

IN THE UNITED STATES DISTRICT COURT  
FOR THE DISTRICT OF COLUMBIA

AMERICAN ACADEMY OF PEDIATRICS;  
NATIONAL ASSOCIATION OF CHILDREN'S  
HOSPITALS AND RELATED INSTITUTIONS,  
INC.; **and** CHILDREN'S HOSPITAL  
NATIONAL MEDICAL CENTER,

**Plaintiffs,**

v.

MARGARET M. HECKLER, **Secretary**  
**of the United States Department**  
**of Health and Human Services,**

**Defendant .**

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CIVIL ACTION

NO. 83-0774

MEMORANDUM OF AMICI-

ASSOCIATION FOR RETARDED CITIZENS, AMERICAN COALITION  
OF CITIZENS WITH DISABILITIES, DOWN'S SYNDROME CONGRESS.  
PEOPLE FIRST OF NEBRASKA, SPINA-BIFIDA ASSOCIATION OF  
AMERICA, **and** THE ASSOCIATION FOR THE SEVERELY HANDICAPPED

Section 504 of the Rehabilitation Act **was** enacted by the Congress **in** 1973 to assure that the recipients of federal financial assistance, including health care providers, extend to handicapped individuals respect, care and services as effective as those extended to non-handicapped individuals.

Section 504 provides:

"No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, **or** be subjected to discrimination under any program **or** activity receiving Federal assistance." (Emphasis supplied.)

**29 U.S.C.** 5794.

"As is apparent from its language, Section **504 is** intended to be part of the general corpus of discrimination law," *New York State Association for Retarded Children v. Carey*, 612 F. 2d 644, 649 (2d Cir., 1979).

"Section 504 is virtually identical to Title VI [of the Civil Rights **Act** of 1964] and was consciously intended by Congress to track that statute," *N.A.A.C.P. v. [Wilmington] Medical Center, Inc.*, 599 F. 2d 1247, **1258** (3d Cir., 1979).

What duty does Section 504 impose upon health care providers?

The duty upon health care providers to make available to handicapped infants, including those with Down's Syndrome, Spina-Bifida or other life-long mental **or** physical disabilities, from the withholding **of** sustenance or treatment which would customarily be provided to infants who are not thus handicapped, arises from the **face of** the statute, itself: **an** infant denied food or care customarily provided **to** other infants because the infant possesses or may possess **a** severe permanent disability surely is denied the benefits **of a** hospital's program **of** treatment **and** care solely by reason of his **or** her handicap .

The May 1977 Final Regulation issued by the Department of Health and Human Services to implement Section 504 (45 C.F. R. 84) specifically prohibits discrimination by federally supported health care providers in the provision of treatment and care services to handicapped patients. By its terms, this regulation prohibits the withholding of life-sustaining sustenance or treatment from handicapped infants because of the existence or suspected existence of a severe permanent disability and in a manner different from which would be followed if such infants were not thought to be severely and permanently disabled (45 C.F.R. 84.4(b)(1)(iv)). The central focus of the Section 504 Regulation is whether or not equality of opportunity exists for a specific class of individuals under programs receiving or benefiting from Federal financial assistance: Thus, with respect to the provision of medical treatment and care, the issue which the Regulation addresses is not the specific medical judgments made or treatment undertaken by a health care provider but rather whether or not handicapped persons are afforded an equal opportunity with non-handicapped persons to benefit from the medical treatment and care provided (45 C.F.R. 84.4(b)(2)). As is made clear in the declarations of purpose accompanying the many Federal statutes providing Federal financial assistance to health services and hospitals, the objective of medical care and treatment is the prevention of patient mortality and the improvement of patient health (C.f., Maternal and Child Health and Crippled Children's Service Program. 42 U.S.C. 701 et seq.). To the extent that medical care and treatment is directed toward a lesser objective for some patients solely because they are or may be permanently handicapped then equal opportunity to benefit from treatment and care is clearly denied (45 C.F.R. 84.4(b)(4)).

