our society places a high value on human life, and we tend to be repelled by the thought of granting any third party, even a parent, the power of life and death.").

48. *Compare In re Quinlan*, 70 N.J. 10, 55, 355 A.2d 647, 671-72 (1976), *cert. denied*, 429 U.S. 922 (1976) (father of severely brain-damaged woman could exercise daughter's right to privacy against bodily intrusion by authorizing removal of artificial life support only upon mandatory involvement of family, attending doctor, and hospital ethics committee); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 757-59, 370 N.E.2d 417, 434-35 (1977) (probate court, not hospital ethics committee, has responsibility to determine whether to administer potentially life-prolonging treatment to terminally ill, mentally incompetent resident of state institution); Note, *A Structural Analysis of the Physician-Patient Relationship in No-Code Decisionmaking*, 93 YALE L.J. 362, 381 n.111 (1983) (if dying child's life "would only be prolonged for a short time during which a normal quality of life would be impossible," parents can give "informed consent" to no-coding, which orders nursing staff not to summon resuscitation team if patient has cardio-pulmonary arrest).

49. See *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925) (state has no general power to force children to accept instruction in public schools); *Meyer v. Nebraska*, 262 U.S. 390, 400 (1923) ("[I]t is the natural duty of the parent to give his children education suitable to their station in life."). But recent Supreme Court cases allow great deference to state officials. See *Ingraham v. Wright*, 430 U.S. 651, 670 (1977) (parents sue on behalf of children punished by disciplinary paddling, but public school teachers allowed to inflict "such corporal punishment as is reasonably necessary for the proper education and discipline of the child"); *infra* text accompanying notes 116-20.

50. See generally *Parham v. J.R.*, 442 U.S. 584, 603 (1979) ("Simply because the decision of a parent is not agreeable to a child or because it involves risks does not automatically transfer the power to make that decision from the parents to some agency or officer of the state.").

51. See *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (Amish parents have interest in raising children

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elements because they involve choices among types of academic and vocational training for the child.⁵² They contain medical elements because they utilize medical science to help maximize a child's potential.⁵³ Finally, these decisions relate to a child's social development because they include training in such areas as the use of leisure time and the ability to interact socially in an appropriate manner.⁵⁴

For the same reasons parents control a child's education, medical treatment, and socialization, they should make habilitation decisions. Parents make child-rearing decisions because of (a) their own unique qualifications to do so; (b) the state's incapacity to make these sensitive decisions; and (c) the stake our society has in diversity, which prevents the state from standardizing its citizens.

in Amish religion and way of life); *Meyer v. Nebraska*, 262 U.S. 390, 402 (1923) (state may not "foster a homogenous people with American ideals" by banning instruction in any modern language other than English).

52. See Bennett, *supra* note 9, at 481 ("A school age developmentally disabled client should be enrolled in a fully certified special education program."). Children in special education programs are required by the Education for Handicapped Children Act (EHCA), 20 U.S.C. § 1401(2)(1) (1977), to have an Individual Education Plan. See 20 U.S.C. § 1401(19) (1977) ("[I]ndividualized education program" is "a written statement for each handicapped child developed in any meeting by a representative of the local educational agency or an intermediate educational unit . . . , the teacher, the parents or guardian of such child, and, whenever appropriate, such child . . .").

The EHCA grants parents the right "to present complaints with respect to any matter relating to the identification, evaluation, or educational placement of the child, or the provision of a free appropriate public education to such child." *id.* § 1415(2)(b)(1)(E) (1977). It also sets up a detailed procedure for hearing complaints. Parents have "an opportunity for an impartial due process hearing which shall be conducted by the State educational agency or by the local educational agency or by the local educational agency or intermediate educational unit." *Id.* § 1415(b)(2). Appeal from findings and decisions rendered in this hearing can be made to the State educational agency which is obligated to "conduct an impartial review" of the hearing. *Id.* § 1415(c). Appeal from the decision of the state educational agency can be made by bringing a civil action in any state court of competent jurisdiction or in a federal district court. *Id.* § 1415(e)(2).

The EHCA does not, however, specify the weight parental wishes are to be given. See SEN. REP. NO. 168, 94th Cong., 1st Sess. 11, *reprinted in* 1975 U.S. CODE CONG. & AD. NEWS 1425, 1435 ("[T]he Committee intends to ensure adequate involvement of the parents or guardian of the handicapped child . . . in both the statement and its subsequent review and revision."). Courts have not consistently decided where to place the burden of proof when IEP's are questioned. Compare *Tatro v. Texas*, 703 F.2d 823, 830 (5th Cir. 1983), *aff'd in part and rev'd in part sub nom. Irving Independent School Dist. v. Tatro*, 104 S. Ct. 3371 (1984) (fairness requires that party attacking terms of IEP bear burden of showing why educational setting is not appropriate) and *Bales v. Clarke*, 523 F. Supp. 1366 (E.D. Va. 1981) (handicapped child has burden of establishing that regional school was inappropriate for her needs) with *Davis v. District of Columbia Bd. of Educ.*, 530 F. Supp. 1209 (D.D.C. 1982) (school district has burden of showing that its proposal is indeed "an appropriate one").

53. For controversial medical elements of a habilitation plan, see *supra* text accompanying notes 10-15.

54. Bennett, *supra* note 9, at 483.

A. *Parents' Qualifications to Protect the Child's Best Interests*

While the interests of parents and children may sometimes conflict,⁵⁵ our society generally allows, indeed expects, parents to assume responsibility for their children.⁵⁶ Parents are expected to evaluate and make judgments about the needs and requests of their children. This responsibility is theirs because most child rearing decisions require the knowledge of parents, rather than the professional expertise of specialists,⁵⁷ and because the natural bonds of affection generally lead parents to act in the best interests of the child.⁵⁸ Indeed, this bond between parent and child is of profound importance to the emotional life of both.⁵⁹ Our legal system enforces the societal assumption that parents should make child rearing decisions by granting parents the freedom to do so unless they are shown unfit and are disqualified at a formal proceeding comporting with due process requirements.⁶⁰

The mental condition or living situation of the retarded child in residential care does not render his parents unfit to protect the child's best interests. Suspicion of these parents appears to follow from their decision

55. The Supreme Court's decisions regarding a minor child's decision to have an abortion reflect an understanding that the interests of parents and child sometimes conflict. *See Bellotti v. Baird*, 443 U.S. 622 (1979) (plurality opinion) (privacy right of mature child requires that if state requires pregnant minor to obtain parental consent for abortion, it must also provide alternative procedure for abortion authorization); *Planned Parenthood of Missouri v. Danforth*, 428 U.S. 52, 74-75 (1976) (state does not have constitutional authority to give parent absolute veto over minor's abortion decision); *see also Carey v. Population Services Int'l*, 431 U.S. 678, 691-96 (1977) (plurality opinion) (state prohibition of nonprescription contraceptives to those under sixteen years of age struck down because of minors' privacy right).

