Hearing Before the United States Commission on Civil Rights

PROTECTION OF HANDICAPPED NEWBORNS

HEARING HELD IN WASHINGTON, D.C.

JUNE 26-27, 1986

VOLUME II

U.S. Commission on Civil Rights

The U.S. Commission on Civil Rights is an independent, bipartisan agency first established by Congress in 1957 and reestablished in 1983. It is directed to:

> Investigate complaints alleging that citizens are being deprived of their right to vote by reason of their race, color, religion, sex, age, handicap, or national origin, or by reason of fraudulent practices;
>
> Study and collect information concerning legal developments constituting discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, handicap, or national origin, or in the administration of justice;
>
> Appraise Federal laws and policies with respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, handicap, or national origin, or in the administration of justice;
>
> Serve as a national clearinghouse for information in respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, handicap, or national origin;
>
> Submit reports, findings, and recommendations to the President and the Congress.

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Thursday, June 26, 1986

The U.S. Commission on Civil Rights convened at 1:30 p.m. in the conference room of the U.S. Commission on Civil Rights, 1121 Vermont Avenue, N.W., Washington, D.C., Chairman Clarence M. Pendleton, Jr., presiding.

Present: Chairman Clarence M. Pendleton, Jr.,; Commissioner Robert A. Destro; Staff Director J. Al Latham, Jr.; General Counsel James B. Mann; Deputy General Counsel William J. Howard; Assistant General Counsel Michael C. McGoings; and Staff Attorneys Eileen Hanrahan and Jon S. Pascale.

PROCEEDINGS

CHAIRMAN PENDLETON: I'd like to call these hearings to order. First, I'd like to make the announcement or ask the question: Are there persons here who are hearing-impaired? Because if so, we are able to accommodate you. If there's no one here, I'm not so certain we need to continue with the actions.

[No response.]

CHAIRMAN PENDLETON: No one. We're sure? Thank you.

The first thing I'd like to do is to swear in the clerks, if I may.

[The clerks were sworn.]

CHAIRMAN PENDLETON: Before we swear in the witnesses, there are opening statements to be made by Commissioner Destro and by me, and then we'll move into swearing in the witnesses, is that correct?

MR. HOWARD: That's correct.

OPENING STATEMENT BY CLARENCE M. PENDLETON, JR., CHAIRMAN

CHAIRMAN PENDLETON: Good afternoon, ladies and gentlemen. I am Clarence M. Pendleton, Jr., Chairman of the United States Commission on Civil Rights. On behalf of my colleague, I welcome you to this hearing, which follows up on a hearing held by the Commission in June 1985 on protection of handicapped newborns. The purpose of the June 1985 hearing was to determine the nature and the extent of the practice of withholding medical treatment and care from handicapped newborns and the appropriate role for the Federal Government with respect to that issue.

The hearing examined whether handicapped newborns were being discriminated against in violation of section 504 of the Rehabilitation Act of 1973, which prohibits discrimination against otherwise qualified handicapped persons in programs or activities receiving Federal financial assistance.

The June hearing addressed several issues from a variety of perspectives. We heard from physicians, nurses, advocates for the disabled persons, medical organizations, ethicists, Federal law enforcement officials, parents of handicapped children, and others.

Now we'd like to supplement that testimony. Since the June 1985 hearing, the Child Abuse Amendments of 1984, addressing the withholding of medically indicated treatment from infants, has been implemented. The Supreme Court also has decided a major case concerning the application of 504 to the withholding of medical treatment from handicapped infants. We will examine the two subjects today.

In addition, we will be hearing from several distinguished witnesses who will discuss the potential of the disabled, the pervasiveness of discriminatory attitudes, the extent of the practice of withholding medical treatment from handicapped newborns, the reasons for such decisions, the point of view of disabled persons on the issue, and the Bloomington, Indiana, case which sparked a great deal of interest in the protection of handicapped newborns.

At the close of the scheduled testimony tomorrow we will have an open session during which members of the public may testify. I may add we have a long list at this point and if you know of those who want to sign up, they can sign up and be on at that period tomorrow.

I would like to announce that we are going to have a break in the session today to accommodate a public witness from California who happens to be here and has to go back today. So we will accommodate that one person as a public witness and continue on with the public testimony tomorrow.

The time is allocated on a first-come, first-served basis and the testimony is limited to 5 minutes. In addition, testimony may not defame, degrade, or incriminate anyone and must be directed to the subject of the hearing. Persons wishing to testify at open session should contact one of the Commission staff persons in this room.

Lastly, I remind all witnesses and the audience that the Commission is expressly prohibited by its statute from addressing abortion. Witnesses likewise are prohibited from addressing abortion in their testimony here today and tomorrow.

I'd like to turn to my colleague, Commissioner Robert Destro. As you give your statement, Bob, I'd just want to thank you for helping us in the Commission to put together this second set of hearings. It has been because of your tireless work that we are having these. Certainly we get a perspective that is important for the Commission to hear and for the public to have some better understanding of it. Thank you very much.

Commissioner Destro.

OPENING STATEMENT BY ROBERT A. DESTRO, COMMISSIONER

COMMISSIONER DESTRO: Thank you, Mr. Chairman.

As we open this supplemental hearing on the protection of handicapped newborns under section 504 of the Rehabilitation Act of 1973, I think it would be well to remind ourselves of the focus of this continuation of the hearing commenced last year is discrimination and the way it manifests itself in medical care decisions affecting the handicapped.

A review of the record of the session of this hearing held on June 12th through 14th of last year reveals some very interesting differences of opinion among the witnesses concerning the application of section 504 to medical care decisions involving handicapped infants, concerning the nature and extent of discrimination against newborn infants with disabilities, and whether or not it is even legitimate to call decisions based on the existence of a disability discriminatory.

A review of the plurality and dissenting opinions by Supreme Court Justices John Paul Stevens and Byron White respectively in Bowen versus American Hospital Association reveals an almost identical difference of opinion, based in large part upon the plurality's view that there was no evidence to support the so-called Baby Doe regulations published in response to claims of discrimination against handicapped infants.

Clearly then, the debate over the protection afforded infants under section 504 is not over, and this Commission, in my view, has a critical role to play in its future direction. In my view, the controversy has simply entered a new round where the issues will be clarified, the evidence deduced and presented for the record, and the true dimensions of the problem fleshed out to the benefit of both legislators and regulators.

I, therefore, commend the members of the Commission for authorizing this supplemental hearing and gratefully acknowledge the cooperation of the Chairman, the work of the staff members, especially that of my own assistants, Deborah Lawrence and Bob Heilferty, and Acting General Counsel Bill Howard and the Staff Director, and those who have worked so hard with me behind the scenes to put this hearing together. Without the help of each of these individuals, this hearing would not have been possible.

If one thing is certain from the record adduced at the first round of hearings in this investigation, it is that the issues are described very differently depending upon the background and perspectives of the witnesses who are called.

To the physicians who testified, including the Surgeon General, Dr. Koop, decisions made in the delivery room--quote--"can be based on ignorance and can also be based on prejudice"--end quote--and that the physician's role and his perception of that role is critical to the approach that will be recommended to the family.

To the witnesses who represented various organizations involved in the litigation in the Supreme Court, section 504's focus on discrimination is not a valid means to describe the issues facing the Commission at this hearing.

To the parents who testified, it was clear--contrary, in my judgment, to the assertions of Justice Stevens in Bowen--that most parents are indeed influenced primarily by the recommendations of their physicians and that those recommendations can be and sometimes are based on a totally erroneous view of the child's abilities and future quality of life.

Whether the giving of such information is indeed discriminatory, based on ignorance, stereotype, or eugenically-based prejudice against the disabled, will be one of the subjects for inquiry this afternoon and tomorrow.

In like manner, this hearing will inquire into the issue of whether, in fact, issues such as these should be considered solely a matter for medical judgment or parental decision based on medical input, and whether it is legitimate to inquire into the attitudes and activities of physicians who treat or recommend treatments for handicapped infants and children.

The Commission will need to learn whether or not State child protective agencies exert the same effort to protect the lives and futures of disabled children whose parents refuse treatment, as they do for those whose parents may refuse treatment for religious or other reasons.

And finally, the Commission will need to inquire into the interface between discrimination against handicapped newborns and the issue of medical care discrimination against the disabled generally.

For there is little doubt in my mind that regardless of the present reach of section 504, the arguments made by several of the witnesses at the previous session of this hearing would apply equally as well to medical care and decisions affecting disabled people of any age or ability.

One last point I believe is worth mentioning by way of this introduction: The issue before the Commission is a mixed one. The testimony at the first hearing made it clear that there is a distinction between cases where the infant is in the process of dying and cases where the question is whether to correct an otherwise correctable defect that will cause death if not attended to. Because this hearing, section 504, and the Child Abuse Amendments are primarily concerned with the disabled infant who will die without attention to a correctable defect, there is no way around the fact that a subissue in this hearing is infanticide.

Justice Stevens' opinion for the plurality of Justices recognized as much when he chastised the Secretary of Health and Human Services for--quote: "employing Federal resources to save the lives of handicapped newborns without regard to whether or not they are victims of discrimination by recipients of Federal funds or not"--end quote.

But discrimination begins with ignorance and prejudice and feeds on the idea that the law can make distinctions that entitle some to equal protection of the laws and relegate others to positions of subservience and inequality.

Otherwise intelligent, sophisticated people have argued that the disabled have no quality of life that either their family or the State is bound to respect. When coupled with society's ambivalence toward the rights of the very young, it is all too easy--as I believe Justice Stevens has done--to assume that a decision to permit a handicapped infant to die because he or she is disabled does not raise substantial constitutional questions concerning equal protection of the laws.

The law forbids infanticide generally. And those who would argue that it should be permitted in cases of disabled infants want an exception to the general rule. The arguments in favor of infanticide are placed in terms of hard cases, the cases in which the child is so badly disabled that death is inevitable in a very short time. These, in fact, were some of the arguments we heard at the last hearing, but the truth is that what we are witnessing is a change in social mores and a change in public perception of the rights of the disabled.

The Baby Doe cases and the overall public policy debate of which this hearing is a part are the means by which prejudices can be given legal effect. Several writers commenting on Mary Tedeschi's excellent article and commentary, "Infanticide and its Apologists," have used terms like "expensive and gut-wrenching vegetables," "creatures that literally cannot become human," and "freaks" to describe these children. In their view, which is not at all uncommon, these children were simply better off dead than disabled. Better off for whom, of course, is obvious: for anyone other than the child himself.

Thus, in my view, civil rights and equal opportunity are expensive propositions. They require us to come outside of ourselves and to treat others as we ourselves would like to be treated. The protection the law affords to those with disabilities is the true test of its commitment to equal rights for all, for although the needs and limitations of those with disabilities may be a bit more obvious than our own, protection offered by the law must be the same.

Thank you, Mr. Chairman. I look forward to hearing from the witnesses today.

CHAIRMAN PENDLETON: Thank you, Mr. Destro. I think your statement is testimony to your concerns in this matter and I must say that you certainly have sensitized me more than I thought I would have been sensitized about these issues, and for that I am appreciative.

COMMISSIONER DESTRO: Thank you.

CHAIRMAN PENDLETON: I'd like for you all to raise your hand and I've got something I've got to ask you.

[The witnesses were sworn.]

BOWEN V. AMERICAN HOSPITAL ASSOCIATION SUPREME COURT DECISION

Testimony of James W. Ellis, Professor, School of Law, University of New Mexico; Evan J. Kemp, Jr., Director, Disability Rights Center, Washington, D.C.; Stuart M. Gerson, Esq., Epstein, Becker, Borsody & Green, Washington, D.C.; Charles J. Cooper, Assistant Attorney General, Office of Legal Counsel, U.S. Department of Justice, Washington, D.C.; and Jack N. Goodman, Pierson, Ball & Dowd, Washington, D.C.

CHAIRMAN PENDLETON: Michael McGoings or who's going--

MR. PASCALE: I'll start off.

CHAIRMAN PENDLETON: Okay.

MR. PASCALE: To begin with, would each of you, starting with Assistant Attorney General Cooper, state your name--

CHAIRMAN PENDLETON: Can you all hear in the back? Could you bring the microphone closer to you?

[Discussion off the record.]

MR. PASCALE: Could each of you, starting with Assistant Attorney General Cooper, state your name, address, and position for the record?

MR. COOPER: Yes, my name is Charles J. Cooper and I'm Assistant Attorney General for the Office of Legal Counsel in the Department of Justice. My office address is 10th and Constitution, Washington, D.C.

MR. PASCALE: Mr. Goodman?

MR. GOODMAN: I'm Jack Goodman. I am a partner in the law firm of Pierson--

CHAIRMAN PENDLETON: Excuse me just 1 second.

[Discussion off the record.]

CHAIRMAN PENDLETON: Okay.

MR. GOODMAN: I'm Jack Goodman, I'm a partner in the law firm of Pierson, Ball and Dowd and my address is 1200 18th Street, Northwest, in Washington.

MR. PASCALE: Mr. Gerson?

MR. GERSON: I'm Stuart Gerson. I'm a lawyer, a member of the firm of Epstein, Becker, Borsody and Green. My office address is 1140 19th Street, Northwest, Washington, D.C.

And as far as my position, given the breadth of interests that I have represented in these cases over the years and many of the discontinuities among the things that those folks believe, I note that I am here in an individual capacity as a lawyer who has litigated bioethical issues, including the Baby Doe case.

MR. PASCALE: Thank you. Mr. Ellis?

MR. ELLIS: My name is James W. Ellis. I'm a professor of law at the University of New Mexico in Albuquerque, New Mexico, and I'm also here in an individual capacity, but I represented the professional disability groups--disability professional groups--in the case of Bowen.

MR. PASCALE: Thank you. Mr. Kemp?

MR. KEMP: My name is Evan J. Kemp, Jr. I'm director of the Disability Rights Center in Washington, D.C. Our address is 1616 P Street, Northwest, Suite 435, Washington, D.C. 20036. And I'm here primarily as a disabled person.

MR. PASCALE: Thank you.

I'd like to address this first question--

CHAIRMAN PENDLETON: Another timeout, if we may.

[Discussion off the record.]

CHAIRMAN PENDLETON: Go right ahead.

MR. PASCALE: Okay. I guess everyone is going to have to get pretty close to the microphone, if you're talking.

I'd like to address this first question to the whole panel. Would each of you please describe your reaction to the recent Supreme Court decision in Bowen versus AHA? I'd like to start with Mr. Cooper.

MR. COOPER: Well, the Department of Justice, of course, was disappointed that the Court affirmed the ruling invalidating HHS' regulations in this area. It obviously was not consistent with the position that we pressed upon them. We, candidly, of course, think that Justice White had the better of it, but will, of course, abide by the Court's ruling in every respect.

MR. PASCALE: Thank you. Mr. Goodman?

MR. GOODMAN: Well, we represented the American Academy of Pediatrics. And the pediatricians were, needless to say, rather quite pleased with the Court's position, believing the Court recognized the primacy of the role of the physician and the parents in making these sorts of decisions.

MR. PASCALE: Thank you. Mr. Gerson?

MR. GERSON: Well I, like Mr. Cooper, had a litigant's reaction to it, as the counsel for the side that prevailed. I, of course, felt that the proper result was reached, though that really didn't end the inquiry. So if you're asking how I felt, the case raised some questions, answered some, didn't answer some, and there is much left yet to discuss about it.

MR. PASCALE: Thank you. Mr. Ellis?

MR. ELLIS: Again, as someone who had represented a group of amici before the Court, we were very disappointed in the plurality decision, but I would draw the distinction between what the Court actually decided and the component parts of the plurality decision. I would draw a distinction between that and the way in which the case has been characterized in the press, which has suggested--as Mr. Gerson, I think, implied--that somehow this ended the debate and foreclosed a role for the Federal Government in this issue, and that is obviously inaccurate. Thus, the decision itself, although muddled and disappointing in lots of ways, doesn't end the debate at all, even on the issue of the appropriate Federal role.