A specific recitation of these and other actions prohibited in the Section 504 Regulation is set forth in relevant part at Paragraph 16 of Amici's Motion to Intervene. The requirements of the Section 504 Regulation specifically focused on the provision of medical care and treatment (45 C.F.R. 84.52) are set forth in relevant particulars at Paragraph 17 of the Motion. The Analysis of the Final Regulation published almost six years ago, 42 Fed. Reg. at 22693, is explicit as to the Section 504 duty under these provisions which bears on a refusal to provide treatment:

Section 84.52(a) also includes provisions concerning the limitation of benefits or services to handicapped persons and the subjection of handicapped persons to different eligibility standards. One common misconception about the regulation is that it would require specialized hospitals and other health care providers to treat all handicapped persons. The regulation makes no such requirement. Thus, a burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness. (Emphasis supplied.)

Thus, while not all hospitals have neo-natal intensive care units, no hospital can withhold the "customary medical care" which it would provide to others because an infant may be born handicapped. C.f. Doe v. Colautti, 592 F. 2d 704, 709 (3d Cir. 1979).

The Section 504 duty, thus, is identical to the treatment "imperative" formulated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

treating [handicapped infants] no less vigorously than their healthy peers, or, than older children with similar handicaps would be treated.

(President's Commission at 219.)

The reasons advanced by the Commission **for** this rule reflect exactly the reasons which were addressed by the Congress in enacting Section 504 in the first instance.

The crucial difference between "sick" children and handicapped children

Most sick children and infants are not handicapped within the meaning **of** the Regulation; many handicapped children, including those with Down's Syndrome **or** Spina-Bifida, are not more frequently "sick" than are non-handicapped children. **As** the President's Commission has **so** properly pointed out, "it is all too easy to undervalue the lives **of** handicapped infants" (page 219). Underscoring an essential purpose of Section-504, the Commission recognizes that "the value society places on promoting the health and welfare of children has implications beyond neonatal intensive care units" and links the provision of life-sustaining treatment to an obligation "to provide the continuing care that makes a reasonable range of life choices possible" (page 228).

**Over** the past ten years, through the passage of a variety **of** Federal statutes establishing programs of education, rehabilitation and independent living, Congress has moved to direct substantial financial resources and significant public attention toward these implications. The success **of** these programs equally has implications **for** the neonatal intensive care unit. **For example, the** implementation of the Education for All Handicapped Children Act (25 U.S.C. 1901 et seq.) has brought about such rapid and radical improvements in the developmental opportunities **of** severely handicapped children that at-birth prognostications made **for** these children **less** than a decade ago **now** appear no more unbiased than the racial eugenics **of** an earlier generation. **As** new community-based programs designed to maximize

the sustained integration of severely handicapped individuals in the social and economic mainstream of society expand dramatically, the "hay, oats and water" realities of State institutions (as noted by the President's Commission, page 228, note 100) which so long characterized another denial of equal opportunity are disappearing through a combination of rapid program development and increased judicial scrutiny. In short, the argument suggested by Plaintiffs that the likelihood of subsequent unlawful discrimination justifies the current denial of equal opportunity health care to handicapped infants amounts to proposing that future compliance demands be obviated by pre-empting the beneficiary. In any event, current developments in the fields of education, rehabilitation and social services demand that the logic be reversed: a current denial of equal health care opportunities for severely handicapped infants would prevent those children and their families from taking advantage of the rapidly expanding developmental technologies of today and tomorrow.

The underlying philosophy of the Regulation is well-summarized by the imperative arrived at by the President's Commission that handicapped infants be treated "no less vigorously than their healthy peers or than older children with similar handicaps would be treated" (page 219). Plaintiffs, themselves, appear already to have arrived at the conclusion that legal intervention may be crucial to insuring that the "best interests" of a child are protected from judgments to withhold treatment made by persons ostensibly acting in the child's behalf.

In paragraph 16 of his affidavit (attached to Plaintiff's Ex Parte Motion for Expedited Discovery) Dr. Robert H. Parrott, Director of Plaintiff Children's Hospital National Medical Center, cites "No fewer than twenty-five times over the past eight years the hospital has successfully petitioned -

the Superior Court **for** the District of **Columbia** to order medical care **for** children when parental **or** guardian authorization was refused." If the Superior Court is a proper forum for the hospital to question the legality of parental treatment decisions, then why should the Secretary of Health and Human Services **or** the Attorney General **of** the United States, acting pursuant to a Congressional mandate and aided **by** the Surgeon General of the United States, be precluded from raising precisely the same questions concerning the legality of the denial of treatment under Federal civil rights statutes in the District Courts of the United States? The absence of parental consent should be no more **a bar** to the United States than it is to Children's Hospital. **As** the Plaintiff's, themselves, point out, legal procedures already exist through which a hospital faced with an unlawful parental refusal to permit treatment can ensure their compliance with Section **504** requirements.