56. "Our jurisprudence historically has reflected Western civilization concepts of the family as a unit with broad parental authority over minor children." *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

57. *See, e.g., M. JABLOW, CARA: GROWING WITH A RETARDED CHILD* (1982) (memoir of life with retarded daughter emphasizes need for parent to evaluate and monitor school and physical therapy programs).

58. *See Parham v. J.R.*, 442 U.S. 584, 602 (1979) ("[H]istorically [the law] has recognized that natural bonds of affection lead parents to act in the best interests of their children.") (citations omitted); *Wisconsin v. Yoder*, 406 U.S. 205, 232 (1972) ("The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children."). Kent begins his chapter "Of Parent and Child" with mention of "those feelings of parental love . . . which Providence has implanted in the human breast." 2 J. KENT, *COMMENTARIES ON AMERICAN LAW* 189 (J. Gould 12th ed. 1896); *see also J. JOYCE, A PORTRAIT OF THE ARTIST AS A YOUNG MAN* 241-42 (1916) (Cranly advises Stephen Dedalus, "Whatever else is unsure in this stinking dunghill of a world a mother's love is not.").

59. *See Franz v. United States*, 707 F.2d 582, 599 (D.C. Cir. 1983) ("the parent's achievement of a rich and rewarding life is likely to depend significantly on his ability to participate in the rearing of his offspring" and "[a] child's corresponding right to protection from interference in the relationship derives from the psychic importance to him of being raised by a loving, responsive, reliable adult") (footnotes omitted); B. RUSSELL, *MARRIAGE AND MORALS* 123-24 (1959) ("The family is important at the present day more through the emotions with which it provides parents than for any other reason.").

60. *See Wald, State Intervention on Behalf of "Neglected" Children*, 28 *STAN. L. REV.* 623, 632 (1976) (unless parental rights have been terminated, even parents whose children have been removed from their care because of neglect retain some rights concerning the child).

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to institutionalize their child,⁶¹ but this decision is unrelated to any ability or inability to make habilitation choices. Parents often have no other choice than to turn to the state for assistance because of the substantial problems associated with keeping or caring for some retarded children at home.⁶² Often they are forced to seek residential care for their child because of an unavailability of those community-based services which would allow the child to remain at home.⁶³ The numerous lawsuits by parents seeking to improve their child's treatment in a state facility attest to the continuance of parental concern.⁶⁴

B. *The State's Weaknesses as Decisionmaker*

Parental choices require a sensitivity which the state, as an impersonal institution, cannot have.⁶⁵ Even well-intentioned social workers do not have to live with their decisions in the way parents do.⁶⁶ Furthermore,

61. See *New York State Ass'n for Retarded Children v. Rockefeller*, 357 F. Supp. 752, 762 (E.D.N.Y. 1973) ("There may be a fundamental conflict of interest between a parent who is ready to avoid the responsibility of caring for an abnormal child, and the best interests of the child."); Murdock, *Civil Rights of the Mentally Retarded: Some Critical Issues*, 48 NOTRE DAME LAW. 133, 142 (1972) (institutionalizing mentally retarded child allows parents to "'distance themselves' from him and to deal with the situation in 'an abstract manner'").

62. Caring for a mentally retarded individual is exorbitantly expensive. See PAST AND PRESENT, *supra* note 4, at 245 ("In current economic values, each severely or profoundly retarded child who survives birth represents a potential economic liability of nearly a million dollars in combined costs of lifetime care and loss of normal lifetime productivity."); see also *Youngberg v. Romeo*, 457 U.S. 307, 309 n.2 (1982) (after death of father, mother unable to handle severely retarded son who sometimes becomes violent and requires twenty-four hour care); *Society for Good Will to Retarded Children v. Cuomo*, 572 F. Supp. 1300, 1302 (E.D.N.Y. 1983) (Weinstein, C.J.), *vacated*, 737 F.2d 1253, 737 F.2d 1239 (2d Cir. 1984):

Mothers and fathers, after courageous struggles to care for their offspring at home, overwhelmed by lack of respite and assistance, felt compelled to turn . . . to the state. They acted reluctantly in order to save a modicum of sane living for their families and because they believed the state could do more for their deprived youngsters than they could.

See also Luna, *A Perspective*, in CHANGING PATTERNS, *supra* note 18, at 83, 84 (great amount of attention mother has to pay to her microcephalic child caused her and her other three children such emotional problems that she saw herself "on the edge of going berserk" and turned to state for assistance).

63. See, e.g., *Society for Good Will to Retarded Children v. Cuomo*, 572 F. Supp. at 1337 (N.Y. State provides almost no funds to maintain clients in their own homes; parents testify "that they felt compelled to institutionalize their children or siblings because no community service or programs were available that would permit them to remain at home").

64. See *supra* note 16.

65. See *Bellotti v. Baird*, 443 U.S. 622, 638 (1979) (opinion of Powell, J.) (parental role in guiding children to become responsible adults "in large part, is beyond the competence of impersonal political institutions"); J. GOLDSTEIN, A. FREUD, & A. SOLNIT, *BEFORE THE BEST INTERESTS OF THE CHILD* 12 (1979) ("[T]he state is too crude an instrument to become an adequate substitute for flesh and blood parents"); see also Goldstein, *Medical Care for the Child at Risk*, 86 YALE L.J. 645, 650 (1977) (policy of minimum state intervention in family is supported by state's inability to respond to child's ever-changing needs and its incapacity to deal on individual basis with consequences of its decisions).

66. See Gaylin, *In the Beginning: Helpless and Dependent*, in *DOING GOOD* 28 (W. Gaylin, I. Glasser, S. Marcus & D. Rothman eds. 1978):

No social institution, regardless of how benevolent or paternalistic, can ever replicate the par-

technical issues are only one of the factors which impinge upon habilitation decisionmaking.⁶⁷ Habilitation choices must be based, in part, upon an individual's ethical, social or religious values.⁶⁸ Finally, decisionmaking authority must be granted to parents to avoid the great potential for "discretionary injustice"⁶⁹ that exists when state officials, unchecked by outside review, choose among possible courses of action or inaction.⁷⁰

C. *Diversity Among Citizens*

Although Plato suggested communal child rearing for his Ideal Commonwealth and ancient Sparta entrusted its males to official guardians,⁷¹ these ideas about the relation between individual and state are "wholly different from those upon which our institutions rest."⁷² In America, the state cannot standardize its children.⁷³ Our society rests not on the "deep paternalism" of Plato or ancient Sparta but on a "liberal paternalism" that grants parents a general right to raise their children as they see fit.⁷⁴ Parents are granted this freedom to protect the pluralism upon which democracy depends.⁷⁵

ent-to-child symbiosis. While individuals within institutions—nurses, attendants, physicians, and the like—may demonstrably exercise affection, tenderness, caring, even love, the power of authority is vested for the most part within the abstract concept of "the institution," and the intuitive responses of biology undergo strange transmutations in the structural organizations of bureaucracies.