MR. PASCALE: Mr. Kemp?

MR. KEMP: As a disabled person, I was sad and depressed by the decision. As an advocate for disabled people, I was heartened that 504 wasn't struck down completely, and only the rules and regulations that HHS put out.

MR. PASCALE: I have a three-part question I'd like to address to Mr. Cooper and Mr. Gerson.

The first part of the question is: To what extent does the Bowen decision limit the Federal Government from intervening in the Baby Doe cases?

Mr. Cooper?

MR. COOPER: Well, I think the decision itself obviously has invalidated the regulations as written, on their face. It was a limited issue before the Court. The Court delivered a very limited decision, one that invalidated the regulations, again, on their face, and thus prohibited, by leaving in place the lower court's injunction, any enforcement activity under those regulations.

I think it's important, however, to note that the Court did quite expressly refrain from ruling on whether or not there could be any Federal role in this area at all. In fact, it indicated that the discrimination paradigm that was advanced by the Government appeared sound; that is, that any time that a recipient of Federal funds makes a decision based upon handicap, even when we're talking about infants, that would be different from the decision it would make if the infant had not been handicapped, then 504 is at least implicated.

So in this area, I don't think that this decision in any way forecloses a Federal response. I don't think it forecloses additional Federal regulations that are not deficient in the way that the Supreme Court found the present Federal regulations deficient and that's primarily a sufficiency of the evidence deficiency.

So I certainly agree with what Mr. Ellis has previously said, that the decision itself does not foreclose a Federal role in this area, a possible future regulatory role, certainly not a role involved in individual claims of handicap-based discrimination.

MR. PASCALE. Thank you.

Mr. Gerson, do you agree with the Assistant Attorney General on that?

MR. GERSON. Mr. Cooper has said a number of things, and there are some that I agree with and there are some that I don't agree with, and there are some things that he didn't talk about that would really be the essence of my focus.

The professor is correct when he says that this is a decision that has been wildly misinterpreted. One, it's not a constitutional case and no one ever described it as such so it does not involve issues of equal protection; they are left for other times and other places and other parties, especially where governmental action might be under consideration.

So it isn't that; it's a narrow statutory case and it's a case in which the Court did not decide the precise issue upon which it granted the writ of certiorari, an issue about which Mr. Cooper and I agreed wholeheartedly was the issue stated. And so both of us probably agree that the Court could have decided that issue and probably should have defined it for all time and perhaps in a way that would have rendered this hearing less necessary.

So I would agree with him that the Court didn't decide the total question of authority, although the Court did say, at least the plurality says in the footnote on page 33 of the slip opinion, that the legislative history of the Rehabilitation Act does not support the notion that Congress intended intervention by Federal officials into treatment decisions of the kind that were being discussed in the case.

In terms of hospitals and in terms of the very regulation that was at issue in the Bowen case, one thing can be said with some certainty: The Court did hold two things, one of which should give great heart to the disabled, though not particularly in terms of applying the case, and that is that infants with birth defects are "otherwise qualified" within the meaning of section 504. That probably has some ancillary meaning as far as Federal ability to do something at some other time in some other case. That's not inconsequential. At least that has been decided.

However, I don't think that there's much doubt that when you focus upon hospitals, which after all were the entities that were those sought to be regulated under the various versions of the Baby Doe regulations, the plurality certainly accepted the view--which is an accurate one, I might say--that hospitals do not make medical treatment decisions, whether they are good ones or bad ones or something in between.

And the result of that is the plurality's holding that if medical treatment, again for well or ill, is denied at the hospital level, 504 cannot be used as a vehicle to affect the conduct of that hospital because the hospital would--even if you accept the discrimination paradigm that Mr. Cooper has posed, which I don't--but even if you do, the hospital will not have discriminated against the child solely by reason of the child's handicap. Nor will that child be viewed as otherwise qualified in terms of the statute because of the lack of parental consent.

It does leave open the question that has never been raised in any concrete case, of what happens where a parent authorizes treatment and a hospital refuses to provide it; but there's never been such a case that has been presented before this Commission, to the Federal Government, or anyplace else, and the Court noted that as well.

MR. PASCALE: Does the language of the decision mean that the Federal Government may not intervene in any cases where the parents have withheld consent to treat the handicapped newborn? Mr. Cooper?

MR. GERSON: Do you want to reverse the positions and I'll go first?

MR. PASCALE: Okay.

MR. GERSON: I don't know the answer to that. I believe that I know the answer under section 504. And if you're limiting yourself, it would suggest that the Federal Government can't intervene at least in--cannot intervene at least in the case where there is a lack of parental consent for treatment.

That's not to say there is no other remedy. And it's not to say that there may not be some Federal involvement insofar, say, as the enforcement of the Child Abuse Amendments if a State agency somehow is not on the scene or refuses to act. We all recognize that there are children here without a voice and we all agree that there are times when inappropriate or uneducated decisions might be made.

At the level clearly specified under statute, in this case in the child abuse area, the Federal Government might have a role. But under 504, it's unlikely that it is going to have that role to affect the hospitals' decision--excuse me, not a hospital's decision, but a hospital's conduct; the hospital doesn't make a decision.

MR. PASCALE: Thank you.

Mr. Cooper?

MR. COOPER: I think it is, first, very important to focus on the kind of claim that might be made, because the decision does foreclose the Federal Government from arguing, or a private party from arguing, that a hospital has withheld treatment on the basis of handicap if the parents have not consented. Mr. Gerson is correct on that point.

And he's also correct on the proposition that there has been no evidence adduced to support the hypothetical of a parent or parents who authorize treatment of a child that a hospital then unilaterally objects to or rejects, and decides on its own account to withhold lifesaving treatment.

If such a hypothetical did exist, if it was to present itself, it seems to me an unremarkable proposition that that kind of decision would be based upon handicap. It could not be argued that it was based upon the parent's lack of consent; and therefore, 504 would at least be implicated and the other questions that 504 requires a resolution to would be raised.

If the claim, however, is that a hospital has acquiesced in a parental decision to deny lifesaving medical treatment to the newborn and that it would have not acquiesced in that decision--in other words, it would have sought to override that decision--had the child not been handicapped, that claim is one that would be based on handicap.

The Court dealt with these two different kinds of claims in different segments of its opinion and dealt with them in different ways. The Court recognized, at least arguably, the soundness, as I say, of that particular discrimination paradigm. It did not suggest that the want of parental consent in that situation would essentially destroy 504's apparent applicability.

So it depends upon the claim that is made. And in the end it depends, as with any other discrimination claim, on whether or not the decision that is being made is based upon the prohibited criterion. And in 504, the prohibitive criterion is handicap. It is not--504 does not protect any individual from decisions made by their parents.

MR. PASCALE: Thank you.

I'd like to address this question to Mr. Goodman and Professor Ellis.

In your opinion, was the Court's view of the evidence of discrimination realistic in finding that there was no evidence of discrimination because it was not presented with any cases where parents wanted treatment and a hospital refused?

Mr. Goodman?

MR. GOODMAN: To our knowledge, yes. We, and the members of the Academy, have not been aware of any case where parents have consented and a hospital, based on a prohibitive criterion, has refused treatment. And in fact, given the nature of hospitals, it's almost a contradiction in terms to expect that if someone is there who wants to go ahead--hospitals are in the business of saving lives and providing medical treatment. So yes, we think it was realistic.

MR. PASCALE: You do.

Professor Ellis?

MR. ELLIS: Well, I disagree with that interpretation of it. I think it was a wholly unrealistic view because it misperceives the nature of the process by which parents, in conjunction with their doctors, make decisions about handicapped newborns.

The Stevens' plurality treats that decision as a sort of cut-and-dried, it either happened or it didn't. The process itself is ignored. It's sort of as if a cert petition is either filed in a timely fashion or it isn't, and if the cert petition isn't filed then there's no case.

And similarly, if consent is not given in some sort of antiseptic fashion, there's no participation by the doctor or the hospital in that decision. All of the literature suggests and all of the accounts by parents, including those who testified before you at the first set of hearings, suggest that isn't how the decision is made, that it's one in which parents look to their physician for information, seek guidance from their physician and, although they ultimately have the formal and ultimate decision, often that's shaped by what they're told. And discrimination can take place in what they're told.

MR. PASCALE: Thank you.

MS. HANRAHAN: Can everyone hear me? Okay.

I think we're running a little over so we'll have to cut down on some of the questions. I'd like to take two questions and address the first to you, Professor Ellis, and to Mr. Goodman. These are some points that Mr. Cooper and Mr. Gerson touched on earlier, and I'm trying to get at the idea of what, under 504, the Court would consider upholding.

Specifically, if you could address whether you think the Court would require, to uphold regulations similar to those struck down in Bowen, evidence of hospitals refusing treatment when parents gave consent.

Secondly, if you could examine the extent to which the Court under 504 could reach discriminatory failure to report cases of withholding consent by parents.

And whether under 504, lastly, you think there are other regulations that the Government could promulgate which the Court would uphold.

Mr. Goodman?

MR. GOODMAN: Taking those questions in order, it seems to me that if there were a situation presented where a hospital had, after parents consented--parents requested surgical treatment and, on the basis of the handicap, essentially a policy of the hospital was: we will not treat babies with handicaps--had refused consent, that that would be a paradigm case, and that would be something that the Court specifically said that they regarded handicapped infants as within the scope of 504.

So were that case to be presented--and I repeat, we don't know of any such cases--there probably would be a basis for going forward.

MS. HANRAHAN: Second, I asked about reporting--whether discriminatory failure to report by hospitals of parents withholding consent.--

MR. GOODMAN: That presents a considerably more complicated question because, again, if you could narrow the issue to a real paradigm--that they said we are not going to report about handicap--then you might have--although you again have a question which the Court referred to in a footnote, which is whether the reporting activity of a hospital is a federally financed activity and even comes within the jurisdictional scope of 504.

Second, you have the question, a very difficult factual question, of where a hospital makes certain decisions that are based on the individual merits of the case. If you could find a hospital that said, "No, we're not going to report any neglect of handicapped children," you would have it, but it's very difficult, and the thing that we have stressed is that all of these cases are very complicated, and they don't present this very neat paradigm situation. So if you could get the paradigm, I think there would be a basis for action under 504, but it's unlikely that the paradigm exists.

And the third question you asked was whether there are regulations that could be imposed, and I think the issue then is again, is one the Court focused on--discrimination by federally funded entities.

And again, they were unable to find, and the Department of Health and Human Services was unable to present evidence that any of this had gone on, that this, in fact, was activity that parents and doctors, who largely are not federally funded entities, were involved in. So in that situation, assuming those facts continue, there probably is a very narrow scope, if any. However, the Court did leave in place the requirement of infant care review committees and other procedures to provide more information and more participants in the process. And those still stand, and that is a legitimate role for the Federal Government.

MS. HANRAHAN: Thank you, Mr. Goodman.

Professor Ellis?

MR. ELLIS: Well, let me maybe try to address it broadly, and then if you--

MS. HANRAHAN: Sure.

MR. ELLIS: --want to pursue those three points separately.

The discussion of paradigm cases that Mr. Goodman presents and that is to some extent found in the plurality opinion, is in a way sort of uncomfortably reminiscent of other kinds of disputes we've had in this country about discrimination.

If the requirement out of Bowen is--or if the requirement out of subsequent interpretations of 504 and other legal requirements is to be that a hospital has to say with a placard on the front, or physicians have to say, or whoever the person is that's being identified as someone who is discriminating--no handicapped need apply here, if that's all the law requires is the removal of that sign and the removal of formal rules that say, or policies that say we don't treat handicapped people, and if that same approach had been applied, for example, in the area of race discrimination or other areas of discrimination with which this Commission has obviously a huge body of experience, then all sorts of discrimination could go on as long as formal acknowledgement of it was not made.

It sort of hearkens back, in a way, to questions with regard to voting rights. If the State doesn't say we're going to exclude black people from voting but we're going to require all of the bizarre convolutions that some States use to prevent black people from voting, whether we--the question is whether we simply look to a de jure policy or whether we look to what actually takes place.

In each area of discrimination that this Commission has investigated and that the Congress and the government have addressed, each kind of discrimination has its own characteristics. And in each instance, the characteristics of discrimination depart in some details from the pure model of how you go at discrimination. And where we care about that discrimination, we've found a way to get beyond the legalisms or the purity of the model.

For example, in the area of race, in the case of Loving against Virginia, which was decided 20 or so years ago, Virginia, which had barred--which had a miscegenation statute that barred people of difference races from marrying one another--claimed, "Look, this isn't discrimination on the basis of race because it affects both black and white people who want to marry one another."

And the Court correctly saw through that and said, "Yes, that departs some from the model with regard to race discrimination, but you can't get away with that; we know this is discrimination based on race, even though it isn't purely within the model because people were treated equal, both black and white people were treated equally."

Similarly and much more recently, in the area of gender, the Supreme Court has upheld the notion that sexual harassment is within the meaning of sex discrimination. A purist view of what the model of sex discrimination is might not have accommodated that, and yet a unanimous Court said, "Look, we know what discrimination is and we know what results from discrimination on--prejudicial views on the basis of gender, and this is included within it."

Similarly here, if we run a shell game that says, "Yes, there may be a decision that's unfortunate that deprives people of their lives on the basis of handicap, but each of the people who participates in that decision is immunized by the participation of others and, as a result, there is no protection afforded," I think that it suggests that we don't care as much about discrimination on the basis of handicap as we do other kinds of discrimination, and I hope that won't be the ultimate result.

MS. HANRAHAN: Is that your answer?

MR. ELLIS: Do you want to go through the three--

MS. HANRAHAN: No, why don't I move on to the last question, so that we can ask Mr. Kemp a few questions.

And I address this question to Mr. Gerson and Mr. Cooper. Do you think that the language in the Bowen decision has any implications for the constitutional rights of the handicapped to be free of discrimination or, secondly, do you think the language in the decision has any implications for the congressional amendment of 504 to include withholding of medical treatment from the handicapped?

Mr. Cooper?

MR. COOPER: I do not think that the Bowen decision has any implications for a constitutional claim of irrational distinction against a handicapped person. The case came up solely as the statutory construction case with no constitutional issues involved in the case, at least not equal protection issues. There were some First Amendment issues that had been disposed of in the Baby Jane Doe case, but no, I do not understand this to provide any insights at all into the equal protection questions.

I should add that the Supreme Court did recently rule in the Cleburne County case that handicapped people cannot, consistently with the equal protection clause, be victimized by irrational distinctions based upon their handicap and one can divine some insights from that case certainly in this area. But Bowen, I do not believe supplies any.

And what was your second question?

MS. HANRAHAN: My second question was whether you thought that the language in the decision would have any implications for a Congressional attempt to amend section 504 to include cases of discrimination against Babies Doe?

MR. COOPER: Oh, well, certainly the decision may inspire some members of Congress to review section 504 in order to see if a statutory amendment is in order to deal more precisely or in some way more directly with this problem or related problems as necessary, but I don't have any particularized knowledge on what may be going on in that respect.

MS. HANRAHAN: Thank you, sir.

Mr. Gerson?

MR. GERSON: In a great sense, Mr. Cooper's answer can be mine. He's a good constitutional lawyer. I hope that I am. And since we've worked on briefs for years in these cases, we know that neither of us raised the constitutional issue and the Court didn't decide one. So that's left for another time and another place. And I don't mean to trivialize the fundamental importance of addressing rights of handicapped individuals; it just is not involved in this case.

Similarly, the possibility of an amendment to section 504 to extend its scope is something the likelihood of which I, like Mr. Cooper, cannot assess, although surely there must be some people on the Hill who would be interested at least in considering it.