If **a** patient **is** suffering from a medical condition which will inevitably result in death, then medical judgments as to whether to provide **or** continue **to** provide treatment which will be of no benefit to the patient are clearly within the class referred to by the President's Commission as "clearly futile therapies" (page **219**) which, thus, **fall** clearly outside of the purview of the Regulation.

**To** summarize, the scope of the underlying Section **504** duty set forth **again in the Interim Final Rule --** misunderstood apparently by Plaintiffs **--** is no less but **no** greater than that addressed by the Commission **as** "clearly beneficial therapies" (President's Commission, pages **217-19**). **As** to clearly beneficial medical treatment, the Commission writes, "parents [and physicians] **should** be able to choose among **alternative** treatments with similarly beneficial

results and among providers, but not to reject treatment that is reliably expected to benefit a seriously ill newborn substantially, as is usually true if life can be saved."<sup>1/</sup> The Commission is clear that its "very strict standard . . . excludes consideration of the negative effects (sic) of an impaired child's life on other persons, including parents, siblings and society (sic)" and requires that any consideration of the value of living life as a handicapped person must adapt the viewpoint of the person with the handicap .

Addressing the instance which is prototypical of this Interim Final Rule and the underlying duty, the Commission rejects the outcome of the Baby Doe case and the predominant attitudes of pediatricians:

"The handicaps of Down's Syndrome, for example . . . do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract." (id. at 219).

Thus, the Commission's imperative -- "treating [handicapped infants] no less vigorously than their healthy peers . . ." -- is exactly the scope of the duty here: not to withhold food or medical care customarily provided to non-handicapped infants.

There should be no mystery as to what, in any civil rights regulation, a prohibition of "discriminatorily denied food or customary medical care" means.

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<sup>1/</sup> Amici take the liberty of making physicians as well as parents the subjects of the Commission's statements, for the surveys, including those noted by the Commission (at 208) show physicians' judgments to be as problematic or more so than parents. See Amici's Motion to Intervene at Paragraphs 7 - 12.



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If the discrimination prohibited is that based upon race or national origin it means no person shall, on the ground of his or her race or national origin be denied food or medical care customarily extended to people who, for example, are not black or Chicano. If, as in Section 504, the discrimination prohibited is that based upon handicap, prohibition means "no person shall on the ground of handicap be denied food or medical care customarily extended to people who are not handicapped." The judgment Section 504 demands of a physician is not a medical judgment concerning what medical treatment shall be provided an individual but rather, given customary, medical judgments about removing a stomach block for an infant who will not be handicapped, or repairing a heart, whether such medical care will be provided the infant who is and will be handicapped. There is no medical standard established by Section 504; rather, as common, pervasive, and never disapproved in any civil rights context (see the argument below), Section 504 sets a standard for equal provision of medical care.

This Regulation does not reach to extraordinary medical intervention -- in the language of the President's Commission, to "futile therapies" (id. at 219-20) <sup>2/</sup> or to problematic medical treatments (id. at 220f) -- for, simply put, there is no "customary medical care" as to them. Ibid.

If this meaning of the Interim Final Rule and the underlying Section 504 - duty were not clear from the basic equal protection nature of the statute and

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<sup>2/</sup> Note that as to futile conditions -- "anencephaly or certain severe cardiac deformities ... when cure or saving of life are out of reach [and] lives are destined to be brief" -- the Commission does find owing to the infant "whatever relief from suffering and enhancement of life can be provided, including feeding, medication for pain, and sedation, as appropriate."

its anti-discrimination context, then it is unavoidably clear from the immediate administrative record underlying the Rule. For example, as to the scope of the Rule and of the problem it addressed, the Surgeon General of the United States testified:

"the President's concern was that this [infant Doe] was a child with a potential mental hardship who also had a congenital anomaly incompatible with life but amenable to surgical correction and because of the mental problem there was no effort made to feed the child and indeed it subsequently died."