67. See PRESIDENT'S COMMISSION FOR ETHICAL PROBLEMS IN MEDICINE, *supra* note 45, at 34 (alternatives in health care "vary markedly in their prospects for success, their intrusiveness, their potential side effects, and their other implications A determination of what is 'indicated' is thus inextricably intertwined with the needs and values of the particular patient.").

68. See Goldstein, *supra* note 65, at 664 ("[T]he law must recognize that it cannot find in medicine (or for that matter in any science) the ethical, political, or social values for evaluating health-care choices.").

69. "Discretionary injustice" is a term Kenneth Culp Davis coined. See K. DAVIS, *ADMINISTRATIVE LAW AND GOVERNMENT* 218, 219 (2d ed. 1975) ("A public officer has discretion whenever the effective limits on his power leave him free to make a choice among possible courses of action or inaction.").

70. Kenneth Davis writes that minimizing discretionary injustice is "the strongest need and the greatest promise for improving the quality of justice to individual parties in our entire legal and governmental system." *Id.* Giving habilitation decisionmaking power to state officials is an example of what Davis terms "unnecessary discretionary power," *id.*, because this authority should rest with parents.

71. See PLATO, *THE REPUBLIC* V 458 (P. Shorey trans. 1930) (The lawgiver will pick men and women who will "have houses and meals in common, and no private possessions. . . and [who will be] commingled in gymnastics and in all their life and education"); E. DAVID, *SPARTA BETWEEN EMPIRE AND REVOLUTION* 60 (1981) (Plato admired Spartan educational methods, which influenced his writings, but he found them narrow "with respect to moral and intellectual values."); see also *Meyer v. Nebraska*, 262 U.S. 390, 402 (1925) (Platonic and Spartan child rearing discussed).

72. *Meyer v. Nebraska*, 262 U.S. at 402.

73. See *supra* note 51.

74. See Richards, *The Individual, the Family and the Constitution*, 55 N.Y.U. L. REV. 1, 15 (1980) ("The concept that separates liberal from deep paternalism is the concept of human rights, the idea of intrinsic limits on the degree to which one person may control the life of another even for benevolent motives.").

75. See, e.g., L. TRIBE, *AMERICAN CONSTITUTIONAL LAW* § 16-12, at 1011 (1978) (certain

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Since retarded children are as a general rule capable of development, it must be left to their parents to shape their formation.⁷⁶ To do otherwise would give the state the power to standardize this group of our republic's citizens.

III. CONSTITUTIONAL ISSUES

Parental rights are protected by substantive due process.⁷⁷ State infringement of a parent's due process rights is permitted only when the state's interest both outweighs the parent's rights and where there is a close correspondence between the state's interest and the actual means that the state employs.⁷⁸ Unlike equal protection analysis, which involves a rigid tier system,⁷⁹ due process balancing involves a "flexible" approach.⁸⁰

decisions "ought to be placed beyond government's reach . . . because, in government's hands, control over those choices would pose too great a danger of majoritarian oppression or enduring subjugation").

76. The Supreme Court has recently stated, in dictum, "[P]rofessionals in the habilitation of the mentally retarded disagree strongly on the question whether *effective training* of all severely or profoundly retarded individuals is even possible." *Youngberg v. Romeo*, 457 U.S. 307 n.20 (1982) (emphasis added) (citing as sole support three articles from 1 *ANALYSIS AND INTERVENTION IN DEVELOPMENTAL DISABILITIES* (1981)). "Effective training" does not receive any definition in the Court's opinion, and it is not a term commonly used by professionals who treat mentally retarded individuals. In habilitation, an attempt is made to maximize individual capabilities, and there is professional agreement that all retarded individuals are capable of development. See T. JORDAN, *THE MENTALLY RETARDED* 127 (4th ed. 1976) ("[R]etarded youngsters, like all young people, develop as a result of the way they are raised."); Roos, *Misinterpreting Criticisms of the Medical Model*, in 2 *MENTAL RETARDATION* 22, 23 (1971) ("[A]ll retardates have potential for growth, learning, and development."); New York State Ass'n for Retarded Children v. Carey, 393 F. Supp. 715, 717 (E.D.N.Y. 1975) ("[R]etarded persons, regardless of the degree of handicapping conditions, are capable of physical, intellectual, emotional, and social growth . . .") (quoting proposed consent judgment); cf. P. INGALLS, *MENTAL RETARDATION: THE CHANGING OUTLOOK* 389 (1978) ("The fastest growing area of special education today is the area of special training for children with IQs below 50 [i.e. the severely or profoundly retarded].").

77. Substantive due process is the "doctrine that governmental deprivations of life, liberty, or property are subject to limitations regardless of the adequacy of the procedures employed . . ." *Developments in the Law—The Family*, 93 HARV. L. REV. 1156, 1166 (1980) [hereinafter cited as *Developments—The Family*]. While the Supreme Court no longer uses a substantive due process analysis to protect economic rights, see *United States v. Carolene Products Co.*, 304 U.S. 144, 152 (1938) (in most cases, law must be upheld unless facts "preclude the assumption that it rests upon some rational basis within the knowledge and experience of the legislature"), it continues to find certain family values "fundamental" and thus subject to heightened judicial scrutiny upon state intrusions. See, e.g., *Zablocki v. Redhail*, 434 U.S. 374, 387 (1978) (right to marry is fundamental interest and statute that precludes parent who failed to comply with child support orders from marrying without court permission is subject to heightened scrutiny); *Griswold v. Connecticut*, 381 U.S. 479, 486 (1965) (marital privacy is "a right of privacy older than the Bill of Rights—older than our political parties, older than our school system" and thus deserves heightened protection from state interference).

78. See *Zablocki v. Redhail*, 434 U.S. at 388 ("When a statutory classification significantly interferes with the exercise of a fundamental right, it cannot be upheld unless it is supported by sufficiently important state interests and is closely tailored to effectuate only those interests."); *Shelton v. Tucker*, 364 U.S. 479, 488 (1960) (due process clause requires that "even though the governmental purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle fundamental personal liberties when the end can be more narrowly achieved").