It's important to note here something of a division among parties who oppose the Government in terms of the Baby Doe regulations. I say without irony, or maybe with a little, that the position that I staked out on behalf of my clients was, in our view, a fundamentally conservative position, that spoke about where regulations should lay in the absence of a clear congressional pronouncement. The plurality discussed that and understood it. The hospitals have never taken the position that the Federal legislature, that Congress, is without constitutional authority to extend 504; simply that 504, as it is now promulgated, does not extend to the sort of activity that the Department sought to have it extend to. And that's an important distinction. Physicians and, indeed, some of their patients might feel differently about it. If you read the briefs, you ought to see something of a difference between what the hospitals have had to say and what the physicians have had to say.

And that's an important distinction for this group and anybody else. You can't lump together physicians--whatever you think about how parents make decisions, whether they do it under the influence of physicians or otherwise, they don't do it under the influence of hospitals.

MS. HANRAHAN: I'm sorry, I think we're going to have to stop you. Mr. Pascale has a couple of questions for Mr. Kemp. Thank you.

MR. PASCALE: Mr. Kemp, in a telephone interview I had with you before this hearing, you mentioned that there were several human aspects of the *Bowen* decision that should be discussed. Could you elaborate on that?

MR. KEMP: Yes, I think--you know, we talked a lot about 504 and parental consent and everything like this, but I think the first question that we should address as a society: Are these infants born with disabilities human beings? Because I think that if they are human beings, considered by society as human beings, they are protected by the U.S. Constitution, their lives cannot be taken without due process of law, that they can't--they're protected by the Sixth Amendment from cruel and unusual punishment.

It does seem to me in the Bowen case that the Court is leading away from the point that they are human beings, that they are some sort of vegetable or something like this. And if society leans this way, then certainly they don't have the protections of the U.S. Constitution or section 504 of the Rehabilitation Act, then parents can discard these infants just as they would discard excess kittens or a sick dog and that doctors can discard these children just as they would used surgical gloves. So I do think that the first question is: Are they human beings?

And I think we have to be exposed to what these people can do, what the mentally retarded can do in their lives--become integrated into society, be independent taxpayers instead of tax consumers; what people with spina bifida can do, that they can become taxpayers instead of tax consumers and perfectly integrate into society.

MR. PASCALE: Do you believe that handicapped newborns are receiving their due process rights under the Constitution?

MR. KEMP: No, as long as there are two standards. If a medical treatment would be done to a perfect baby and not done to a baby with a perceived handicap, then they're not receiving their constitutional protections.

MR. PASCALE: How would you humanize the legal debate, following up what you said after the first question?

MR. KEMP: I think you humanize it by bringing to this hearing and to the public's attention disabled people--disabled children who are becoming integrated into society, who are going to school, who are getting jobs; that you talk to mentally retarded people and have mentally retarded people before this Commission; that 60 Minutes and 20-20, who I think slandered and libeled Washburn and others--I think that those programs owed an obligation to show disabled people, to show Baby Jane Doe, to show children with spina bifida and adults with spina bifida, show adults who are mentally retarded.

MR. PASCALE: Thank you very much.

Mr. Chairman?

CHAIRMAN PENDLETON: Thank you.

Mr. Destro?

COMMISSIONER DESTRO: I have a few questions here with respect to the issues. Let me address my first question to Mr. Goodman.

I think you basically said that--and I know that Mr. Gerson said basically the same thing, but correct me if I'm wrong--is that basically hospitals don't discriminate. Is that basically your position in cases like this, even if the doctor is involved in the procedure, that really you can't blame it on the hospital? Am I making myself clear?

In a situation where the parents are ambivalent and the doctor influences the parents in such a way that they decide not to go ahead with the surgery, that regardless of his motivation for so influencing the parents, that the hospital should not be chargeable with any discrimination?

MR. GOODMAN: Well, the first thing is Mr. Gerson is correct. In the typical situation, doctors are not employees of a hospital; they often are independent and, therefore, what they do, the hospital has no control over or any relationship with essentially the advice they give to their patients. And in that sense also doctors are not, at least on their face, within the scope of 504.

But I think I'd like to add--broaden that a bit because there is a considerable amount of discussion about the pediatrician or the doctor as being the motivating factor here, and I think the fact is that most pediatricians and certainly neonatologists, who are the people who are really at stake here, are people who went into their profession to save lives of children. And it's very difficult to see that these people are the bad guys that the dissent, Justice White, paints them as, and that certain other individuals have. Their goal is largely to save children and to advise parents in the ways--in the best way to handle what are very, very difficult and very, very complicated situations.

But in the sense of whether the doctors' advice is something that is attributable to the hospital, I would agree with Mr. Gerson, it's not.

COMMISSIONER DESTRO: After the Meritor Savings Bank case of last week, do you think that a doctor's sex discrimination against a nurse would be attributable to the hospital if the hospital knew that it was going on?

MR. GOODMAN: If the hospital knew what was going on and the hospital took action--in other words, it affected the nurse's job in the hospital, that might be one thing. But again, the one distinction between Meritor and a hospital is that the vice president or whatever he was in Meritor was an employee and an agent of the bank; it's not entirely clear with respect to doctors.

COMMISSIONER DESTRO: The reason I asked the question is that in some of the cases that we saw in the hearings we had last year, it was the hospital, not the doctor, who brought the case against the parents. And so I'm not sure that the record supports the proposition that the hospitals are totally ignorant of what goes on in the advising process.

MR. GOODMAN: I didn't suggest that. But certainly I would suppose in the majority of situations the hospitals are the ones who bring complaints, and they certainly are aware of what is going on, so it's not as if they're totally ignorant. But hospitals arguably stand ready to perform the services that doctors order, and that is their role.

COMMISSIONER DESTRO: Okay.

Let me ask Mr. Kemp and Mr. Ellis: Would you deal with the question that we've been touching on here? We talked about consent of parents, and the Supreme Court certainly takes the position, or the plurality took the position that the consent of parents is the critical factor.

Would you address from your own perspectives the question of how informed consent fits into all of this as a basis for parental choice?

MR. KEMP: I think that parents are being used very cynically by doctors in this whole controversy about informed consent. I think there is certainly a string of cases that hold that if doctors want to treat a minor, the religious beliefs or other beliefs of parents will not interrupt their desire to treat, and they'll go to court to get an order to so treat.

I think that at time of birth, when parents are very distraught, when they find that they don't have a child that measures up to the children of their friends, they're very impressionable at that time and under a great deal of stress, and I think that doctors have tremendous power to influence them, and I think they do influence them and then use them cynically to base their nontreatment decisions on the desires of the parents.

MR. ELLIS: I fully agree and I would come at it somewhat differently. The law of informed consent, both as a matter of tort law and as a matter of constitutional law, in a way provides some guidance, whether it's by analogy or whatever, because legally adequate consent requires that the individual have the capacity to make the judgment--that isn't much in doubt here--but that he also have a sufficient amount of information to make a legally adequate judgment and that it be a voluntary judgment, that is, without undue influence by others.

And both on voluntariness and particularly on the point of information, to suggest that the involvement of parents, who are often ratifying a judgment which they think to have been made by a professional on the basis of current knowledge that may not indeed be without prejudice, looking to the kinds of requirements in consent law may suggest to us that it is inadequate to essentially launder discriminatory decisions by saying, "Yes, well the parent acquiesced in them" when their consent may not meet those tests.

COMMISSIONER DESTRO: Let me ask a question of Mr. Gerson and Mr. Cooper. Let me give you a hypothetical case and I would like to explore your understanding of what the Supreme Court has forbidden the government to do in the terms of that injunction. There was a lot of debate in the Bowen case about how far the injunction reached, and I'd like to explore this with you for a moment.

If we were to set up a hypothetical where it were alleged to the government that a group of physicians working at a hospital, or a single physician, based treatment recommendations to the parents on a formula somewhat akin to the Gross or Shaw-Shurtleff kinds of criteria, and that the parents had refused treatment based on that recommendation because--and later they found that the information was in error, do you think that kind of investigation by the Department would be covered by the injunction entered by the District Court in New York, or is that the kind of a case that the government could go ahead and investigate?

MR. GERSON: The short answer is I don't think you can know, based on the limited facts that you described, and I'll tell you why and hope that I can produce something of an answer quickly on it.

You're describing what--for the sake of shorthand let's call an erroneous medical decision in which physicians have undue influence over parents. The regulation that was struck down was focused on hospitals and sought hospital information and hospital reporting. The two things don't meet.

The injunction is extremely broad. It is unlikely that the government would be able to do anything at all under 504 without going back to Judge Brieant in New York and seeking some relief under his ancillary powers.

There is a jurisdiction that can deal with the issue of medical neglect: the erroneous decision, the ill-motivated decision, and it's a State-based remedy. The Federal Government does have a role in seeing that that State-based remedy is within the prescriptions of Federal law, particularly the Child Abuse Amendments. So the Federal Government at least can do that.

But that decision is not and cannot be the decision of a hospital that would admit the patient and would treat the patient if the physician-parents combination, to assume your hypothetical, decided it in the other way, gave the authority. I think that's the most that can be said about it.

COMMISSIONER DESTRO: Well the reason I asked the question is: I reread Dr. Gross' article and he indicated that they put together a team that included a number of different people on the hospital staff and that the team came up with a recommendation that was then brought to the parents based on the facts of each individual case.

And as I understood, one of the primary concerns in, certainly in the Baby Jane Doe case, was that the government wanted to find out what went into the decisionmaking process.

And my question--and I think you may have answered it and if I misunderstand you, please correct me--is that even in the situation where the parents came back later and complained that they may have been misled, that that kind of a situation would in fact be covered by that injunction entered by Judge Brieant.

MR. GERSON: I'm not so sure that the injunction speaks to that.

If the parents, in other words, come back and voice an objection to the advice that they've gotten from their physician. Assuming that they've adopted it, that they were swayed by it, however you want to describe it hypothetically, they're not without avenues of redress, nor is the Federal Government without an avenue of correct participation under the Child Abuse Amendments.

It does not pose a 504 problem.

COMMISSIONER DESTRO: That's the question I asked you though. If the parents come back and say, "we were misled," is there a possibility of a 504 violation, notwithstanding Judge Stevens' opinion for the plurality?

MR. GERSON: The reason that I answered that no is because the hospital, is a neutral in the sense that if the other decision were reached in the first instance, the hospital would have acted, in other words performed surgery, in your hypothetical.

It would not be a question of the hospital, in terms of Judge Stevens' opinion, denying treatment to an individual who was otherwise qualified, because of the lack--thereby, the lack of consent, or solely on the basis of the handicap. That never changes. The hospital doesn't make that decision. Whether or not the physician is on staff--in other words, the hypothetical that you raise is certainly worthy of consideration, but it doesn't have a 504 focus if you're not talking about a decision that the hospital itself makes.

COMMISSIONER DESTRO: Mr. Cooper?

MR. COOPER: Two quick points. First, as I testified here on the last occasion when hearings of this kind were held, the Baby Jane Doe case was indeed a case only in respect of information--no claim was ever made by the government in that case that any discrimination had taken place; we only sought information that was relevant to that issue.

With respect to your hypothetical, you will forgive me, I hope, Mr. Commissioner, if I refrain from responding to it. The hypothetical as you put it is remarkably closely tailored to a case that does indeed exist and is a 504 case that is proceeding now in a Federal district court.

The Federal Government has been requested to consider the possibility of becoming involved in that case by parties involved in the case, and that consideration is pending, so obviously it would not be appropriate for me to discuss the matter.

COMMISSIONER DESTRO: Okay. Another question.

I believe I heard Mr. Goodman say that, in reference to the amount of evidence that was before the Supreme Court in the Bowen case, that there was no evidence with respect to the dealings of child welfare agencies.

To your knowledge, is there any reporting mechanism where the government is collecting evidence that you felt would have supported the finding in the Supreme Court?

MR. GOODMAN: Well, the Department, of course put out the proposed rules for notice and comment and assembled a fairly massive record and undertook considerable investigation itself. And of course, as has been noted, what the case came up on was a very narrow issue of whether the rules were supported and were authorized by the statute, and in terms of the decision that the Court made, whether there was factual support. It had to be limited to what evidence the Department had when it made the rules.

COMMISSIONER DESTRO: And what about now? Would the American Academy of Pediatrics object to reporting requirements that ask hospitals and others to give them data with respect to the numbers of cases of handicapped infants being born and the kind of outcomes that those cases had, the kinds of treatment decisions or nontreatment decisions, which cases were reported, and which cases not reported?

Would that be objectionable to the Academy?

MR. GOODMAN: I think that depends on the detail. In other words, if the request is how effective the Child Abuse Amendments are in terms of are cases not being reported or being reported, that's obviously a legitimate enforcement goal, and something that--and since the Academy supported the Child Abuse Amendments and supports the infant care review committees, that's certainly something that would be legitimate.

But, at a certain point, it begins looking into, again, a review of decisionmaking in individual cases, and that, I think, the Academy would object to a Federal presence in.

COMMISSIONER DESTRO: In other words, the Academy would object across the board--am I understanding you correctly that the Academy objects across the board to the application of 504 to handicapped newborns?

MR. GOODMAN: The Academy believes that 504 does not apply to individual treatment decisions of newborns because it does not believe that they fit into the definition of "otherwise qualified" handicapped individuals.

COMMISSIONER DESTRO: Okay. And then the last question. I think this would be more for Mr. Ellis. In your experience, have you looked into the operation of the Child Abuse Amendments, both pre- and--well it's a little early to be post-Bowen--but how have they been operating? Is there any evidence? If Mr. Kemp has anything on that, or anybody else on the panel, on that particular issue, how do they operate and have they been effective, to your knowledge?

MR. ELLIS: Well, I don't have an empirical study of it, but I can give you some impressions with regard to it.

First, there are some substantial limitations of the way--in the structure of the Child Abuse Amendments that makes it an inferior vehicle for protecting these kids as compared to 504, and there has been nothing, at least anecdotally, with our experience with the Child Abuse Amendments' implementation, to suggest that those limitations have somehow been overcome.

It's a disjointed sort of way of getting at the problem. It only applies in those States that have--that receive assistance under the act. There are lots of limitations.

With regard to the committees themselves, I would hope that empirical study would be done, because anecdotal evidence suggests that they are very hit-and-miss as to whether or not they effectively investigate cases that are like the ones that have been under discussion here, and there is anecdotal evidence to suggest that some of them have not been very effective. And to place all of our civil rights enforcement resources in such a hit-and-miss kind of mechanism when the stakes are so high for the kids involved is distressing.

CHAIRMAN PENDLETON: Thank you, sir.

Mr. Kemp, go right ahead.

MR. KEMP: I think there's a bit of a problem in basing too much resources in the child abuse statute. Basically those statutes were set up so that doctors could report on parents that abuse their children, and this situation is sort of the reverse. We're asking them now to report on doctors who are denying treatment, and I think that this whole setup is bad for the protection of infants born with disabilities.

CHAIRMAN PENDLETON: I just have one or two questions.

Mr. Goodman, reading the interview summary of our staff's session with you, I am fascinated by your statement that, you know, what is it that we seek to compel or prohibit in this whole matter? I'm not quite so sure the public understands that and could you help us to understand what you mean by compelling or prohibiting what?

MR. GOODMAN: If I recall the statement, it was a question of--and I believe this goes to something that Justice Stevens wrote towards the end of the plurality opinion, which was what the actual--comparing what the Court or the plurality perceived as the goal of the regulations versus the goal of the statute. And the goal of the statute was very explicit--to prevent discrimination by federally financed entities. And the Court, or at least the plurality, seemed to perceive that the goal of the Department was to effect a change in the treatment of seriously ill newborns, regardless of whether that fit within the rubric of discrimination.

And I think that's very important, at least in terms of talking about 504 as opposed to a generalized goal. But in terms of the application of a discrimination statute, you need to find discrimination, and that is what was lacking in the record here.

CHAIRMAN PENDLETON: Just one other question. What is the future role for the Federal Government in 504 Baby Doe cases? What do we have here, what can we look forward to from the Feds?