Transcript at 39.

As to what the Interim Final Rule does not reach, the Surgeon General testified, in colloquy with the Court:

THE COURT:

So what does the regulation mean when it says customary medical care?

THE WITNESS:

Well, I think that every physician knows what is essentially customary. . . . It differs for every case but let's take the ones you mentioned a moment ago when you talked about a child who is born without an intestine. That almost never happens, sir, but many times a surgical procedure results in a child having essentially no intestine and these regulations never intended that such a child should be put on hyper-alimentation and carried for a year and a half.

. . . [we] would consider customary care [of] that child the provision of a bed, of food by mouth, knowing that it was not going to be nutritious but not just shutting off the care of that child, so customary care for a child who has had a mid-avalvolus (spelled phonetically) and gangrene and an operation would not necessarily be nor do we intend to say that this child should be carried on intravenous fluids for the rest of its life."

\* \* \* \* \*

. . . When **you** talk about a baby born without a brain I suspect **you** meant an encephalic (spelled phonetically) child and we would not attempt to interfere with anyone dealing with that child. We think it should be given loving attention and would **expect** it to expire in a short time. (Emphasis supplied.)

Accord, President's Commission at 219-221.

Properly understood -- and narrowly, at least from the perspective of the Plaintiffs' pleadings here -- the Interim Final Rule comports fully with Section 504. Section 504 by its terms does not include **as** qualified handicapped individuals any and all persons who are sick **or ill or** in acute medical distress. Rather, it includes, and guarantees equal opportunity to (as was intended by the Congress) those citizens who have long-term, permanent, life-long disabilities. 3/

The narrow question here is whether the Interim Final **Rule** is lawful:

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3/ In March 1983, Dr. Parrot, plaintiffs' chief affiant, discussed the Regulation with an official **of** the Department **of** Health and Human Services in a radio broadcast originating in Washington, D.C. In response to a statement that the only effect of **the** Interim Final Rule **is** to 'make clear that the withholding **of food** or medical treatment from an infant **only** because the infant will **have** a lifelong handicap such **as** Down's Syndrome **or** Spina-Bifida **is** prohibited, Dr. Parrot stated: "Wow, if that's what the Regulation means, we agree."

..

it is not whether there could be a better Rule **or** a worse Rule 4/ but whether this Rule is authorized **by** Section 504, the civil rights provision **for** handicapped people and otherwise a proper exercise **of** the Secretary's rule-making authority.

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4/ Amici themselves believe the Interim Final Rule can be improved **and** will submit their comments to the Department of Health and Human Services in the period announced and expect modifications which the Interim Final Rule itself holds open. Our point here **is** that this Interim Final Rule is not unlawful; **For** example, Amici may propose that the final rule:

- require health care providers to perform self-evaluations on their policies and practices concerning services to handicapped infants.
- require health care providers to institute "review boards" to review cases where the parents and/or physician has decided to withhold life-sustaining treatment ■ Individuals expert in disability and advocates on behalf **of** the infant must be part of these review bodies ■
- require the review board and/or providers to notify appropriate public agencies when the parties fail to agree on treatment.
- clarify the definition of "discrimination" in the Regulation to eliminate the double standard of treatment for "normal" babies and non-treatment for otherwise handicapped babies **for** the same malady -- examples in the **rules** may be **of** some assistance.
- clarify the definition **of** "handicap" **in** the Regulation to distinguish between the handicapping condition (e.g., Down's Syndrome) and the medical problem (e.g., intestinal blockage) requiring a decision on treatment.
- require health care providers to develop, obtain and disseminate information on public and private agencies and services which can assist parents **of** newborn handicapped infants.
- lessen the adversarial nature **of** Federal intervention **by** reinforcing confidentiality assurances and spelling **out**, via guideline, Office for Civil **Rights** investigative procedures.