79. This rigid tier system has, however, become flexible enough to permit semi-suspect classifica-

Although courts utilize ready-made tests in examining challenged state procedures under due process claims,⁸¹ no exact threshold divides the most minimal and the most exacting due process standards. Courts are supposed to weigh the balance of the interests involved.⁸²

The constitutional rights at stake in habilitation decisions are found in the interplay of three interests. First, there is the usual authority parents have over their children. Second, the retarded child has an individual liberty interest. Finally, the state has interests in the family and in managing its institutions. In deciding the nature of the interests involved in habilitation decisionmaking, courts must individually examine and balance them.

A. *The Parents' Rights in the Family*

Although the rights of parenthood are not without limits, the Supreme Court has declared that there is a "private realm of family life which the state cannot enter."⁸³ Within this realm, the boundaries of which have been neither consistently located nor firmly fixed,⁸⁴ parents are protected

tions and intermediate review. See L. TRIBE, *supra* note 75, §§ 16-29, 16-31 (discussing semi-suspect classifications and identifying circumstances that trigger intermediate review).

80. See *Morrissey v. Brewer*, 408 U.S. 471, 481 (1972) ("It has been said so often by this Court and others as not to require citation of authority that due process is flexible."); cf. *Poe v. Ullmann*, 367 U.S. 497, 542 (Harlan, J., dissenting) (1961) ("Due process has not been reduced to any formula; its content cannot be determined by reference to any code."); *Mullane v. Central Hanover Bank & Trust Co.*, 339 U.S. 306, 313 (1950) (due process hearing must be "appropriate to the nature of the case").

81. The most popular of these tests was formulated in *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976) (assuming existence of interest that deserves protection, three factors must be balanced: (1) private interest that will be affected by official action; (2) risk of erroneous deprivation of such interest through the procedures used and probable value of additional or substitute procedural safeguards; (3) government's interest, including function involved and fiscal and administrative burdens entailed by additional or substitute procedures). See *Parham v. J.R.*, 442 U.S. 584, 599-613 (1979) (application of *Mathews v. Eldridge* test); *Smith v. Organization of Foster Families for Equality & Reform*, 431 U.S. 816, 848-56 (1977) (same).

82. See *supra* note 80; *Developments—The Family*, *supra* note 77, at 1197 (rather than create "arbitrary tests," Court should weigh demands of state and individual liberty interests on case-by-case basis).

83. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944). The Court has alluded, often in strong terms, to the strength of parents' interest in their children. See, e.g., *Santosky v. Kramer*, 455 U.S. 745, 753 (1982) ("The fundamental liberty interest of natural parents in the care, custody, and management of their child does not evaporate simply because they have not been model parents or have lost temporary custody of their child to the State."); *Lassiter v. Department of Social Services*, 452 U.S. 18, 27 (1981) (It is now "plain beyond the need for multiple citation that a parent's desire for and right to 'the companionship, care, custody, and management of his or her children' is an important interest that 'undeniably warrants deference and, absent a powerful countervailing interest, protection.'") (quoting *Stanley v. Illinois*, 405 U.S. 645, 651 (1972)).

84. It is difficult to discover a consistent methodology behind the Supreme Court's decisions to place some parental activities within the protected realm and other activities outside of it. Compare *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (state law requiring formal education after eighth grade invalid as applied because it would gravely hinder interest of Amish parents in raising their children in Amish religion and way of life), with *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944) (although practice of Jehovah's Witness religion involves public distribution of religious literature, state can prohibit children raised in this religion from engaging in activity). Either one of these cases can easily

from state authority in making many decisions relating to family life.⁸⁵ Among the personal rights the Supreme Court has deemed “‘fundamental’ or ‘implicit in the concept of ordered liberty,’” there is “some extension” to child rearing.⁸⁶

The Constitution protects the sanctity of the family, according to the Supreme Court, “precisely because the institution of the family is deeply rooted in this Nation’s history and tradition.”⁸⁷ When a retarded child is placed for care in an institution, however, he has been removed from the structure of the traditional nuclear family—a decision that raises novel constitutional questions. Fortunately, other nontraditional family arrangements have received judicial examination. For example, some “families” that lack the presence of biological parents can be entitled to constitutional protection. In *Moore v. City of East Cleveland*,⁸⁸ the Supreme Court found that extended families of uncles, aunts, cousins, and grandparents deserved protection from a restrictive city ordinance because “[O]urs is by no means a tradition limited to respect for the bonds uniting the members of the nuclear family.”⁸⁹ For a parent’s interest in his child to reach a constitutional dimension, neither marriage nor current residence of the child and parent together are required: Unwed fathers who live apart from their children have a constitutional interest in their child if they have demonstrated a past commitment to the responsibilities of parenthood.⁹⁰ Furthermore, although the term “family” implies the existence of a biological relationship, the importance of the familial relationship to the indi-

be rewritten in terms of the other. The *Prince* Court, for example, might have foreshadowed *Yoder* by deciding that the state could not prevent parents who were Jehovah Witnesses from allowing their children to distribute religious literature because to do so would hinder the parental interest in raising them in their way of life. See *Prince*, 321 U.S. at 171 (Murphy, J., dissenting).

85. See, e.g., *Zablocki v. Redhail*, 434 U.S. 374 (1978) (divorced parent’s decision to remarry); *Moore v. City of East Cleveland*, 431 U.S. 494, 499 (1977) (plurality opinion) (housing ordinance may not make it a crime for a grandmother to live with her grandson); *Roe v. Wade*, 410 U.S. 113 (1973) (during stage of pregnancy prior to end of first trimester, abortion decision and its effectuation left to woman and her doctor); *Griswold v. Connecticut*, 381 U.S. 484 (1965) (state law forbidding use of contraceptives is unconstitutional intrusion upon right of marital privacy); *Skinner v. Oklahoma*, 316 U.S. 535 (1942) (sterilization of prisoners interferes with basic civil right: procreation).

86. *Roe v. Wade*, 410 U.S. at 152–53 (citing *Prince v. Massachusetts*, 321 U.S. at 166; *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923)).

87. *Moore v. City of East Cleveland*, 431 U.S. 494, 503 (1977) (plurality opinion).

88. *Id.*

89. *Id.* at 504. See *Smith v. Organization of Foster Families for Equality & Reform*, 431 U.S. 816, 844 (1977) (foster family can hold “the same place in the emotional life of the foster child, and fulfill the same socializing functions, as a natural family” and thus court “cannot dismiss the foster family as a mere collection of unrelated individuals”); *Stanley v. Illinois*, 405 U.S. 645, 651 (1972) (unwed father entitled to hearing on fitness as parent after death of natural mother because law recognizes “family relationships unlegitimized by a marriage ceremony”).