MR. GOODMAN: Are you asking me?

CHAIRMAN PENDLETON: Anybody on the panel, I guess.

It really wasn't you, Chuck, but you can try.

MR. COOPER: As the only Fed on the panel, I guess I feel that all eyes are on me, Mr. Chairman. The nature of the Federal Government's response to the decision and what the Federal Government may do in this area as a regulatory, or as a litigating matter is under study. And I really simply am not at liberty to disclose what our thinking is at this time or what the considerations are.

Chairman Pendleton. Okay.

We want to thank you very much. It's a very distinguished panel. Thank you for your time, thank you for sharing your thoughts with us, and if there's anything else you want to say to us and tell us, you can surely do so for the record later on.

Thank you very much.

We'll take a short break.

[Recess.]

EXTENT OF DISCRIMINATION

Testimony of H. Rutherford Turnbull, Professor, Department of Special Education, University of Kansas; and Carlton Sherwood, Journalist, Annapolis, Maryland

CHAIRMAN PENDLETON: We want to move now to our second panel of the afternoon, and that involves Mr. Turnbull and Mr. Sherwood.

Gentlemen, would you please raise your hand so that I can swear you in as witnesses.

[The witnesses were sworn.]

CHAIRMAN PENDLETON: We will start with questions from counsel.

MS. HANRAHAN: Would you please state for the record your name, address, and occupation, Mr. Sherwood?

MR. SHERWOOD: My name is Carlton Sherwood. I live at 2661 Ogleton Road, Annapolis, Maryland, and I'm a journalist.

MS. HANRAHAN: Professor Turnbull?

MR. TURNBULL: My name is H. Rutherford Turnbull, the third. I'm a professor of special education and law at the University of Kansas. My address is at the University of Kansas in Lawrence. I am also a parent of a child with mental retardation.

MS. HANRAHAN: I understand, Mr. Sherwood, that you do have an opening statement. We are asking all witnesses, if they do have opening statements, if they could keep them to 5 minutes or less.

Professor Turnbull, I'll start questions with you, so if you do have an opening statement and you'd like to read it.

And then, Mr. Sherwood, we'll get back to you shortly.

MR. TURNBULL: Thank you very much. I do have an opening statement and I have three pages of written testimony that I would like to submit, Mr. Chairman, for the record.

CHAIRMAN PENDLETON: For the record it is so ordered. Thank you very much.

MR. TURNBULL: Thank you very much.

I would also like to include with that written testimony the Principles of Treatment of Disabled Newborns, which was signed in 1983 by a series of disability and physician organizations.

CHAIRMAN PENDLETON: We have no problem.

MR. TURNBULL: Thank you very much.

CHAIRMAN PENDLETON: It will be so included in the record.

CHAIRMAN PENDLETON: Mr. Turnbull, I don't know what time you had to write that, reading your resume, your vitae; I don't know what time you've had to write anything at all recently.

MR. TURNBULL: Mr. Pendleton, I've had a lot of help with this, thank you very much, sir. I'll pass those kind words along to people--

CHAIRMAN PENDLETON: Thank whoever it is. Thank you very much.

MR. TURNBULL: Thank you.

Mr. Chairman, Mr. Destro, I'd like to make six points concerning the issue before the Commission:

First, there is--and I think this is important to recognize--there is widespread contemporary evidence of attitudes among physicians and health care providers that justify a Federal role with respect to the enforcement of section 504 and the Child Abuse Amendments Act because that evidence shows, as the prior evidence did, discrimination by the medical profession with respect to the treatment and nontreatment of newborns with birth defects.

I would call your attention in particular to pages 4 through 5 and 8 through 18 of the written testimony that I have submitted. I would indicate to you now that I would ask your staff to refer in particular to the Syracuse University study involving the discrimination of children with Down's syndrome, a study that occurred through the years 1977 through 1982.

I would also ask the staff in particular to look at pages 10 and 11 of the testimony, where persons with mental retardation are characterized by a physician as persons who may be made into happy household pets.

My second argument to you is that although it is difficult to obtain data indicating the incidence of withholding that results in death, that data does occur, is available, and it is even fairly recent data coming into the 1980s. I draw the staff's attention in particular to pages 4, 19 through 21 of my written testimony.

Third, although the data itself is not the best available evidence, because obviously the reporting of that kind of incidence is sometimes difficult, there is a clear Federal role with respect to three issues, and that is, first, the monitoring of infant care review committees, second, the monitoring of the hospital human rights committees, and third, the monitoring of the State child protective service agencies.

Commissioner Destro, as well as Professor Ellis and Mr. Cooper, suggested to you this afternoon that there is a role for the Federal Government in monitoring. And I would say to you that because we do not have all the data that we need, that is a particularly important role at this point.

Fourth, there is another Federal role that I think this Commission should fix upon and argue for, and that is for viable alternatives where parents or physicians or other health care providers argue in favor of nontreatment of newborns with birth disabilities. And those alternatives include expanding the adoption alternatives, expanding foster care alternatives and, even though it is unpleasant for me to say so, expanding interim institutionalization, so long as those three alternatives work consecutively with and concurrently with active medical treatment as required by the Child Abuse Amendments Act, section 504 regulations, and the Principles of Treatment.

Fifth, contrary to the widespread belief of some professionals in the medical and health care field, to some professional ethicists and to other professionals that the quality of life of the child and of the family is horrific, I would argue to you and I can adduce evidence that there is a very positive quality of life of both the child and the family of the child. I draw your attention in particular to pages 27 through 33 of my testimony.

And finally, I dispute the predicate upon which Bowen's plurality decision rests: that predicate being that parents make the decision. I think that kind of aseptic view runs contrary to the published literature in the health field and it also runs contrary to some of what I have been told by physicians who are neonatologists, pediatric surgeons, and pediatricians.

I suggest to you that the process of decisionmaking is not one that is nearly so clean-cut as is represented in the Stevens' opinion and, for that reason, I think the factual predicate of Bowen is faulty and Bowen itself is faulty.

Thank you.

MS. HANRAHAN: Thank you, Professor.

With respect to the incidence and extent of discrimination, are you able to tell us any conclusions that you were able to make on the basis of research that you have conducted?

I refer specifically to your statements to me in an earlier interview that you've examined comments of parents submitted in response to proposed 504 regs and also that you examined certain data that you were able to uncover respecting the incidence.

MR. TURNBULL: Yes. There are six articles or reports ranging from the year 1973 through 1983 from which we can derive some sense of the amount of withholding of treatment that occurs. They range from 2.7 percent to approximately 47.8 percent; that's the figure derived from the Goss article of 1983.

In addition, I have discovered through the Freedom of Information Act access, the letters written to HHS as part of the public comment on the second round of 504 regulation. What I obtained were letters written by persons with disability, family members, namely parents, and other relatives.

As a result of analyzing those letters, it appears that there were 9 percent of the correspondents who indicated that there was an inaccurate medical prediction concerning the child with the disability and--I think this is related, but tangentially--30 percent of them expressed a loss of confidence in the health care providers.

I would be happy to introduce 174 of those letters into evidence. And Mr. Chairman, without objection, I'll leave them with you.

CHAIRMAN PENDLETON: Thank you, sir.

Without objection.

MR. TURNBULL: Thank you.

MS. HANRAHAN: Previously, Professor, I would like to refer to an article that you wrote which is entitled "Incidence of Infanticide in America, Public and Professional Attitudes." At different points in that article you discuss the scantness of the data that's available to determine the incidence of infanticide and also, a couple of times, reservations about the accuracy of the data. Given that, what is the reliability that one could fairly place on the conclusions that you were able to draw from that data?

MR. TURNBULL: I believe the reliability is not nearly at the 100 percent level, but on the other hand, the fact that the articles, the six articles, have been published and show the incidence of child abuse to be what it is, and that the articles are written by physicians and health care providers themselves, I would have to say that the reliability is fairly high.

Precisely because it's not as high as we want it to be as a matter of science--not as a matter of law, it's plenty high for that--I would think that the Federal Government has to monitor ICRC's [infant care review committee], the human rights commissions and the State CPS's [child protection service].

MS. HANRAHAN: Are you able to draw any conclusions from your research on whether cases of discriminatory withholding of treatment are on the increase or on the decrease and, if you see such a result, what are the influences that have brought about that result?

MR. TURNBULL: I can't really answer that with any certainty. What I suspect is that on the one hand we have perhaps overagressive intervention of a kind that may not be warranted by the Child Abuse Amendments of '84. On the other hand, I suspect that we are finding out less about cases of unwarranted treatment, unwarranted under the Child Abuse Amendments. And so, I don't have any data to give you and I don't think anyone else does either.

MS. HANRAHAN: Can I ask you, with respect to your findings about the incidence of discriminatory withholding, what form does that discrimination take and, specifically two points: Do you find that discriminatory attitudes are more prevalent in, say, physicians or certain classes of physicians such as pediatricians or neonatologists, parents or professional social workers? And secondly, do you find that the discriminatory attitudes vary according to the nature or the severity of the disability?

MR. TURNBULL: I think that discriminatory attitudes are held by the following groups of health care providers, because these are the ones reported in the literature: pediatricians, neonatologists, pediatric surgeons, and nurses. I think that the attitudes do not limit themselves to a certain kind of child, although there are discussions by the respondents in these surveys and by people--health care providers who don't respond to surveys but who write--indicating that it's not just the child with the multiple, severe/profound disability who is the subject of discrimination but it is, as well, the child who has simple Down's syndrome or simple spina bifida.

And I would draw your attention to Dr. Strain's testimony before this Commission in 1985 in which he indicated that most children with spina bifida and most children with Down's syndrome are now being treated and I would suggest the negative inferences that some are not.

MS. HANRAHAN: Thank you, Professor. I'll turn the questioning over to Mr. Pascale, who will speak to Mr. Sherwood.

MR. PASCALE: Mr. Sherwood, I understand you have an opening statement that you'd like to read?

MR. SHERWOOD: Yes, I'll try to keep it brief. As I said earlier, I'm a journalist. I've been one for 18 years, both as a newspaper and television correspondent.

Since 1983 I have authored three separate indepth series dealing with so-called Baby Doe cases, two for television and one for print. Roughly speaking, I have devoted about 18 months of direct field research to the subject and perhaps another year of study on Babies Doe and the host of related medical, social, legal, and ethical issues.

During the course of my research, I traveled to 28 States, visited 19 intensive care hospital nurseries, and interviewed more than 250 physicians, nurses, lawyers, hospital officials, and parents who, at one time or another, were directly involved in Baby Doe cases.

In all, my research staffs and I reviewed upward of 700 cases where there was a probability that infants died as a result of decisions to withdraw medical treatment. From that number, we targeted 300 cases where there was an admitted or a high degree of certainty, based on first-hand eyewitness testimony, that nonheroic or extraordinary medical care had been withheld based solely on the real or perceived presence of a mental or physical handicap.

Of that 300 we targeted, approximately 120 cases were acknowledged outright, sometimes in writing, by the physicians who actually took part in the process. So there's no misunderstanding, these were instances where it could be said beyond any doubt that newborns who otherwise would have been provided with routine but life-saving treatment--sometimes just food and water--were deliberately deprived of that care because of the presence or anticipated presence of mental or physical disabilities.

On a secondary level, we were able to document through records and the supporting testimony of other physicians, nurses, and parents directly involved, an additional 27 incidents where beneficial medical care was withdrawn or withheld because of a real or perceived mental or physical handicap.

Now the methods we used in this were neither scientific nor normal journalistic practices. The organizations I worked for, realizing that there was a high potential for litigation in dealing with so many doctors, brought in teams of lawyers, so consequently we were put in a position where we had to develop these stories according to the rules of evidence in a courtroom.

Also, we were excluded from looking at the so-called hard cases; all of our research dealt with the easy cases, that is to say, infants who would have lived with nonheroic care.

Interestingly, we never got sued.

Although these restrictions severely hampered our research and limited the number of cases we reviewed, there was the beneficial effect of having developed a solid, incontrovertible body of evidence that, at the very least, presented a conservative overview of the practice of denying medical treatment to a select group of newborns.

All this is not to suggest that my reports went unchallenged by the doctors, although no physician ever confronted me directly with that.

One of the things we did find while we were doing this, before, during, and after, was a pattern of reactions among physicians. The first reaction among most physicians we talked to was simply to deny it ever happened. I would argue if that were true, then why would this country's most prestigious medical journals publish detailed accounts--some of them how-to manuals--chronicling the programs where handicapped newborns have been systematically eliminated en masse?

Better yet, if these things never occurred, then why have the country's leading medical associations been so adamantly opposed to even civil prohibitions against such practices as withholding food and water from handicapped newborns?

The second fallback position that we ran across with physicians dealt with something like this: Well, maybe there are some rare cases like the Bloomington, Indiana, case, but the medical community doesn't condone this type of practice.

Again, I would point to the volumes of medical literature on this subject that has already been published, not to--to say nothing of the textbooks in the medical schools which actually teach that there is an option whenever a child is born with a handicap--whether or not they have to treat.

Physicians and spokesmen from medical organizations frequently render off-hand criticism of nontreatment incidents. Yet you'll note that not one physician or medical organization has ever formally or informally filed a complaint against any of the physicians who conducted these experiments, including Bloomington, Indiana.

Indeed, rather than being censured, several of the physicians went on to more prestigious hospitals where they continue to practice medicine, and some even teach, presumably, the same methods that they were practicing when they authored these articles.

This fact alone, I submit, says more than any poll or survey concerning the true attitudes of the medical community. It also belies assurances by medical organizations who have testified here that they can or will police their own profession without outside interference.

A third frequently argued position by physicians is that the newborns in question suffer from a host of--quote--other life-threatening anomalies--unquote--in addition to their birth defect and that I and other laymen oversimplify the seriousness of the illness.

My usual reaction to that is to ask to see the medical records; and, of course, no one has ever done that, even when I have secured parental permission to see those records.

On several occasions, however, I was fortunate enough to have the medical records before I interviewed the physicians, and let me tell you what some of the other anomalies, the other serious anomalies, were.

According to the medical charts of one baby boy with spina bifida we looked at, there were the additional complications of a hernia and an ear infection, both of which went untreated.

Another spina bifida boy also developed bronchitis, but because antibiotics might have saved his life and prolonged it, none was prescribed to alleviate his chest congestion. He died.

A Down's syndrome baby who had an esophageal atresia also suffered from a hernia and a kidney infection. This severely handicapped child died after 23 days; he died of hydration which, I'm told, is a remarkable feat for any healthy baby.

I don't mean to minimize the seriousness of the problems associated with some birth defects or to suggest that these infants won't need medical attention throughout their lives; in all, probably they will, many with surgery. What I am saying is doctors frequently exaggerate the degree of the handicapped newborn's illness in an effort to justify their decisions and their prejudices.

To bring that point into sharp relief, I would ask each of you to consider for a moment what would have happened to Baby Jesse or Baby Nicky if they had been born with Down's syndrome or spina bifida. Do you think any physician would have recommended them for a heart transplant? Do you suppose there would have been a national effort to find heart donors? Can you imagine, after all the testimony you've heard, that a hospital and doctors would be out front volunteering to perform this risky and expensive surgery?

As a historical reference, it should be noted that just 3 years ago and only miles from where these infants are being treated today, another boy, 12-year-old Phillip Becker, also needed a heart operation to survive. Phillip's problems were minor compared to Jesse's and Nicky's, yet it took a year and a half of litigation and court appeals to secure the operation. There were no pleas from the media or gestures of support from the medical community for Phillip. Why? Because he was retarded.

As a final last-ditch position, many physicians claim that it's the parents, not the medical staff, who actually decide so-called nontreatment plans. Frankly, I find this argument despicable, not just because it's false, an outright lie, but because it's used to shift blame and guilt to those who have already suffered a tragic loss. By any standard, an unconscionable and cowardly act.