The interim final regulation proposes only minor technical changes in compliance procedures which have been in effect for over twenty years

The Interim Final Rule does not and does not purport to make any changes in the substantive non-discrimination provisions (cited and discussed above) concerning the provision of medical care and treatment to handicapped persons contained in the May 1977 Section 504 Final Regulation. Rather, the Interim Final Rule only:

1. Prescribes the specific manner in which beneficiaries of Federal financial assistance are to be notified of the non-discrimination requirement of the statute and regulation in so far as they affect the provision of medical care and treatment to handicapped infants; (Interim Final Rule, Section 84.61(b)); and
2. Formally establishes emergency exceptions to the current civil rights procedural regulations of the Department relating to the provision of advance notice to recipients before initiating suit in Federal court and to the provision generally limiting investigation by Government officials to normal business hours. (Interim Final Rule, Section 84.6(c) and (d)).

The procedural regulation adopted in 1964 by the Department of Health, Education and Welfare to implement Title VI of the Civil Rights Act of 1964 was initially issued in 1964 and subsequently amended in 1967 and in 1973. It was incorporated by reference into the Section 504 Final Regulation in 1977 (45 C.F.R. 84.61). The Interim Final Rule actually proposes to amend only the provisions of these procedural regulations. No changes in the main body of the Section 504 Regulation are even proposed in the Interim Final Rule.

The procedural regulation currently states with respect to the provision of information to beneficiaries, e.g., patients and their families, by recipients (including health care providers) the following:

- (d) Information to beneficiaries and participants. Each recipient shall make available to participants, beneficiaries, and other interested persons such information regarding the provisions of this regulation and its applicability to the program for which the recipient receives Federal financial assistance, and make such information available to them in such manner, as the responsible Department official finds necessary to apprise such persons of the protections against discrimination assured them by the Act and this regulation.

The procedural regulation also currently requires that recipients provide responsible Department officials access to information and its facilities "during normal business hours" (45 C.F.R. 80.6(c)). Further, the procedural regulation currently provides that no action to effect compliance may be taken by the Department unless and until "the expiration of at least 10 days from the mailing of such notice to the recipient or other person" (45 C.F.R. 80.8(d)).

Plaintiffs assert that the Interim Final Rule is invalid because:

1. The rule does not contain appropriate procedures for investigation of complaints (Complaint, Paragraphs 4, 29 and 30);
2. The rule would violate privacy and confidentiality rights of children and their parents and the physician-patient relationship (Complaint, Paragraphs 6, 31 and 32); and
3. The rule is vague (Complaint, Paragraph 27 and 28).

In their discussion of these claims Plaintiffs repeatedly discuss the content and meaning of the unofficial summary accompanying the Rule and ignore the plain meaning of the rule, itself. Even a cursory analysis of the specific content of the Interim Final Rule demonstrates the extravagance

and even irrelevance of these claims. With respect to the required posting of a notice, the effect of the Interim Final Rule is simply to specify the manner in which information regarding the rights of handicapped infants is to be brought to the attention of parents and health care personnel. The requirement with regard to the posting of notices is a time-honored and reasonable method for providing notice to concerned individuals with respect to civil rights protections now utilized under a variety of programs (Cf., the Contract Compliance Program administered by the Department of Labor pursuant to **E.O. 11246**; Title VII of the Civil Rights Act of '1967). The current procedural regulation has for over ten years properly addressed the requisite balance between access to information and the need to preserve confidentiality:

"

\* \* \*

Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this Part. Information of a confidential nature obtained in connection with compliance evaluation or enforcement shall not be disclosed except where necessary in formal enforcement proceedings or where otherwise required by law. "

**(45 C.F.R. 80.6(c)).**

These appropriate protections are unaffected by the Interim Final Rule and, thus, remain unchanged. The fact that specific investigative procedures governing the composition of investigative teams and the precise investigative approach to be used by the Department are not included in the Rule in no way renders the Rule legally vulnerable. General investigative procedures are already included in the current procedural regulation **(45 C.F.R. 80.6)** and Plaintiffs, despite their concern, raised no concern about the adequacy of

the investigations conducted to date (Complaint, Paragraph 21).

With respect to the emergency exceptions proposed in the Interim Final Rule, the changes are neither vague nor intrusive and would serve only to allow Department officials to take expedited investigative and enforcement action under extraordinary, life-threatening circumstances.