90. Compare *Caban v. Mohammed*, 441 U.S. 380, 389 (1979) (unwed father who “participated in the care and support of [his] children” has right to veto adoption of child) with *Quilloin v. Walcott*, 434 U.S. 246, 256 (1978) (in rejecting unwed father’s constitutional claim, Court emphasizes importance of his failure to take “any significant responsibility” for child).

vidual involved and to society stems from "emotional attachments" as well as "the fact of blood relationship."⁹¹

These cases suggest that a relevant principle can be derived from the family law decisions of the Supreme Court. This principle is that parents of mentally retarded children receiving residential care in a state facility are entitled to a protected "private realm of family life" if they are emotionally attached to the child and have shared the responsibilities of child rearing.⁹² Parents who meet these standards and whose mentally retarded children are receiving residential care are entitled to constitutional protection for their habilitation choices; in addition, these parents are entitled to procedural due process if the state attempts to terminate their parental interests.⁹³

B. *The Child's Rights*

Of the constitutional rights that belong to children,⁹⁴ the most critical one for a mentally retarded child is his liberty interest.⁹⁵ A mentally retarded child has a constitutionally protected liberty interest in conditions

91. *Smith v. Organization of Foster Families for Equality & Reform*, 431 U.S. at 844; *see Franz v. United States*, 707 F.2d 582, 599 (D.C. Cir. 1983) (father of children relocated along with mother pursuant to federal witness protection program has continuing constitutional interest in parent-child relationship because "what is important is the nature of the bond in question"); *Halderman ex rel. Halderman v. Pennhurst*, 707 F.2d 702, 714 (3rd. Cir. 1983) (Rosenn, J. concurring) ("careful judgment by loving and emotionally attached parents" entitled to "substantial weight" in proceeding concerning transfer of voluntarily committed, retarded minor child from state school to community living arrangement), *aff'd without op.*, 723 F.2d 897, 723 F.2d 898 (3rd. Cir. 1983); *Developments—The Family*, *supra* note 77, at 1218 ("[P]rotected family relationships are defined not by objective factors such as formal marriage and blood ties, but rather by the degree to which they provide intimacy, support, and protection for individual family members.").

92. *Cf. Halderman ex rel. Halderman v. Pennhurst State School & Hosp.*, 707 F.2d 702 (3d Cir. 1983) (plurality opinion) (parents' constitutional right to direct and control upbringing and development of their minor children was not afforded sufficient consideration in proceeding in which parents' voluntarily committed, profoundly retarded minor child was transferred from state school to community living arrangement), *aff'd without op.* 723 F. 2d 897, 723 F. 2d 898 (3d. Cir. 1983).

93. *See supra* note 3.

94. Children possess first amendment rights, *see Erznoznik v. City of Jacksonville*, 422 U.S. 205, 212-14 (1975) ("[M]inors are entitled to a significant measure of First Amendment protection . . ."); *Tinker v. Des Moines Indep. Community School Dist.*, 393 U.S. 503 (1969) (schoolchild's wearing black armband to school in protest of governmental policy in Vietnam within protection of first amendment's Free Speech Clause), and fundamental privacy rights, *see cases cited supra* note 55.

The constitutional rights of children are not, however, coextensive with those of adults. *Erznoznik*, 422 U.S. at 214 n.11 (Stewart, J., concurring). *See Bellotti v. Baird*, 443 U.S. at 622, 623 (constitutional rights of children cannot be equated with those of adults because: (1) children have "peculiar vulnerability"; (2) children have "inability to make critical decisions in an informed, mature manner"; (3) "the importance of the parental role in child rearing.").

95. *See Parham v. J.R.*, 442 U.S. 584, 600 (1979) ("It is not disputed that a child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment . . ."); *In re Gault*, 387 U.S. 1, 27-31 (1967) (liberty interest of child demands procedural due process safeguards before confinement in institution for juvenile delinquents).

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of reasonable care and safety, in freedom from restraint, and in such training as may be required by these interests.⁹⁶

The protection of these interests should rest with the child's parents and not the state. Placing one's child in a state health care facility is not equivalent to a finding of abuse or neglect, which is necessary to terminate parental rights and to shift the protection of these interests elsewhere.⁹⁷ Such a placement is also not equivalent to a voluntary relinquishment of parental rights, as is the case when parents put a child up for adoption.⁹⁸ While the constitutional rights of children may sometimes conflict with those of parents, as in a minor's decision whether or not to terminate her pregnancy,⁹⁹ in the residential care situation parents and child have the same interest in seeing that the child gets the best care possible. Habilitation choices are the kind of choices parents traditionally make for their children, and retarded children should have a right to have their parents, and not other adults, make them.¹⁰⁰

C. *The State's Interests*

The state has interests in the family, as well as in the operation of its institutions, which may impinge upon the rights of children and parents. Its most important interest in the context of parental habilitation decision-

96. *Youngberg v. Romeo*, 457 U.S. 307, 324 (1982); *see also Parham v. J.R.*, 442 U.S. 584 (1979) (liberty interest of minor child whose parents sought state-administered mental health care for him, when added to risk of error in commitment process, prevents parents from having absolute and unreviewable discretion to decide whether to institutionalize him). The parental right at issue in *Parham* is different than the parental right to make habilitation decisions. *Parham* concerned the decision to institutionalize a child. A parental habilitation decision does not arise until *after* the institutionalization decision has been made and, thus, the state should already have acted to confine use of its health facilities to cases of genuine need. This Note concerns a mentally retarded child who is *already* in residential care, and whose liberty interest against commitment has already been protected.

97. *See supra* notes 3 and 83.

98. *See Garrison, Why Terminate Parental Rights?*, 35 STAN. L. REV. 423, 443 (1983) (when it appears that parents will not be able to resume custody of their child placed in foster care, parental rights terminated to free child for adoption).

99. *See supra* note 55.

100. *See* L. TRIBE, *supra* note 75, § 15-21, at 988 ("Once the State, whether acting through its courts or otherwise, has 'liberated' the child . . . from the shackles of such intermediate groups as family, what is to defend the individual against the combined tyranny of the State and her own alienation?"); Goldstein, *supra* note 65, at 647 ("reciprocal right" of children to have parents make medical decisions for them). When granted habilitation decisionmaking power, mental health workers will base these decisions upon their own personal values. *See* Roth, *Some Contingencies of the Moral Evaluation and Control of Clientele*, in HUMAN SERVICE ORGANIZATIONS 499, 500 (Y. Hasenfeld & R. English eds. 1974):

There is no evidence that professional training succeeds in creating a universalistic moral neutrality. On the contrary, we are on much safer ground to assume that those engaged in dispensing professional services (or any other services) will apply the evaluations of social worth common to their culture and will modify their services with respect to those evaluations *unless discouraged from doing so by the organizational arrangements under which they work.* (citations omitted) (emphasis in original).

making, however, is helping parents care for the health and well-being of their children.

1. *In the Family*

Even though parental decisionmaking is often entitled to constitutional protection, "the family itself is not beyond regulation in the public interest."¹⁰¹ The state's power to regulate the family can derive from either its police power or *parens patriae* power.