For the record, not one parent we interviewed--and we spoke with several dozen who were personally involved on both sides of the treatment issue--not one said they took any initiative in the decisionmaking process; invariably, it was the physician, often teams of physicians, who approached the parents and recommended, strongly and persistently sometimes, for a course of treatment or nontreatment.

In all but a few cases, the parents said they went along with their physician's recommendations and would have followed the same doctor's advice had his recommendation been different.

All, and I emphasize all, the doctors we spoke with confirmed this decisionmaking process. Even physicians who directed nontreatment experiments--like Dr. Richard Gross from the Oklahoma Children's Hospital--admitted on camera that it is the medical team that decides the course of treatment, and that parents merely rubberstamp those decisions.

Incidentally, all of this is done verbally. We never encountered a case where a physician put his recommendations in writing. Likewise, when death was being discussed, parents were rarely, if ever, told exactly what method was planned. Euphemisms like "let nature take its course" cover everything from starvation to deliberate efforts to infect the newborns. One can only speculate what would happen if doctors were required to put their nontreatment recommendations in writing and spell out clearly for parents what it was they intended to do in their names, along with the consequences of such actions. Which brings me to my final point, Mr. Chairman.

Through deceit and large doses of Orwellian doubletalk, some physicians and medical organizations have managed to frame this entire subject as a parental rights issue. That is ludicrous. Strip away all the self-serving, vague and convoluted rhetoric, and it all boils down to a matter of medical authority: the rights of physicians to eliminate, to kill infants they believe might be a burden to their families, society, and themselves, and to do so without any legal or governmental interference.

By any name--call it a process of selection, as physicians themselves do--this clearly qualifies as a discriminatory practice and, at very least, represents an egregious violation of civil rights.

That concludes my statement.

MR. PASCALE: Thank you.

How widespread do you think this--among physicians--is this attitude you just mentioned, about their feelings that handicapped newborns should be eliminated? Is it limited or is it among most physicians, in your opinion?

MR. SHERWOOD: From the physicians we talked to, it was pervasive within the pediatric community, which is a very small section of the medical community. One of the things we found interesting as we talked to other doctors, general practitioners and surgeons, and so on and so forth, is that many of the doctors, other physicians who worked in the same hospitals with pediatricians, didn't know anything about this.

I live in a neighborhood where there are three doctors, thoracic surgeons and so on and so forth. They didn't know anything about it, although their wives, who were nurses, did. It didn't make for very good summer conversation out on the back porch, I can tell you.

MR. PASCALE: So you think it's pretty widespread among the pediatricians in this country?

MR. SHERWOOD: I think the attitude is pervasive, the attitude that these children are disposable is pervasive. The practice--since the spotlight has been put on it in 1982, I think it probably has been cut down somewhat, but it still goes on and goes on--I think it's widespread. And they're probably a lot more careful about it.

MR. PASCALE: What do you think accounts for this attitude? Why do they feel this way, anything in their training or tradition?

MR. SHERWOOD: At the risk of playing armchair psychologist, one of the things that we couldn't help--my staff and I were looking at this after we interviewed. The people we interviewed were some of the leading men in this field, at Yale, at Harvard, at Johns Hopkins, in Seattle, Chicago, and one of the things, a couple of the things we came away with--

One is that many of these gentlemen went through medical school at a time when technology was coming in full force. And I believe, because we've talked to them and they told us horror stories, that many of them were traumatized by the overuse of machines early on in the late sixties, and they carry that with them into their practice. Consequently, there is a--it's almost a rebellion within this group, if you will, this 40 to 50 age group of physicians who are now at the top of their forum or the top of their profession--it's almost a rebellion against the use of technology. They saw a lot of abuse of that. That's one.

Two, by their very nature, the people that we interviewed, the doctors, are very competitive; these are the best and the brightest in the business. And they, themselves, are not accustomed to dealing with anything less than perfection.

In fact, one of the doctors we talked to, the chief of neonatology at Harvard, even referred on camera in his discussion to being part of the creation of something that wasn't perfect as though he--it was a slip, it was a Freudian slip, obviously--but they see it that way. And I think third--and this is maybe the most important--we talked to these physicians. They're making decisions based on other reasons than medical reasons; they're basing them on what their perception is of the parents, the financial resources of parents, and they say that right out.

And there's a cultural bigotry, if you will--it's not conscious, but it's there. These fellows are living on an entirely different stratum. I interviewed one doctor who had a black eye from a squash game he just played; both his kids go to Ivy League schools; he's got a yacht and he's got a horse farm. And he is making decisions--he told me he was making decisions--based on what he thought this child's life potential would be in the real world. Well, his real world is not mine, but that's where he's coming from, and that's where these other fellows are.

MR. PASCALE: Thank you.

That's all I have, Mr. Chairman.

CHAIRMAN PENDLETON: If my colleague will let me, I want to stumble into a question.

A year or so ago, the Chicago Tribune did a series on Lawndale in Chicago and the conditions of the black community of Lawndale. And one of the stories in the series that caught my attention was about a third-generation, young black woman, maybe 15--third-generation welfare, 15 years old. And it had her picture there in the maternity ward in a hospital. And she says, "I want my boo-boo." That was her term for baby.

And in reading the story, you got a real frightening sense of what goes on with teenage pregnancies that are on the rise in this country.

Let's face it, among blacks and whites, the numbers are astounding.

But what really caught my eye that relates to this situation we're discussing today is the fact that this young lady only had one prenatal visit, and she gave birth to an 800-gram baby. That child had to stay in the hospital in neonatal ICU [intensive care unit] for something like 3 months, and the young lady visited the hospital twice in 3 months.

When the social worker went to the home they found out that there was no space at all for the baby at home; there were no swaddling clothes, if you want to call them that, there was absolutely nothing for the baby to go home to, and nothing to wrap around the baby to take it from the hospital. Certainly we can assume that there are going to be some effects of that low birth weight and the treatment of life at some point down the line.

I guess what bothers me is: Are we going to see this situation on the increase because of, as you call them, the cultural values of society. And in your terms, in your area, Dr. Turnbull, of special education--and we have all this attention to teenage pregnancies and the like--what do we do in the interim?

I am not being judgmental about what we do when we treat people and I'm certainly not getting into the abortion issue at all. What I'm saying is that I am appalled that this is the second hearing that we've had and there's nobody black here from any black organizations, as I know them, dealing with this issue. And we wind up with one out of two black teenagers in this country, I think it is, winds up as a possible teenage pregnancy victim. How do we transmit a lot of what we know to be conditions in the attempt to return to traditional cultural values?

And when I said I wanted to stumble into a question, I meant that by citing a situation that is disturbing to me. I mean, this Commission gets criticized for its attitude about civil rights. We talk about racial situations. This thing we're talking about now, Babies Doe or Baby Does, is not a racial situation at all. I think when Bob and I went over to see the tape in Secretary Will's office, that was a black child, what's his name, Carlton Johnson, that--

So what do we do? I'm trying to take us a bit of the racial realm, but you've got to be at the table to understand what really goes on. And how do we use what we have here in this kind of a hearing to disseminate the information?

I could go on and on and on, but I'm probably not asking a question, I'm making a statement, looking for some kind of response. But I am really concerned about what kind of future we are developing, and if there's a need to take care of the conditions as they exist. Do we perpetuate that, or do we take the knowledge we have here and pass it on as to what the conditions can be in the future?

MR. SHERWOOD: Just let me respond real quickly to one thing. In one case or one series of cases we looked at, you mentioned the child's name, in Oklahoma. There was no question that the underlying factor in that wasn't just the handicap, it was also the racial makeup--primarily because that was the lower end of the financial spectrum. And that was the equation on which they developed this program where they eliminated children whose social stratum and financial stratum was lower.

For reasons that I don't understand, and I think some doctors don't either, there is a disproportionate number of black children in the southeast and southwest who come down with spina bifida. And I've always wanted to get in an organization that would give me enough money to go down there and look at those hospitals--these are rural hospitals in Arkansas, South Carolina, Georgia, and the rest, Louisiana.

If you're challenging me, I'd just throw it right back in your court. It is--it's racial, it's racial because it's economic, and it's economic because it's racial. Just--one follows the other.

CHAIRMAN PENDLETON: I'm not challenging you, I'm just trying to put out a condition that I, you know, that exists and to say that it may have those implications to it but--

MR. TURNBULL: Mr. Pendleton, let me suggest four responses, if I might.

First, obviously, the issue of parent education is a way of dealing with the teenage pregnancy issue and also with dealing with pregnancy at any age where the education consists of training on how to be a good pregnant person and then how to be a good mother. And I think that that's one avenue into this problem.

A second avenue has to do with prenatal, perionatal and postnatal care, and the allocation of medical resources, specifically with respect to those kinds of care.

A few months ago I represented the American Academy of Pediatrics, and I was preparing testimony as part of a hearing we were going to have with Secretary Bowen. Unfortunately, the hearing was cancelled and we never had a chance to meet with the Secretary. However, in preparation for that testimony, Dr. Al Healy of the University of Iowa, a very good friend of mine, a man with whom I've worked a lot on the Academy's business, suggested to me that one of the arguments he was going to make to the Secretary was that a redistribution of medical care might be a way of getting at a prevention, and certainly a postnatal care system that is better than we have today.

Third, the Federal Government can do a whole lot more with respect to prevention of disability. The labeling of cigarettes ought to be carried forward to the labeling of alcohol. There is a perfectly clear syndrome, called fetal alcohol syndrome, that can be the subject of a public alert. Lead-based paint--we all know about that--but we also know about the insufficiency of the Federal response to that. Women, infants, and children programs, nutrition programs, again, an insufficient Federal response. So a way of getting at the kind of situation that you describe for Lawndale is by stepping up the State and Federal efforts at prevention.

And fourth, and finally, I would emphasize the early childhood education of children with disabilities. I very much approve of the emphasis on taking the age range for education, optional or mandated, down to as early as possible. And second, as part of that special education, extending access to people with disabilities into other kinds of ameliorative programs.

We talk a lot about section 504 here, but we haven't talked an awful lot about the nonaccess that people with disabilities have to the generic, that is to say, nonspecialized services when they're growing up and when they're adults. And I would think that a good Federal role would be to especially enforce 504 with respect to those areas of preschool education and post-school education. Fortunately, we have a competent, committed Assistant Secretary of Education who has drawn our attention to those things, but there's a lot more to be done.

CHAIRMAN PENDLETON: Thank you very much.

Mr. Destro?

COMMISSIONER DESTRO: Dr. Turnbull, could you address with the literature--you may have said this already, I just want to make sure that I've got it on the record. What does the literature say with respect to parental dependence on medical advice in the decisionmaking process?

MR. TURNBULL: In summary, Mr. Destro, it says that physicians set the agenda. The person, as anybody here in this room knows, who has the ability to set the agenda has to a large degree the ability to control the outcome.

Second, that the information provided by physicians to parents is not always the thorough information that is requisite to the legal doctrine of informed consent, with emphasis on information.

Third, that there are factors other than purely medical factors that physicians present to parents as legitimate considerations, mainly having to do with quality of life and economic burden.

And fourth, that the process itself is not a clean, logical process in which information is given to parents cooly, rationally to have an opportunity to respond to it. It is a far more dynamic situation than that and because of the interrelationship of what is given, the mode in which it's given, the attitudes behind what is given--and the parent decisionmaking process is not what the Supreme Court thinks it is--it's a much more complex matter than that.

And the power relationship that Mr. Sherwood talked about, and others have talked about, permeates that relationship, so that the person with power is the person with knowledge. And it's that kind of power relationship that we simply don't want to look at as the law, but I think it is inevitably there.

COMMISSIONER DESTRO: Would both you and Mr. Sherwood address the question that basically Justice Stevens raised in his plurality opinion for the Court, which is that there really isn't any evidence that such rules were necessary? Given the reports I saw that you did, Mr. Sherwood, and the literature, some of which was even cited in the Supreme Court opinion, I'm rather baffled about how the Court was able to come to that kind of a conclusion.

MR. SHERWOOD: Let me take this. First of all, let me go back to your other question. I have a little anecdote. The child you saw in that tape, Carlton Johnson--let me tell you how his mother was informed. A team of five surgeons and a social worker--five doctors and a social worker approached her within minutes after she gave birth, while she was still under sedation, and described to her in medical jargon or legal jargon spina bifida and what would have to be done. They told her her child was blind, they told her he'd have to have a shunt put in his skull, that he would need all these operations, that he would be crippled in any case, and he would die within a year; even if they operated, he would die within a year.

Now she described the shunt as a pipe--she said they described it as a pipe they would have to screw into his head that would come out and come down into his stomach--this is while the woman is right out of the delivery room. That's the informed consent that she got. She was led to believe, she was told, that it would be almost inhumane to operate, that they could operate but he would die within a year anyway. And of course he was still there--the photographs you saw were a year and a half later, he just wouldn't give up.

In terms of the proof, everybody's relying--or everyone seems to rely on HHS' [Department of Health and Human Services]--quote, unquote--investigations of 69 or 169 cases. I could sit here and bore you to tears with the cases they didn't investigate. Oklahoma is a classic one; they never investigated that although there were telegrams sent to HHS to do that.

They never investigated Yale-New Haven, although a State senate committee spent a year investigating that case and formally requested the Justice Department and HHS to investigate that case. The first letter was lost behind a file cabinet at the Civil Rights Division of HHS. This is true. They had to resubmit another letter. A year passed. Not one response from HHS or the Justice Department.

I called them and they finally sent a letter acknowledging--this is to Connecticut now--acknowledging they were going to look at--this is three starvation deaths and one death by lethal injection--they sent a letter acknowledging that they would do an investigation. Another year passed; they never sent anyone down there to do an investigation.

I just talked to the Senator 2 weeks ago, a week and a half ago, when I knew that I was going to come here. It's been 5 years, nobody has even lifted the phone to call Yale-New Haven.

Most of those investigations HHS says it conducted--and I can tell you this because we did, my staff and I, called the hospitals--consisted of a phone call, not a visit, a phone call, merely asking the hospital if they would turn over their records so that HHS could look at them, and they were denied in every case. Only one incident did we find where somebody actually--one person actually--went into a hospital and said, "Can we have the records?" and the hospital said, "No, get out of here," and they got out of there. That's it. They were never investigated.

Now to be fair to HHS, they're not qualified to investigate these types of incidents. These are essentially murder--not to exaggerate--but these are essentially murder investigations or homicide investigations.

CHAIRMAN PENDLETON: I asked you that question.

COMMISSIONER DESTRO: What about, do you see, in your experience in dealing with HHS or other Federal officials--and certainly if you want to expand that to include local officials, because we have also talked about the State child care and child abuse agencies as well--I mean, do you see that the attitudes affecting the pediatricians and the others also affect OCR at HHS, and that either it's not important enough or that they're just handicapped infants or--I'm trying to get a sense for why this wouldn't really incense the agencies.

MR. SHERWOOD: In my experience, the State child abuse--they consist of the same people, these are basically social workers, these are not criminal investigators. And they work hand-in-glove with the local hospitals for child abuse reports; they're one and the same. Some of the State child abuse agencies actually have offices in the hospitals where they actually work right there so the physicians can report something. They know these guys, they work with them.

Why do you think the AMA and the rest of these organizations are willing to let the State child abuse agency come in and look at anything they want to but not somebody from HHS? They're friends. They work together, and they also know--these organizations are notorious.

You've got a case right up here in Baltimore where they failed to report--a child died as a result of their reluctance to move on a parent who was abusing. They had a case out in Texas where for 5 years they had had evidence that a mother who was psychiatrically ill was abusing three of her children; that was just on 60 Minutes. These organizations are notoriously loathe to move against parents anyway.