In sum, Plaintiffs are attempting to challenge, through the Interim Final Rule, basic aspects of procedural regulations now in effect under three Federal civil rights statutes (i.e., Title VI of the Civil Rights Act of 1964; Title IX of the Education Amendments of 1972 and Section 504) which have for almost twenty years worked so well to protect the rights of beneficiaries and recipients alike. The actual technical changes proposed by the Interim Final Rule do no more than attempt to effectuate the fundamental procedural provisions.

Federal Civil Rights Laws Have Applied to Medical Treatment and Care for Almost Twenty Years

In fact, the direct application of Federal civil rights laws to the operation of hospitals and other health care facilities which receive Federal financial assistance was first established in 1964. The Final Regulation implementing Title VI of the Civil Rights Act of 1964 issued on December 11 of the same year prohibited discrimination on the basis of race, color or national origin in the operation of health care facilities receiving funds under a wide variety of Federal health care programs including: "Grants to States for ... medical assistance (42 U.S.C. 1396 et seq.)" and "Grants, loans, and loan guarantees with interest subsidies for hospital and medical facilities (Title VI, Public



Health Service Act, 42 U.S.C. 291 et seq.)". These two grant programs, commonly referred to as "the Medicaid program" and "the Hill-Burton program", respectively, provide funds to a substantial number of American hospitals and health care facilities. Civil rights obligations which bear upon hospitals and other health service providers are neither new nor secret.

Specifically, the Title VI Regulation has required since 1964 that the assurance of compliance of a hospital relate \*directly to the non-discriminatory treatment of "individuals as . . . patients" (45 C.F.R. 80.4(d)(2)) and has contained the following prohibition: "In Federally assisted programs for the provision of health or welfare service;, discrimination in the selection or eligibility of individuals to receive the services, and segregation or other discriminatory practices in the manner of providing them, are prohibited." (45 C.F.R. 80.5(a)). The original Title VI Regulation (as amended in 1967 and 1973) establishes provisions regarding access to information (Section 80.6(c)), information to beneficiaries (Section 80.6 (d)), conduct of investigations (Section 80.7), and enforcement procedures (Section 80.8(d)) subsequently incorporated by reference in the Section 504 Regulation issued on May 4, 1977. (45 C.F.R. 84.61).

The applicability of Title VI requirements to the treatment practices of Federally assisted health care institutions was brought directly to the attention of hospital administrators seventeen years ago in 1966 in a letter from the Surgeon General transmitting "Guidelines for Compliance With Title VI of the Civil Rights Act of 1964". The 1966 Title VI Health Guidelines list nine specific non-discriminatory practices which health care facilities must

undertake, including:

- 1. The hospital provides in-patient and out-patient care on a non-discriminatory basis; all patients are admitted and receive care without regard to race, color or national origin.. ■■

\* \* \* \* \*

- 6. All services rendered by the institution, its employees or vendor6 to patients or others are provided without regard to race, color, or national origin. This would include:

\* \* \* \* \*

- B. Medical and dental care for in-patients and out-patients (all clinical, diagnostic and other pathology services).

\* \* \* \* \*

- 8. Hospitals which have recently changed from discriminatory practices have taken steps to notify those who previously had been excluded from hospital services (e.g., ■■■posting of signs in hospitals, etc.).

In November 1969, the Office for Civil Rights of the Department of Health and Human Services issued Revised Title VI Hospital Guidelines which provided, inter alia:

3. Services and Physical Facilities Provided by the Hospital:

- a. All therapeutic, diagnostic, preventive, nursing and personal care services are provided without discrimination.

\* \* \* \* \*

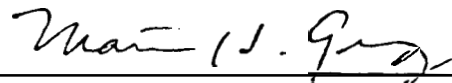
Thus, for the past nineteen years the provision of treatment and other services to patients by federally assisted health care providers has been an important and virtually non-controversial area of Federal civil rights regulation.

Amici strongly support the uninterrupted protection of the rights of handicapped infants assured by Section 504 to an equal opportunity to benefit from medical treatment and care provided in federally supported health care facilities. While recognizing the need for deference to medical judgment, Amici believe that such deference need not extend to the abrogation of the rights of a child to live solely by reason of the prospect of severe permanent handicap.

Respectfully submitted,

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