The police power is the state's inherent power—once it has met procedural safeguards—to promote all aspects of public welfare or public safety.¹⁰² With due process, the state can justify exercising its police power to control habilitation decisions only if this action would further a legitimate social goal¹⁰³ such as disqualifying unfit parents. This goal is not met, however, by disqualifying all parents with children in residential care because all these parents are not unfit to make habilitation decisions.¹⁰⁴ Thus, this disqualification is overinclusive: It so disadvantages individual parents as to outweigh the benefit of disqualifying some parents who are actually unfit.

Under its *parens patriae* power, the state can advance—in certain circumstances—the interests of individuals, such as mentally incompetent adults, who lack the capacity to act in their own best interests.¹⁰⁵ Substan-

101. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

102. See generally *Jacobson v. Massachusetts*, 197 U.S. 11, 25 (1905) ("According to settled principles the police power of a State must be held to embrace, at least, such reasonable regulations established directly by legislative enactment as will protect the public health and the public safety.").

103. See *Goldblatt v. Town of Hempstead*, 369 U.S. 590, 594-95 (1962) (exercise of police power must advance some aspect of public welfare with statutory means that are "reasonably necessary for the accomplishment of the purpose, and not unduly oppressive upon individuals.") (quoting *Lawton v. Steele*, 152 U.S. 133, 137 (1894)).

104. See *Parham v. J.R.*, 442 U.S. 584, 603 (1979) ("The statist notion that governmental power should supersede parental authority in *all* cases because *some* parents abuse and neglect children is repugnant to American tradition.") (emphasis in original); cf. *Stanley v. Illinois*, 405 U.S. 645, 654-59 (1972) (even if most unmarried fathers are unsuitable and neglectful parents, *all* are not and so Illinois law whereby children of these fathers, upon death of mother, are declared dependents without any hearing violates due process); B. FARBER, *MENTAL RETARDATION: ITS SOCIAL CONTEXT AND SOCIAL CONSEQUENCES* 152 (1968) (families with retarded children exist in all segments of society).

105. *Parens patriae*, which means "parent of the country," refers to the "role of state as sovereign and guardian of persons under legal disability." BLACK'S LAW DICTIONARY 1003 (5th ed. 1979). Its origins in the English common law derive from the care of material interests of infants by the King's Chancellor, with the first mention of *parens patriae* in a case involving a child occurring in 1696. Cogan, *Juvenile Law, Before and After the Entrance of "Parens Patriae,"* 22 S.C.L. REV. 147, 166 (1970). In the United States, the scope of the *parens patriae* power has been expanded beyond that which existed in England. See generally *Hawaii v. Standard Oil Co.*, 405 U.S. 251, 258 (1972) (citing series of cases that "establish the right of a State to sue as *parens patriae* to prevent or repair harm to its 'quasi-sovereign interests.'") Despite this expansion, *parens patriae* remains as troublesome a concept in America as it has been since its origins in England. See *In re Gault*, 387 U.S. 1, 16 (1966) ("[I]ts meaning is murky and its historical credentials are of dubious relevance."); cf. *Wellesley v. Wellesley*, 4 Eng. Rep. 1078, 1080-83 (1828) (Lord Redesdale expresses his own doubts about

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tive due process bars the state, however, from exercising a *parens patriae* interest to make habilitation decisions for an institutionalized retarded child; the Constitution entrusts the child's own parents with the protection of this interest unless they have been disqualified with a judicial finding of unfitness.¹⁰⁶ Procedural due process requires that the state show parental unfitness on a case-by-case basis;¹⁰⁷ unless the state can do so, the child's own parents protect his best interests. The state's *parens patriae* interest here is in helping parents care for the health and well-being of their child.¹⁰⁸ It can serve this interest by improving the education and medical treatments given to retarded children¹⁰⁹ and by making counseling services available to parents.¹¹⁰

2. *In Its Institutions*

The Supreme Court allows states "considerable discretion" in allocating resources towards the retarded people in state institutions.¹¹¹ This discretion follows from a state's significant interests in confining the use of its facilities to cases of genuine need,¹¹² in efficiently distributing the resources it allocates to the treatment of retarded children,¹¹³ and in ensur-

grounds on which *parens patriae* is based, before concluding that it does not really matter because doctrine really does exist).

106. See *O'Connor v. Donaldson*, 422 U.S. 563, 583 (1975) (Burger, C.J., concurring) (due process requires *parens patriae* legislation be "compatible with the best interests of the affected class"); cf. *Developments—The Family*, *supra* note 77, at 1225-26 (when acting under its *parens patriae* power state should advance only interests of child or incompetent person and not attempt to further collective goals, which can be supported only by use of its police power), and *supra* note 3.

107. See *supra* note 3.

108. Cf. *Parham v. J.R.*, 442 U.S. 584, 605 (1979) (state has *parens patriae* interest in helping parents care for mental health of their children).

109. See *Society for Good Will to Retarded Children v. Cuomo*, 572 F. Supp. 1300, 1353-63 (E.D.N.Y. 1983), *vacated*, 737 F.2d 1239 (2d Cir. 1984) (seven goals established in detailed court-ordered plan for improving state institution for mentally retarded individuals); see also *supra* text and accompanying note 16 and *infra* note 120 (long history of poor treatment accorded mentally retarded citizens in state facilities).

110. Cf. S. PROVENCE & A. NAYLOR, *WORKING WITH DISADVANTAGED PARENTS AND THEIR CHILDREN: SCIENTIFIC AND PRACTICAL ISSUES* 4, 8 (1983) (by giving parents guidance, counseling and developmental evaluations of child, social workers protect and promote development of child "through a continuing and close association with his parents—a partnership in behalf of the child"). Psychoanalytic research shows that the psychological impact of the birth of a congenitally defective child can result in a mourning process for the lost child on the part of the mother. Solnit & Stark, *Mourning and the birth of a defective child*, 16 *PSYCHOANALYTIC STUDY OF THE CHILD* 523 (1961). The mother works through this process more easily when she has "an opportunity to review her thoughts and feelings about the wished-for child" and "an active role in planning for the child." *Id.* at 534.

111. "As a general matter, a State is under no constitutional duty to provide substantive services for those within its border." *Youngberg v. Romeo*, 457 U.S. 307, 317 (1982) (citations omitted). When a person is institutionalized and wholly dependent on the state, the state still has "considerable discretion in determining the nature and scope of its responsibilities." *Id.* (citations omitted).

112. See *Parham v. J.R.*, 442 U.S. 584, 604-05 (1979) ("The State obviously has a significant interest in confining the use of its costly medical facilities to cases of genuine need.").