MR. TURNBULL: Mr. Destro, let me come back to your next to last question. I don't know how to explain the insufficiency of the record for HHS, but

I would hope that the record being developed here would trigger a hard look by HHS at what the record is so that new regulations under 504 might be promulgated. I think we're doing what--doing here what perhaps should have been done, clearly should have been done before in HHS, and that is giving a sufficient factual basis for regulations under 504.

COMMISSIONER DESTRO: Let me ask a couple of other questions.

One that I wanted to ask Mr. Sherwood, it's a bit off the point, but you, I understand, have won both the Peabody Award and the Pulitzer Gold Medal. You have won those awards, right?

MR. SHERWOOD: Yes.

COMMISSIONER DESTRO: And could you just tell me what the difference between the Peabody Award and the Pulitzer Gold Medal is?

MR. SHERWOOD: The Pulitzer is for print journalism, the Peabody is the--for television, that's the equivalent for reports for television.

CHAIRMAN PENDLETON: Just a minute. How did you get somebody to give 93 spaces, 93 shows, it was 93 hours--what was that?

MR. SHERWOOD: --a 93 part series on child abuse--

CHAIRMAN PENDLETON: How did you get a 93-part series?

MR. SHERWOOD: I'm very persuasive.

CHAIRMAN PENDLETON: We need to talk to you. We've got a little problem.

MR. SHERWOOD: Can I have more time?

[Laughter.]

COMMISSIONER DESTRO: All right.

I wanted to ask--both of you have raised it in different ways: Could you talk a little bit about the relationship of physician and hospital attitudes toward the treatment of handicapped infants as it crosses over into the treatment of handicapped individuals generally?

You mentioned the Phillip Becker case, a case that I was involved in, as an amicus brief writer back in California. And it seems to me that the theory of the Baby Doe case really has no stopping point: if you presuppose that the surrogates are making the decision, it really doesn't make any difference whether or not the object of the decision is 3 days old, or 35 or 51, or 87. Is that a true statement or am I exaggerating a bit?

MR. SHERWOOD: Very quickly. During the course of our investigation, I had to interview the vice region of the AMA in Atlanta and his specialty is geriatrics. And as soon as we sat down the camera just started: "I don't know why you're looking at Baby Does, you ought to be looking at Granny Does," he says, "that's where the action is, son."

This goes across the board. This is--look, let's not kid ourselves, this is just a foothold, the door is opening with this. See once they get--once the medical community gets you-all and everybody here in town to give them sanctions to move in this area, to have the latitude to make these decisions--it's already started. I mean, you've seen the Court decision--it's going to go right up, it's going right up to everyone, including us Yuppies, somewhere in between. If we are unconscious long enough in a hospital, we're not going to have anything to say about what happens to us. If somebody decides that I'm a writer, my hands are broken, what's my quality of life.

Now maybe I'm being facetious there, but I had posed the question. I dealt with doctors up in Harvard. I asked them--they had a little girl on the eighth floor who was brought from South Africa at great expense. She was born without an intestinal tract. And I asked them--they had her up there for 3 years and had done some wonderful things, but she was still bedridden--and I asked him how much they had spent on her and he said roughly between $4 and $5 million. And I said hypothetically, "What would you have done, would you have done that, would you have operated on her if she were retarded?" And he just stared at me. I said, "Okay, how about if she were missing an arm?" He looked at me. I said, "How about if she were blind?" He said, "I'm not going to answer those questions." I said, "Well all you have to do is say yes, we would have operated on her if she were retarded, if she were born with one arm, if she were blind." The fact of the matter is they wouldn't have. He could have said they would have, but they wouldn't have. She wasn't worth saving. She happened to be cute as a button, a beautiful, white, blue-eyed, blonde-haired girl, and her parents had some money and, I suppose, some influence.

MR. TURNBULL: I think the Bowen case is troublesome for a lot of reasons, but one of them is precisely the one you suggested, Mr. Destro, and that is that it's not cabined or contained according to the age of the person; it's cabined or contained according to a factual predicate that I disagree with.

CHAIRMAN PENDLETON: Mr. Howard.

MR. HOWARD: I'd like to address a question to Mr. Sherwood.

Near the beginning of your statement, Mr. Sherwood, you referred to 300 cases that you had isolated, I think, of 700, and you used the language "heroic or extraordinary treatment" and then you also mentioned something about the withholding of routine but lifesaving treatment.

It seems to me those expressions are inconsistent. I wondered what you meant--if you could clarify what you meant when you said those things and if you could just generally address what criteria a doctor should use, if any, in withholding medical treatment from the handicapped.

MR. SHERWOOD: What we did is we sat down with these legal teams, and what we tried to do is define for ourselves what language we were going to use. Already the Bloomington case started to create a whole new language for reporters: nontreatment, for instance; a nontreatment plan was considered to be treatment. Not in my neighborhood it isn't. And we had a problem, we had a problem with a lot of the language.

Now, what we did is we tried to define for ourselves what other physicians outside of pediatrics would define as extraordinary and heroic treatment. Certainly, keeping somebody on life-support systems for months with no hope of recovery is extraordinary and heroic. Certainly, operating on somebody for 8 or 9 hours replacing organs is heroic and extraordinary.

We were not allowed--we targeted these 300 deaths, we looked through death records of various States. It's very easy to do, I don't know why somebody hasn't done it. It shows right up, the death records, the doctors who signed the most death records for cardiopulmonary arrests for infants who were just born in a 9-day period. You go and talk to them.

But what we did is we had to draw a line. We were only allowed to look at the easy cases, not the hard cases, the cases where--no matter what was done. And the easy cases--in cases of spina bifida, antibiotics, we considered that--we determined that was routine care, although some doctors tried to argue with us, but not the people. It was a simple injection. Some doctors actually want to make that extraordinary or heroic care. We determined that was routine care after talking--getting a consensus from many physicians.

Closing the back, not performing any extraordinary surgery, going in and trying to do anything, just simply closing the back: we considered that to be routine care, not heroic, not extraordinary.

In the case of Down's syndrome, an esophageal or a duodenal atresia--that's a simple, they call that a zipper operation--we consider that to be routine, nonextraordinary and nonheroic care.

Food and water, I say food and water--we decided food and water--I had to argue with doctors over this even, that food and water was not routine care. You saw just recently the AMA came out with a statement of principles on that, and apparently they want to make that also extraordinary care in some cases, food and water.

So those--am I answering your question specifically?

MR. HOWARD: Yes, I think so.

MR. SHERWOOD: Very good. If it was inconsistent, it wasn't meant to be.

MR. HOWARD: Do you have a copy of that AMA statement? I don't think I've seen it.

MR. SHERWOOD: No, I don't have it with me.

MR. HOWARD: Could you send it?

MR. SHERWOOD: Sure. I think that was issued in January. When was their last convention this year?

CHAIRMAN PENDLETON: You've got me.

Well gentlemen, thank you very much for attending and for your precise and candid testimony.

MR. TURNBULL: Thank you, Mr. Pendleton.

MR. SHERWOOD: Thank you, Mr. Chairman.

OPEN SESSION

Testimony of Connie Martinez

CHAIRMAN PENDLETON: Before we have a break, could Ms. Martinez give us her statement, if you would? Come right up here.

I hope that we will accommodate you to catch your plane on time.

MS. MARTINEZ: I hope so, too.

CHAIRMAN PENDLETON: What time is your plane?

[Discussion off the record.]

CHAIRMAN PENDLETON: Ms. Martinez, go right ahead.

MS. MARTINEZ: Long ago--My name is Connie Martinez--also Dee Dee Concert.

Long ago, a doctor tell my parents that I'm going to be retarded, I would not function. Well, like I was teenager I have--my parents take me to a doctor, you know. And I was sitting down on the chair waiting for the doctor, and a nurse gave this test--I don't know what kind of test, but a test. I imagine it tells you intelligence or whatever. And she was very snob and very rude. So I do my thing.

The time I wait 'till they call me I would picture the doctor--I mean I never meet him before. And I would picture him. He was a heavy white doctor with a cigarette, put his desk on his foot and already judgment. I have not seen him.

After they called me and I went in there, my God, it was true. He was a heavy doctor with a cigarette and he just looked at me, and I say I'm not going to have a chance. It's been a while, but I am able to tell you this. He was saying Connie--Ms. Martinez, you are going to--I was looking at the test and was telling me that you cannot function, you have to live with your parents. I understood you get mad and all that. And I said do you get mad, too?

And then he was saying a lot of things and I was getting--I can't exactly remember what he said--but whatever he say it really make me really mad. And then he was saying Ms. Martinez. I said, hey, you're telling me that I can't function, you're telling me that this is it. And I--you're not God, how many people you lock the key and you have the power, you are not God, and whatever you're telling me one day I will prove it.

I got news for you. I tell you what I did. I go to independent living, I went to classes at what's supposed to be adult school. Hogwash. It's not, it's retarded. If you--a bunch of people, a lot of people, you do not function. And that's everybody, the black, chicano, every mix, they're denied to grow.

I started to--inside my gut tell me it's time for me to move on. I studied to be independent. What happened? As a teenager, one of the teachers convinced my mother to let me go. She would not let me go, and I asked her why? Because I'm your parent, I don't need to give you a reason. To make the point, the teacher did her way to let me go. All except I have that feeling to be independent, but to be independent--being involved with people first--I see a lot of things what's going on.

One of my friends had been in a workshop, left there. What I've been is an art student at the art school. It's the same thing. I was going to teach modern dance. Of course they've got a staff for modern dance, but in passing let me tell you the result. I've been there and I can tell you it stinks.

Long ago my friend--he works for me--named Bob, he had to have a piece of paper--would you explain it, Bob, what I'm thinking?

MR. ROSENBERG: To identify myself--I'm--

CHAIRMAN PENDLETON: Thank you.

MR. ROSENBERG: I'm Robert Rosenberg and I work for Ms. Martinez as a facilitator. She was appointed by Governor Dick Deukmejian last year to the California State Council on Developmental Disabilities.

What she's referring to is a so-called adult school that she was forced to attend in Sacramento for some years which recently advertised for an aide, and the advice of vacancy circular read adult school for mentally retarded was looking for an aide, a teachers' aide, responsibilities would be to remove the children's galoshes, to supervise the children on the playground and to help the children mix clay for arts and crafts.

The--we have brought for the Commission a copy of a report that Ms. Martinez and colleagues of hers in an organization called People First prepared that is called "Surviving in the System: Mental Retardation and the Retarding Environment."

MS. MARTINEZ: Let me say something and let me--the people who are there, they are not a child, they are 21 and over that, attend me, they are my familia, I don't care what color their skin could be: black, or pink, or blue, for me they are my familia. You start being used to there--if somebody decides for you--I thought, and I must admit I thought it was the best thing, you know, somebody decide for you.

And so I went to this place. It wasn't happy, it was just a grey building, you know. And I was bitter, I didn't like myself because you have a negative end of the world, you know. You don't have nothing to give this world. And so I started to believe that. But there were some people who cared what I speak, and somebody listened to me and somebody give me a chance to grow.

At the same time, I'm here to speak up. I want to give a chance to my familia and, again, black or blue doesn't matter, I want to give them a chance. And I know there's a lot of people in my case is there and I want to be the one open the door.

It offends me that people who's making a living saying this is a best thing. It's a babysitting place, it's babysitting. And they think it's a bad thing. Well I've got news for you, it's not a bad thing, and people say for years and years that retarded people cannot function or retarded people don't know how to dress up. You poor child, we do you a favor. Hogwash.

They also remind me I can't cuss a lot. I say, hogwash.

CHAIRMAN PENDLETON: We'll just cut it out. You can say it, but we'll just delete it.

MS. MARTINEZ: But it really offends--who is making a living. I tell you, it's not us.

One of my friends, Tom, he wanted to make a table, you know, make a table, and they led him to believe that is not enough. Hogwash.

And the point is the day that he was involved in People First he speak up, he didn't mention the name of the workshop or nothing, and when he went back one of the--the head of the workshop say "How dare you stab me?" He didn't mention the name, he just speak up. This is United States, this is not Washington, this is to speak out. And they angered him--you know, was angered because he speak up against them. And this is a fact.

CHAIRMAN PENDLETON: Well, thank you very much, Ms. Martinez. We'll have your information put into the record. And if you have anything else you want to send to us, please feel free to do so.

MR. ROSENBERG: If I might, sir, we have included with the information we brought an issue that you may wish to keep an eye on, it has to do with substitute consent for sterilization of the retarded, which is rearing its ugly head in California.

CHAIRMAN PENDLETON: Could you please tell us, Mr. Rosenberg, what the--or Ms. Martinez, what the Developmental Disability Council does?

It's not a question, Mr. General Counsel, I'm just trying to find out for the record what it is. Is that all right?

MR. HOWARD: Yes.

MR. ROSENBERG: This is a federally mandated State organization--federally mandated, federally financed State watchdog organization that exists in every State under the Vocational Rehabilitation Act and that is charged with developing a State plan for service of persons with developmental disabilities, most of whom have mental retardation.

CHAIRMAN PENDLETON: Thank you very much. Thank you, have a good trip.

We'll take a short break and then we'll go to Judge Baker.

[Recess.]

THE BLOOMINGTON BABY DOE CASE

Testimony of Judge John G. Baker, Monroe County Superior Court, Bloomington, Indiana

CHAIRMAN PENDLETON: Judge, I've never done this before.

[The witness was sworn.]

CHAIRMAN PENDLETON: Be seated and thank you. Thank you for really coming, I really appreciate this.

COMMISSIONER DESTRO: Judge Baker, would you state your name, address, and occupation for the record?

JUDGE BAKER: My name is John G. Baker, Judge of Monroe Superior Court in Bloomington, Indiana, and located there in the Justice Building.

COMMISSIONER DESTRO: Would you, for the record, state for us the connection you had with the original so-called Bloomington Baby Doe case?

JUDGE BAKER: On April 10, 1982, I was contacted by the attorney for the Bloomington Hospital, who stated that he had contacted the regular Monroe Circuit Court judge who would normally handle this type of matter and had found that the Circuit judge was unable to attend because of other family obligations, and he invited me to come to the Bloomington Hospital because of a conflict between a group of physicians and some questions on the part of the hospital as to what to do, given the circumstances that then existed.

COMMISSIONER DESTRO: Okay. Let me ask you some questions about the case, with the understanding certainly that anything that you might feel is an inappropriate question, given that the Code of Judicial Ethics would take precedence, and if you don't feel that you can answer it, please don't hesitate to indicate that you can't.

I just want to make clear that we're not asking for anything that is otherwise not permissible. One of the things that I reviewed in preparation for your coming today was the findings of fact and some of the conclusions, and if you could elaborate on some of the wording that was used, I think it would be helpful for the Commission.

In one of the findings of fact, there seemed to be an agreement among the physicians--and if I'm wrong, please correct me--that there was not any possibility for a reasonable quality of life for Infant Doe. Could you elaborate on what--what was the discussion about in terms of what is a reasonable quality of life?

JUDGE BAKER: I don't know that I can necessarily explain that, although I understand that tomorrow you will have an opportunity to visit with Dr. Owens, who was one of the attending physicians, and I am sure that he will address that question for you. I would like to explain the context under which the findings were written and the hearing held.

We are gathered here in a formal hearing room with electronic devices that permit us to record statements and to review the same at a later date. We're also--we also have been discussing these issues raised by Baby Doe cases, whether it be in Bloomington or somewhere else, for many years. As you might imagine, a trial judge in Indiana would not anticipate dealing with this type of an issue, especially at 11:00 in the evening. We did not have the benefit of, nor was it ever suggested by any of the parties involved, of having a recorded transcript. It was only suggested that the findings be entered Monday, after a Saturday night hearing. They were dictated for the purposes of making--they were dictated for the purposes of appointing a review panel.

And the findings to which you have made reference lead to the appointment of a group from the Department of Health and Welfare and the Child Protection Team to review the judge's ruling and, in fact, to substitute the group for what has later been suggested as an ethics committee. Of course, we did not have those regulations in 1982.