113. See *Dandridge v. Williams*, 397 U.S. 471, 487 (1970) (state officials must be allowed "diffi-

ing the security of others institutionalized in that facility.¹¹⁴ A state's discretion in the employment of its resources when providing social services has not, however, justified infringement of constitutional rights.¹¹⁵

Recent Supreme Court decisions have also urged federal courts to show deference to the decisions of medical professionals and state agencies.¹¹⁶ Nevertheless, this judicial deference towards professional decisionmaking in an institutional setting is unwarranted, and even dangerous, when it allows mental health workers to control habilitation decisions. It ignores the growing need for external review over narrowly based state bureaucracies that now act as substitute parents.¹¹⁷ It denies that professional knowledge is only one of the determinants that impinge upon thinking about such choices as habilitation decisionmaking.¹¹⁸ Professionals do not always know best, and may even face pressures from which parents are

cult responsibility of allocating limited public welfare funds").

114. See *Youngberg v. Romeo*, 457 U.S. 307, 324 (1982) ("The State . . . has the unquestioned duty to provide reasonable safety for all residents and personnel within the institution [for mentally retarded persons].").

115. Cf. *Cruz v. Beto*, 405 U.S. 319, 321 (1972) (prison officials are accorded latitude in administration of prison affairs, but federal courts must "enforce the constitutional rights of all 'persons,' including prisoners."); *Johnson v. Avery*, 393 U.S. 483, 486 (1969) (state has function in maintaining discipline and administration at state detention facility, but regulations to do so may be invalidated when they conflict with constitutional rights); see *Wyatt v. Alderholt*, 503 F.2d 1305, 1315 (5th Cir. 1974) (state legislature is not free "for budgetary or any other reasons, to provide a social service in a manner which will result in the denial of individuals' constitutional rights."); *Jackson v. Bishop*, 404 F.2d 571, 580 (8th Cir. 1968) (Blackmun, J.) ("Humane considerations and constitutional requirements are not, in this day, to be measured or limited by dollar considerations . . .").

116. See *Youngberg v. Romeo*, 457 U.S. 307, 322 (1982) (in determining what is "reasonable" in any case presenting claim for training by state, "courts must show deference to the judgment exercised by a qualified professional" in order to minimize "interference by the federal judiciary with the internal operations of these institutions"); *Parham v. J.R.*, 442 U.S. 584, 607 (1979) (rather than a formal hearing or a simple reliance on parents, decision to institutionalize a child for mental health care requires inquiry by physician at institution); cf. *Board of Educ. of Hendrick Hudson Cent. School Dist. Bd. v. Rowley*, 458 U.S. 176, 206-08 (1982) (in assuring that requirements of EHCA have been met, "courts must be careful to avoid imposing their view of preferable educational methods upon the States," entrusting child's education to state and local agencies with parents playing an important role as advocate for child).

In *Pennhurst State School & Hosp. v. Halderman*, 451 U.S. 1 (1981), the Court deferred to state autonomy by concluding that because the DDA did not unambiguously require states to provide mentally retarded citizens with appropriate treatment in the least restrictive environment, its "bill of rights" provision was "hortatory, not mandatory." *Id.* at 24. But see Burt, *Constitutional Law and the Teaching of the Parables*, 93 YALE L.J. 455, 497 (1984) (DDA "plausibly—I would say most plausibly—reflected a general congressional endorsement of . . . judicial findings that institutional conditions violated constitutional rights, a directive that increased use of community facilities has some important role in correcting these violations, and a commitment of federal funds and executive power to this corrective purpose.").

117. See Burt, *Developing Constitutional Rights Of, In, and For Children*, LAW & CONTEMP. PROBS., Summer 1975, at 118, 143 ("[S]ome external review is needed over the narrowly-based state bureaucracies that now act as substitute-parents in a broadening range of settings.").

118. See J. KATZ, *supra* note 41, at 98 (technical issues are only one factor relevant to medical choices; for most maladies more than one treatment can lead to favorable result—and chosen intervention may significantly affect patient's subsequent state of well-being); *id.* at 166 ("[M]edical knowledge is engulfed and infiltrated by uncertainty."); *supra* note 67.

free.¹¹⁹ Most importantly, the long history of poor treatment that mentally retarded citizens have received in the United States argues against deference towards professionals in this area.¹²⁰

This constitutional analysis suggests that parents have significant interests in the care and treatment that their institutionalized mentally retarded child receives, and that these interests in many cases may outweigh the interests of the state. There are, thus, grave infirmities in the way almost all states deal with habilitation decisionmaking. The states that fail to involve parents at all¹²¹ engage in a "[p]rocedure by presumption" against which the Supreme Court has said the Bill of Rights in general and the due process clause in particular were designed to protect.¹²² Furthermore, those states that fail to involve parents adequately violate the substantive, constitutional rights of parents to direct the upbringing of their children.

IV. ONE STANDARD ARTICULATED

A number of possible approaches to habilitation decisionmaking are possible under the Constitution. This Note will propose one appropriate for state statutes.

A. *Reliance on Parental Decisionmaking*

Rather than selectively involving some parents, states should allow all parents to become involved, if they want to be, in developing the habilitation plan of their institutionalized child. Doctors, staff members, and the parents of the child should develop the IHP in careful conversations. As members of the habilitation team, parents should be encouraged to partici-

119. See, e.g., *Society for Good Will to Retarded Children v. Carey*, 572 F. Supp. 1298, 1299 (E.D.N.Y. 1983) (professionals at institutions for mentally retarded persons "are part of a team and statewide structure" and may feel "desire to comply with budgetary pressures and statewide standards" which will cause "a yielding of professional judgment to personal career perspectives"); S. SARANSON & J. DORIS, *EDUCATIONAL HANDICAPS, PUBLIC POLICY AND SOCIAL HISTORY* 89, 94 (1979) (all institutions for mentally retarded citizens, including community-based centers, are part of political system "intended to serve the community, not to upset it, and heads of public institutions and agencies know this well").

120. See *Pennhurst State School & Hosp. v. Halderman*, 451 U.S. 1, 7 (1981) (district court's findings are undisputed: conditions at Pennsylvania institution for mentally retarded citizens "are not only dangerous, with the residents often physically abused or drugged by staff members, but also inadequate for the 'habilitation' of the retarded"); *Wyatt v. Stickney*, 344 F. Supp. 387, 394 (M.D. Ala. 1972), *aff'd in part and remanded in part sub nom. Wyatt v. Alderholt*, 503 F.2d 1305 (5th Cir. 1974) ("inhumane conditions" plague mentally retarded citizens of Alabama); Blatt, *The Pariah Industry*, in *CHILD ABUSE* 185, 197 (L. Gerbner, M. Ross & N. Zigler eds. 1980) (after decade of attempts to improve care of mentally retarded citizens, finding of "ameliorated abuse"); *supra* note 16.