There were discussions by certain groups of physicians, and apparently those discussions had also been undertaken with the parents involved, concerning the quality of life and a reasonable degree of life. I cannot specifically recall the extent of those discussions, and it is not my recollection that they were dispositive in that case.

COMMISSIONER DESTRO: What would you say was the real dispositive issue as it appeared before you that evening?

JUDGE BAKER: As it appeared that evening--as I recall, I think I wrote down four words on the yellow piece of paper that I had before me, and as I recall I wrote down "child," "parent," "government"--I think I substituted the word "State" at that time--and "practice of medicine."

I determined rather quickly that I was the representative of the government or the State and I determined that the issue before me appeared, at least at that time, to be: If there is conflicting medical advice as to this type of situation, who should be left with the decision, the government or the parents?

And I believed, under those circumstances, if it is so defined, that Indiana law at that time dictated that the parents be left with that decision, as grave as it may be.

Indiana law, as I know you know, Commissioner, and I'm sure the record should reflect, has since been modified.

COMMISSIONER DESTRO: In terms of the conflicting medical testimony, it seemed, from my reading of the findings of fact, that one group of doctors wanted to treat, the other group of doctors didn't want to treat, but there was a concurrence that the child had no reasonable quality of life prospects for the future; is that correct?

JUDGE BAKER: I believe that those physicians--or at least one of the three physicians that suggested intervention or the heroics that were referred to earlier--or were thought to be the heroics that evening at least--suggested that that was not appropriate discussion; the quality of life should not be discussed, that it wasn't an issue for the court.

And I think--if I could suggest, there's got to be something good that comes out of everything. And I suspect that, if nothing else, we have opened up public debate about--as we have just seen by the last witness, and you're going to talk about with your next witnesses, that maybe the public is not as informed as I thought they were.

CHAIRMAN PENDLETON: Getting away from the legal side, that's what interests me, and I hope that we do get to that in the next panel.

But what do you suggest--if you can suggest--what is that public information process, or do you have some idea what that would be either here, federally, or in the State of Indiana?

JUDGE BAKER: I suggest that I'm going to have to, as Commissioner Destro has suggested, stay within my purview of the judiciary.

But if you were to solicit John Baker's opinion as opposed to Judge Baker's, I suggest that the more the public knows about the question, or the more the public knows about the quality of life as you have raised that issue, I think it dispels certain fears. But the legal issue, I think I'm going to have to confine myself to--

CHAIRMAN PENDLETON: I appreciate it. I was just trying to take advantage of the situation.

JUDGE BAKER: That's all right. I have engaged in those discussions on many occasions as John Baker but now probably as judge.

CHAIRMAN PENDLETON: Okay. Fair enough.

COMMISSIONER DESTRO: As I read the Child In Need of Services statute in Indiana, in light of your last comment that it was deemed to be inappropriate to discuss the child's future quality of life, basically were you presented with simply a medical treatment option of surgery or "let nature take its course." Were those the two options?

JUDGE BAKER: My recollection is that most of the physicians felt that at the time I was finally asked to make that determination--I believe it was about 1:00 in the morning on Sunday--that it may well have been too late at that time. Hindsight, of course, is always 20-20 and I know now that the baby lived until Thursday.

That may be an oversimplification to suggest that it was either treatment or "let nature take its course." I believe that there was a feeling of those that advocated the nonheroics that there were many things that needed to be discussed with the parents, and they felt that they had engaged in a discussion before they solicited their consent. And I would say that that involved the impact on the rest of their family, impact on the custodial parents, the impact on their other children, the ability to provide the care that they thought was going to be anticipated; all of these things, as I understand, were discussed with the parents before this consent was given.

I should explain--because I do not believe that it has been appropriately addressed in the record--that after I completed the hearing on Saturday evening or Sunday morning and made my findings on Monday morning and asked that the Child Protection Agency team review that finding, they conducted a similar hearing, although much more extensive, on Monday evening and they chose not to appeal my decision. I still appointed an attorney to do so to the Indiana Supreme Court, and the Indiana Supreme Court then had an emergency hearing on that issue.

There were other hearings in Bloomington, of which I was not a part, until the other hearings--which involved the Child In Need of Services statute to which you made reference and that was addressed on, I believe, Tuesday and Wednesday or Monday and Tuesday and Wednesday--they were all consolidated back to me. And I think Mr. Bopp has suggested to me or reminded me that it was a Thursday, at which time it was suggested that some intervention should be given in order that the child be sustained for purposes of prosecuting an appeal to the United States Supreme Court. Although, at that time, all physicians agreed that any intervention, even such intervention as water and food, or food--I don't know--would be inappropriate at that time, that the child was terminal.

COMMISSIONER DESTRO: There was no question though that the child was not terminal when this first--let me strike that and start over.

The question really before the hearing, as I understand it, the hospital brought the action. Is that correct?

JUDGE BAKER: Quite frankly, there was no formal bringing of an action. We finally decided that the appropriate way to term it was an action In Re action for declaratory judgment, because there was no movant or plaintiff or petitioner, whereas there was on

Monday when we had the petition of the State's representative in the Child In Need of Services--which we refer to as CHIN--filed in the circuit court. That was different. There was a movement and there were advocates for both sides.

COMMISSIONER DESTRO: And in that case the--well in the whole proceeding, from yours through the other one--the question was whether or not the parent was not supplying the child with necessary medical care. Would that be a fair indication?

JUDGE BAKER: That was not the way the issue was couched, quite frankly, because whether or not the nonintervenors--those are the physicians that you have since addressed--whether or not that was a medical treatment was not then raised.

COMMISSIONER DESTRO: Whether or not nontreatment was a medical treatment?

JUDGE BAKER: That was discussed, but that was more formalized I believe on Monday and Tuesday in the CHIN's matter.

COMMISSIONER DESTRO: I guess what I'm trying to get at, in a way that doesn't cross over the boundary lines, is that there was, from what I understand of your testimony, that there was a difference of medical opinion--

JUDGE BAKER: That's correct.

COMMISSIONER DESTRO: --as to what to do--

JUDGE BAKER: That's correct.

COMMISSIONER DESTRO: One was to treat, the other was not to treat. Do you have any sense for what the reason was not to treat?

JUDGE BAKER: I was led to believe--although I don't know if it's dispositive--that some of the advocates felt that it was futile.

COMMISSIONER DESTRO: That what was futile, that treatment was futile?

JUDGE BAKER: --that intervention was futile, that it would be prolonging the child's suffering.

COMMISSIONER DESTRO: And that the--did you hear--I looked in the findings of fact, there were no--was there a guardian ad litum appointed in either of the proceedings?

JUDGE BAKER: Yes.

COMMISSIONER DESTRO: There was. In yours?

JUDGE BAKER: Not at the initial hearing because there wasn't time to do so, but there was after--if you'll note in the findings that I made, I think on the 11th or 12th, I don't remember the date, of April '82, I asked that the Department of Public Welfare and the child protection agency team investigate or review and act as guardian ad litum. Thereafter, after they chose not to--they assumed that position, held their hearing and chose not to intervene. I then appointed an attorney to do so.

Later, the State of Indiana intervened through its deputy prosecuting attorney, who was appointed by both courts to act as a guardian ad litum, and, he continued to do so even to the extent of prosecuting an appeal to the United States Supreme Court for Baby Doe.

COMMISSIONER DESTRO: I guess one last question, and that is struggling with an understanding of what you mean by "treatment would have been futile." What was your understanding of the statement that "the treatment would have been futile": that the child would have died if he had had the surgery to correct the atresia or what? That I guess I don't understand.

JUDGE BAKER: I believe--I was led to believe that the child was terminal and that may be stayed or prolonged, and in doing so, the child would suffer as a result. Although I think as medical things are--I think it's fair to ask me how I reacted, but the doctors are the ones that are going to have to provide the medical evidence.

I know you've got a lot of people to move on to, and I do want to thank you--

CHAIRMAN PENDLETON: No, no, no, I think that where you are in this situation is very important to the record and to us. I think it enlightens us considerably.

JUDGE BAKER: I want to make the Commission very mindful that although we have discussed here today some of the--one of the questions that I've heard discussed was what I think of consent of the parents.

And I think in reviewing the transcript that was provided me--and I thank you for that--there seemed to be some question as to the consent in this instance.

I think in the Bloomington case, the consent was as knowing as it's going to be and that the parents discussed this matter with both sets of physicians, with the hospital administration and the chief of staff, who was not involved as one of the six advocates one way or the other, with their priest and with others, their friends; and Daddy Doe was there at the hearing. It impressed me that somebody had struggled with this to come to the conclusion that this was the right thing for their family and their child, not an unloving decision on their part. I don't want anyone to perceive that that was the case in Baby Doe; Mr. and Mrs. Doe loved that baby.

COMMISSIONER DESTRO: But do you think that they came away from the informing process feeling that any treatments were futile for their baby?

JUDGE BAKER: I am of the opinion that they believed that it was not appropriate for their child to have such treatment, that's right, and that it would not be an appropriate thing to do--for them to do that to their child. I was left with that impression.

Now, we also discussed that evening--but it may not be reflected and I hope that Dr. Owens discusses that--the probability of--and as you well know, as an instructor in the law, sometimes we have burdens that we have to deal with--the probability of other maladies--

And I've heard some of the commentary on "oh well, there were other maladies," but that makes it a little bit harder to define and to deal with. We had to look at the totality of circumstances that then existed, in that hospital conference room, that evening, or early morning.

CHAIRMAN PENDLETON: Did you have a question?

MR. HOWARD: Very quickly.

Judge Baker, how was the Indiana statute amended?

JUDGE BAKER: The Child in Need of Services statute was amended--I do not have that amendment before me, I will be more than glad to provide that--which set forth, by just definition, that withholding of food and nutrition was in and of itself--made one a neglected child. And it also required the physician to make his diagnoses without any regard whatsoever to the handicap. So the Indiana General Assembly, in my opinion, attempted to define the problem away.

MR. HOWARD: So under the new statute this Baby Doe situation would not recur?

JUDGE BAKER: As you well know, Counselor, I have difficulty enough deciding the 75,000 cases I have done. I can't decide one that's not before me, but I know that that was their intent. I don't think that there was anybody that could read the local newspapers that would not have been made aware of the fact that that surely was the intent that was discussed then. Whether they got the job done or not, I have not, nor do I anticipate I would have to, ever rule on that.

CHAIRMAN PENDLETON: Judge, thank you very much. We appreciate your being here.

JUDGE BAKER: I appreciate your courtesy.

POTENTIAL OF THE DISABLED

Testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education, Washington, D.C.; Ed Roberts, President, World Institute on Disability, Berkeley, California; Ruth Luckasson, Professor, Department of Special Education, University of New Mexico

CHAIRMAN PENDLETON: We will convene the next panel immediately, and we're pretty much sticking to schedule.

That is Secretary Will, President Roberts, and Professor Luckasson.

[Discussion off the record.]

CHAIRMAN PENDLETON: Would you raise your hands, please?

[The witnesses were sworn.]

CHAIRMAN PENDLETON: Thank you very much.

MS. HANRAHAN: Would each of you please state for the record your name, address, and occupation, Mrs. Will first?

MS. WILL: Madeleine C. Will.

MS. HANRAHAN: Address--office address is fine.

MS. WILL: 330 C Street, Southwest, Washington, D.C. I'm the Assistant Secretary for the Office of Special Education and Rehabilitative Services in the Department of Education.

MS. HANRAHAN: Thank you.

Professor Luckasson.

MS. LUCKASSON: I am Ruth Luckasson, associate professor and Presidential Lecturer of Special Education at the University of New Mexico in Albuquerque, New Mexico.

MS. HANRAHAN: Mr. Roberts?

MR. ROBERTS: I'm Ed Roberts. I am president of the World Institute on Disability, which is at 1720 Oregon Street, Berkeley, California.

MS. HANRAHAN: Thank you, Mr. Roberts.

I have received copies of opening statements or drafts of opening statements for you, Professor Luckasson, and you, Mrs. Will, and if you do have one--

MR. ROBERTS: I don't have one.

MS. HANRAHAN: Okay. Then I would ask the two of you, if you could limit the opening statement to 5 minutes so that there will be opportunity for questions and answers from the Commissioners. Thank you.

Mrs. Will, would you like to start?

MS. WILL: In the early 1960s, a young mother gave birth to the last of her five children. The child was born with Down's syndrome and a congenital heart defect that the attending physician offered not to repair. The parents chose a less pessimistic strategy. They elected to pursue an arduous and expensive series of surgical procedures to repair the heart defect. In the years to follow, they educated their young son at home, and at age 13, enrolled him in a public school program for the educably mentally handicapped. Now an adult, he takes public transportation from his home to his two part-time jobs, each paying competitive wages. He was recently the keynote speaker at the National Down's Syndrome Congress convention. After his speech, someone asked him about his plans for the future. He responded that he was open for suggestions.

Twenty years ago, the opportunities available to a severely impaired young adult might well have been meager, no matter how open to suggestions he or she might have been. Today, as a result of the opportunities offered by the Education of the Handicapped Act and the Rehabilitation Act of 1973 and the technological advances that are in no small part related to these landmark pieces of legislation, the possibilities are limitless.

Recently, the parents of a 3-year-old Down's syndrome boy described their experiences as follows:

"The Prince George's County school system sent a specially-trained teacher to our home for a 1- to 2-hour session per week during Will's first 2 years. In addition, he received occupational therapy services for 1 hour per month at first, subsequently increased to 2 hours per month in his second year, and now to 1 hour per week. These people worked hands-on with Will to develop his abilities, but to an even greater degree, their role was to serve as guides and consultants to us as parents. In his third year, Will has moved on to a school-based toddler program; he goes to class with five other children twice a week."

The two examples that I have cited are substantially different. In the first example of a child born some 20 years ago, the parents were the sole source of support for the first 13 years of the child's life. Now, however, in Will's case, the educational system is prepared to provide an extensive array of services within the first 3 years of life.

For over a decade, infants with severe impairments associated with Down's syndrome and spina bifida have been placed in programs within weeks after birth. In States where services are mandated at birth, educators and therapists provide instruction within the child's home on a regular basis. In many instances, before they reach the age of 3, children are enrolled in preschool programs, often with nonhandicapped children as classmates.

Currently, for school-aged children, the Education of the Handicapped Act guarantees a free appropriate public education for all handicapped children.

During the school year 1984-85, 93 percent of the handicapped children served under the EHA were placed in integrated settings. Increasingly, some of the most severely handicapped children are receiving at least part of their education in integrated environments. In addition, an increasing number of public schools are providing a broader array of programs for children exhibiting a range of low-incidence handicapping conditions.

The tremendous success of the Education of the Handicapped Act in improving the educational opportunities available to handicapped children is now challenging the adult service system to provide services to a group of children who are accustomed to strong programs and broad support. In response to this challenge, more emphasis is being placed on providing for the transition from school to work. New responses, in the form of supported work and independent living opportunities, are being created to meet the ever expanding capabilities of these severely handicapped individuals who expect to more fully participate in adult society.

Although we had made tremendous progress in the provision of services to handicapped individuals, much more remains to be accomplished. The extent of implementation across the Nation is uneven. However, in the various States, in almost every instance, there is demonstration, or evidence of remarkable or exemplary services. What remains to be developed and strengthened is a comprehensive network of services that stretches, unbroken, throughout the life span of the individual.

Thank you.

CHAIRMAN PENDLETON: Thank you.

Counselor?

MS. HANRAHAN: Yes.

Mrs. Will, you mentioned in your testimony the Education of All Handicapped Children's Act. Could you briefly tell us about that and what other Federal programs there are that fund or otherwise facilitate providing services for handicapped children?

MS. WILL: I think it would take me the rest of the afternoon to outline Federal programs. About 8 percent of the gross national product is devoted to serving the disabled. There are 50--I'm sorry, 40-odd programs that provide services to disabled, and another 100 that provide some services to some disabled individuals in certain circumstances. And the total is about $60 billion at the Federal level. And the entire State, Federal, and local contribution would be about $200 billion.