121. See *supra* note 31.

122. *Stanley v. Illinois*, 405 U.S. 645, 657 (1972).

pate and should be treated with respect.¹²³ The doctors and staff members on the IHP team should make recommendations based on their medical knowledge, but parents can rely on their own values to make decisions. The state, as represented by these doctors and staff members, must present parents with real choices regarding the nature of the long-term goals and short-term objectives for their child.¹²⁴

The presentation of real choices and a true reliance on parental decisionmaking will be ensured by obliging the institution to obtain parents' "informed consent" to the IHP that is developed.¹²⁵ Before giving their consent to any plan, parents must be apprised of: (1) the prognosis for the child;¹²⁶ (2) the nature of the treatments in the IHP;¹²⁷ (3) the risks and benefits of the plan;¹²⁸ and (4) alternatives to the plan.¹²⁹

123. See H. BURSZTYN, R. FEINBLOOM, R. HAMM & A. BRODSKY, *MEDICAL CHOICES, MEDICAL CHANCES* 184 (1981) (doctors sometimes fail to respect human feelings and family prerogatives by placing pressure on parents when they disagree with their decisions, but "[s]hame is a dangerous drug, with severe side effects and high costs attendant upon its use."); Katz, *Disclosure and Consent: In Search of Their Roots*, in *GENETICS AND THE LAW* II 121, 123 (A. Milunsky & G. Annas eds. 1980) (recommends new dialogue between doctors and those they treat "in which both, appreciative of their respective inequalities, make a genuine effort to voice and clarify their uncertainties and then to arrive at a mutually satisfactory course of action").

124. These choices will not, however, include control over: (1) life or death decisions for the child; (2) procedures which are not generally accepted medically; (3) emergency situations; (4) routine health care maintenance. See discussion text accompanying *supra* notes 39-48.

125. Courts have established a general requirement that physicians inform their patients about the nature, risks, and alternatives to proposed therapies. See, e.g., *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972) (requirement of reasonable divulgence by physician of options and risks makes true consent to medical decisionmaking possible); *Salgo v. Leland Stanford, Jr., Univ. Bd. of Trustees*, 154 Cal. App. 2d 560, 578, 317 P.2d 170, 181 (1957) (physician violates duty to patient and opens himself to liability if he withholds any facts necessary for patient to consent intelligently to treatment).

126. See PRESIDENT'S COMMISSION FOR ETHICAL PROBLEMS IN MEDICINE, *supra* note 45, at 74 (inaccurate and incomplete information limits ability to understand effects and significance of treatments).

127. Requiring doctors to inform their patients of the nature of the medical procedures they are about to experience is an ancient legal requirement for surgical interventions, which predates "informed consent" by two centuries. See *Slater v. Baker*, 95 Eng. Rep. 860, 862 (K.B. 1767) ("it is reasonable that a patient should be told what is about to be done to him that he may take courage and put himself in such a situation to enable him to undergo the operation," and trespass will lie for unauthorized surgical procedure); see also *supra* note 125 (discussing informed consent).

128. The risks of an IHP are all of its possible negative consequences, see Meisel & Kabnick, *supra* note 42, at 429 n.85 ("risks" embrace other terms found in common law and statutes, such as hazards, dangers, side effects, and complications), except for those that are commonly known, remote, or minor, see, e.g., *Butler v. Berkeley*, 25 N.C. App. 325, 330, 213 S.E.2d 571, 582 (1975) (commonly known and unlikely risks need not be disclosed), or unforeseeable, see, e.g., *Holt v. Nelson*, 11 Wash. App. 230, 235, 523 P.2d 211, 218-19 (1974) (no duty to disclose unforeseeable risks).

Disclosure of "benefits," that is, information with positive connotations, Meisel & Kabnick, *supra*, at 436, is needed if patients are to balance the risks of the IHP and to evaluate its overall goals. See OHIO REV. CODE ANN. § 2317.54(A) (Page Supp. 1978) (need to inform "what the [medical] procedures are expected to accomplish").

129. See PRESIDENT'S COMMISSION FOR ETHICAL PROBLEMS IN MEDICINE, *supra* note 45, at 76 (given a range of acceptable responses to most health conditions, discussions of *whether* to treat and *how* to treat must include "a comparison of several treatment options and an airing of . . . preferences"); see also *supra* note 67 (alternatives in health care vary markedly in implications for patient).

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The administrative costs of such a system are manageable: No more is required than giving all parents a chance for participation and then requiring their consent to the IHP. In addition, institutional costs will be unaffected by many of the choices parents will make. For example, parents might choose whether a child with speech problems will be taught sign language or the use of a language board. And actual disagreements about IHP's may well be infrequent once parents are involved. One doctor has suggested that the "silent guerilla warfare" between doctors and their clients will cease once mutual distrust ceases to govern their relations.¹³⁰

B. Court Review

If parents refuse to give their consent following an informed appraisal of the IHP, the institution should be able to appeal the decision to the state court with jurisdiction over family law matters or to federal district court.¹³¹ The initial burden will be on the state to show that the parental decision is not in the best interests of the child.¹³² If the state cannot do so, the court will order the institution to implement the parents' wishes. If the state meets the initial burden of proof, the court should appoint a guardian ad litem for the child for the duration of a hearing.¹³³ Following this hearing, the court should order the IHP that protects the best interests of the child.

CONCLUSION

This Note has shown that public policy reasons support letting parents make habilitation decisions for their institutionalized retarded child. Denying them this power also infringes their constitutional rights in their family. States should protect these parental rights by adopting the system set forth in Part IV of this Note. This system protects the institutionalized

130. J. KATZ, *supra* note 41, at 103; see PRESIDENT'S COMMISSION FOR ETHICAL PROBLEMS IN MEDICINE, *supra* note 45, at 7-8 (study finds "treatment refusals were usually triggered by too little information rather than too much").

131. These provisions follow procedures of the EHCA, 20 U.S.C. § 1415(2) (1977), discussed *supra* note 52.

132. See J. GOLDSTEIN, A. FREUD & A. SOLNIT, BEYOND THE BEST INTERESTS OF THE CHILD 105 (1973) ("[T]he child's interests should be the paramount consideration once, but not before, a child's placement becomes the subject of official controversy.").

133. See *de Montigny v. de Montigny*, 70 Wis. 2d 131, 141, 23 N.W.2d 463, 468-69 (1975) ("The guardian *ad litem* is more than an adjunct to the court. He is the attorney for the children and their interests."); J. GOLDSTEIN, A. FREUD, & A. SOLNIT, *supra* note 65, at 114 (children sometimes require legal representation that will assure that their interests are paramount).

child's welfare by involving his parents in the development of his habilitation plan.

—*Paul Schwartz*