The programs that I administer include special education programs, that is, educational programs for handicapped children ages 5 to 17, which provides services that are mandated by the Education of the Handicapped Children Act.

In addition, there is a variety of programs across the government that provide for or assist in training and job development, job placement services, in addition to medical services and residential programs.

MS. HANRAHAN: Could you tell us about the population that these programs serve? Is there a class of handicapped child that is not able to benefit at all?

MS. WILL: All handicapped children are entitled to a free appropriate public education.

MS. HANRAHAN: Do you have any knowledge, with respect to State programs, how many children may be in programs--

MS. WILL: There are 4.2 million children in special education programs ranging from very mildly handicapped--speech impaired, hearing impaired, visually impaired, cognitively impaired--to very severely and profoundly, multiply mentally and physically handicapped children.

MS. HANRAHAN: Can I ask you to comment on the value of early intervention to later educational development?

MS. WILL: Yes, a great deal of research has been undertaken in this area and it is, I think, a safe conclusion now to state that early intervention is extremely beneficial to the individual, to the family, and to the society, and that we've seen demonstrable evidence that the younger a child is in gaining access to service, the less likely that child is to require more intensive services, the less likely the child is to remain in special education. Many children are provided with an intervention, and they go on to be fully integrated in the regular classroom and not to be identified as special education or handicapped children.

MS. HANRAHAN: How about for the other end of the spectrum? What kind of services are available for the high school- or college-age child for transition into a working life?

MS. WILL: That's an area of great focus, immediate focus, where there is a substantial wave of young people moving through the system, graduating from high school and needing assistance in finding employment or a post-secondary program, maybe some help in getting into a higher education institution.

We know that there is a very high percentage of unemployment among disabled people, and yet when these people are surveyed, they all indicate that they would, in fact, very much like to work and would accept a job if only they could find a job.

Both Congress and the President have indicated that the area of movement from high school to whatever comes after high school, the next step, is a crucial area of focus--should be a crucial area of focus for all programs. And Congress appropriated funds and created a new authority to allow us to fund demonstrations in the area of transition from school to work. And in the President's budget request, we asked for an additional $5 million appropriation to help develop models of support in employment for the most severely disabled youngsters, who need ongoing assistance in order to be trained to survive in the work force.

MS. HANRAHAN: Okay.

Can I ask you lastly, other than what you've already mentioned, are there any other legislative initiatives that you particularly endorse to better improve the education for the handicapped child, either on the State or Federal level?

MS. WILL: I think I can't address any specific piece of legislation at the moment, but in general I think it is very important that we have cross-Federal agency efforts to resolve some of the problems of differing definitions of handicap, differing eligibility requirements, different outcomes in programs to more effectively serve handicapped children; more interagency work, more cooperative agreements at the State and local level as well as the Federal level.

MS. HANRAHAN: Thank you, Mrs. Will.

Mr. Chairman, I have no further questions for Mrs. Will. Would you like to pick up questioning there or--

CHAIRMAN PENDLETON: I think we should go through the panel first.

COMMISSIONER DESTRO: I think Mrs. Will has to leave.

CHAIRMAN PENDLETON: You have to leave?

COMMISSIONER DESTRO: Why don't we go ahead and finish off the questions with her?

CHAIRMAN PENDLETON: Why don't you go ahead?

COMMISSIONER DESTRO: Mrs. Will, would you--you said something during your testimony--it may have been during your statement, I don't recall--would you describe for us what the range, in your understanding, as someone who's in charge of special education, is between what you might call mild handicapping conditions and more severe? I mean, could you give some examples of the range of disabilities that you deal with in your work?

MS. WILL: That's not a simple answer to provide, because the act is based on a premise that children are provided with an individualized education program, because we find that children have unique individual needs and it's hard to generalize.

A mildly handicapped child might be a child with a perceptual problem, identified as learning disabled, or a mild speech impediment, a child with a minimal loss of hearing.

But you might take that same child, say a child with a mild speech impediment, and add to that an overlay of serious behavioral problems, and that child may be identified as emotionally disturbed and may in fact function as a severely handicapped child.

Traditionally, we tend to think of severely handicapped children as cognitively impaired, very severely cognitively impaired, mentally retarded, multiply handicapped child with difficulty in mobility, in speech, in managing daily living requirements.

COMMISSIONER DESTRO: Where would a Down's syndrome child fit?

MS. WILL: All across the ranges, from mildly handicapped to severely handicapped. You may know I'm a parent of a Down's syndrome child. I have seen very, very mildly handicapped and mildly affected Down's syndrome children in my work; and children who are profoundly retarded all over the spectrum, and one cannot predict that at birth.

I would venture my opinion as Madeleine Will, parent--as opposed to Assistant Secretary.

COMMISSIONER DESTRO: What do you see as the relationship between the work you do in your office as Assistant Secretary in charge of Special Education Programs and the issue that the Commission is looking at with respect to treatment of handicapped newborns under section 504.

MS. WILL: I'm not sure I understand. The relationship between my office, meaning the--

COMMISSIONER DESTRO: No, the relationship between the types of programs--in my understanding of the types of programs you administer are designed with the notion that a child ought to be given an individualized chance. What we're talking about in the question of 504, I suppose, is whether or not they ought to be given any chance at all to even reach your programs.

Is that an accurate statement of the relationship? Do you see it some other way?

MS. WILL: I think the role that I try to define for my office with respect to treatment--and it's a very limited role because we focus on educational services, not medical services--but to further expand services to children in the 0 to 5 population, which is now an option for States. Most States serve some part of that population, but few States serve the entire range of children in their State, ages 0 to 5.

We have seen a tremendous increase just in 1 year in the number of children in the 3 to 5 range; we've gone from 243,000 to 260,000 children. So that is certainly one role for my office and the Department of Education.

Beyond that, we use discretionary funds to try to fund projects that disseminate information about the availability of services, about the capabilities of handicapped children to both parents, lay public, physicians, whomever, allied health professionals. We are working with the American Academy of Pediatrics, which is developing a series of training manuals for interns and residents, nurses, hospital administrators, and other health professionals, to insure that they are aware of the range of services available to youngsters. And they know how optimistic we are about the future for these youngsters.

COMMISSIONER DESTRO: Do you have a sense that a program like that is needed, that it's necessary to inform pediatricians in the general public and everyone else about the need for such services?

MS. WILL: Yes. And again I would say that as a professional and as a parent.

I know other perhaps more qualified individuals have struck the theme of the nature of the consent that is given by parents. I have not ever been in the situation regarding treatment, but a parallel situation for other parents of handicapped children is whether to institutionalize or not. And again, it is the quality of the information that one is given by physicians that is all important.

A parent may have had no experience with a person with a disability, and suddenly, at a moment's notice, finds himself or herself at an existential cliff, and one is very much dependent on this physician who is in some way going to protect you, one imagines, from a cataclysm, and one is dependent on the quality of information that he or she provides. I do think there is a need to educate lay public and the professional world.

CHAIRMAN PENDLETON: Secretary Will, we had some discussion earlier, kind of a scenario that I stumbled around with and fumbled with trying to make a point.

There is an internal discussion that we are having now among those of us that are aware of the conditions; I have some concern about that external discussion.

Now HHS has, I think, many programs that deal with children, school-age children, among other agencies that have--there is a lot of money being spent to educate and to inform. How does this fit in with some of the Department of Education's role in the--if you want to call them, the sex education classes or hygiene classes that go on in schools. How does this really fit so you begin to inform people about what the conditions may be when you have low birth weight babies, from lack of prenatal care, from teenage pregnancies, all those things that you know much more about than I know. How do we get that word out that these are some conditions that you may have to expect at some point in the future if you have this child?

And I cited, of course, the Chicago situation of Lawndale that came out in the The Chicago Tribune.

MS. WILL: Those programs that would support those efforts are really funded by the Department of Health and Human Services as opposed to the Department of Education, at least my portion of the Department, which is really developing special services for handicapped children, special education programs.

But there are discretionary monies that we use to develop information systems, and information networks to disseminate whatever--

CHAIRMAN PENDLETON: Is there some way you can provide kind of a straddle in there--we are talking about the financing--a straddle that gets between where you are and where some of the HHS programs are, as updating schools?

MS. WILL: We work very well with the Office of Maternal and Child Health, for example. We do a lot of joint funding with them, because they often are focusing on children and the provision of medical services to certain children who may be impaired in some way but not requiring, special education, a child with say some piece of--part of a limb missing. That child may never require special education, may be in a regular classroom environment his entire life, but still requires certain medical services, perhaps support services to the family. So we work jointly to try to make sure the gaps are bridged.

CHAIRMAN PENDLETON: Aren't you really saying in your testimony or opening statement that people should be judged by their abilities, not their disabilities, if we could get around to that kind of attitude we might be a little better off?

MS. WILL: Yes, indeed, you said it very well. I think it matters a great deal how we choose to value these infants, these disabled individuals.

CHAIRMAN PENDLETON: I have no other questions. Thank you very much for coming, Secretary Will.

Counsel?

MS. HANRAHAN: Professor Luckasson, would you like to open with your statement?

MS. LUCKASSON: Yes, thank you very much.

I'm Ruth Luckasson, an attorney and associate professor of Special Education at the University of New Mexico. I'm the coordinator of Mental Retardation Programs there. I was cocounsel for several disability groups in the Bowen case and on the amicus brief filed for the disability groups. I am a member of the Ethics ICRC Committee of the local hospital and the chair of the American Association on Mental Deficiency's standing committee on Legal and Social Issues, although I am testifying in my individual capacity today.

I would like to be able to submit my written statement, and also the brief that we filed in that case and two articles on these issues.

CHAIRMAN PENDLETON: So ordered without objection.

MS. LUCKASSON: The lives of the infants born with disabilities or who acquire disabilities after birth have more potential now than at any other time in our history. Babies who receive nondiscriminatory medically indicated treatment can expect to become participating citizens leading rich lives as members of their community.

Testimony that discriminatory medical care may cause--you have received testimony today that discriminatory medical care may cause children to die. But it must also be pointed out that discriminatory denial of medical care may actually create additional handicaps or aggravate existing handicaps.

Traditionally, children with disabilities were excluded from education opportunities in this country. Not until 1975 did Congress, finding that "more than half of the handicapped children in the United States do not receive appropriate educational services which would enable them to have full equality of opportunity," Congress passed Public Law 94-142, the Education for All Handicapped Children Act.

The Department of Education has reported that over 4 million handicapped children were served in the last school year in special education classes. Schools all over the country are educating children whose disabilities are along the full continuum of disability, from very mildly handicapped children to students who have severe and profound medical and physical impairments.

In my own community, essentially all handicapped children, regardless of the severity of their disability, are educated on regular school campuses, not on isolated campuses, and are integrated to the maximum extent appropriate with nonhandicapped children.

Around the country, college and university teacher training programs provide preservice as well as inservice training for teachers who work solely with students with handicaps, as well as to teachers who work in classes where handicapped children and nonhandicapped students study together.

Education, of course, has long been recognized as the very foundation of citizenship. The United States Supreme Court, in overturning the so-called separate but equal school systems in the racial context, stated that "it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education."

The importance of education is paramount in the lives of individuals with handicaps. Special teaching techniques, related professional services, advancements in medicine and technology and implementation of antidiscrimination legislation, such as section 504, are enabling persons with handicaps to learn and to lead fuller lives.

All handicapped children can benefit from education. Children who, in a less enlightened era, might have been relegated to attics or basements or geographically isolated institutions can now participate in the normal give-and-take of a family, attend school with their friends and neighborhood children, and work toward independence and adult status as citizens in this country.

Research such as that conducted in the case of the deinstitutionalization of all of the residents of Pennhurst State School indicates that handicapped people, irrespective of the severity of their disability, can live in the community. The fact that they don't is a policy decision that has been made by this society, not a reflection of their functioning ability.

Work in job training and transition services, initiated and supported by the Office of Special

Education and Rehabilitative Services and the Administration on Developmental Disabilities, demonstrates that the vast majority of individuals with handicaps can participate in the world of work.

Successful teaching strategies have been developed to teach even the most severely handicapped students self-care skills, such as dressing and eating; mobility skills, such as taking public transportation; social skills; and communication skills. The professional literature reports research in all of these areas. Improvements will surely continue.

Regrettably, reports of the advances in special education, habilitation and rehabilitation have not yet received wide dissemination in either the popular media or the literature of other professions. In preparation for our brief to the Court in the Bowen case we reviewed--our review of the medical literature and the literature of the new bioethicists revealed that typical physicians and bioethicists have little or no familiarity with life possibilities or community resources available to individuals who are born with handicaps.

Parents, who typically receive the information on the life prospects of their disabled son or daughter from their physician, cannot uniformly expect information free of false stereotypes and archaic prejudices. To the extent that parents rely on such misinformation as they make life and death decisions about their sons and daughters, their children's vulnerability to discriminatory treatment is aggravated.

I urge this Commission to take a strong position affirming the citizenship of these infants and other disabled people, endorsing the applicability of section 504, and opposing discriminatory denial of indicated medical care, food, and water.

Thank you.

MS. HANRAHAN: Thank you, Professor Luckasson. If I may ask you a couple of questions.

You talked today about the concept of integration, and earlier in conversations that I had with you, you talked about that and the movement from more restrictive environments to less restrictive environments.

Could you talk about that a little bit more now? And with respect to three areas: from institutionalization to residential homes in living arrangements, from a separate educational system to the more integrated school system with other children, and also in the work environment, from sheltered workshops and other segregated settings to more integrated settings.

And in discussing that, could you please talk about the merits of the segregated versus the integrated setting?

MS. LUCKASSON: Traditionally, people with handicaps have been isolated from their families and their communities into places where they wouldn't be seen and where they couldn't participate, and where they wouldn't presumably offend anyone. That is clearly not the state-of-the-art at this time, and it is widely accepted that all people with handicaps can participate in their communities, can become full citizens and can live in the world. The movement has been, in terms of living arrangements, from isolated self-contained large institutions into integrated living environments that are in the community.

When Pennhurst State School and Hospital was ordered by the court to deinstitionalize, all of the people who were held at Pennhurst--a 5-year longitudinal study was conducted by Temple University and Human Research Institute. That is one of the best longitudinal studies that we have studying deinstitutionalization of a large facility for people with mental retardation.

The data from that clearly indicate that all individuals with mental retardation can get out of institutions and can live in the community. They made substantial intellectual gains when they left that facility; they are leading lives in regular neighborhoods, and even family members who opposed the deinstitutionalization, after a number of months became very supportive of deinstitutionalization. So it has been clearly demonstrated that people with mental retardation can live in the community. The fact that they don't is not a function of those people and their disabilities, but is a function of us and our inability to facilitate that movement.

In the education system, as late as the sixties, most students with disabilities were excluded from the public schools. And in our research on exclusion, we have found a case that goes back earlier than that in which a child with cerebral palsy, who was mentally typical, who did not have a mental disability, was removed from school, and his parents opposed the removal. The court upheld the removal because the court found persuasive the school's argument that the child had a--quote--disgusting and nauseating effect on the teacher and the other schoolchildren.

With the passage of the Education of All Handicapped Children Act, that sort of prejudice can no longer be used to exclude children from public schools.

MS. HANRAHAN: Professor, may I interrupt for a moment to ask you a question?

With respect to the school system, in your testimony today you talked about children in educational systems along the whole range of disability being able to go into the regular public school classroom.

MS. LUCKASSON: I didn't say in the regular public school classroom, I said on regular public school campuses.

MS. HANRAHAN: I see.

MS. LUCKASSON: So that although a child's disability might, if it were severe enough--and that means very, very severe--might justify a separate classroom but would not justify his exclusion from a public school setting or the public school campus. That separate classroom would still be on the public school campus.

As a matter of fact, most kids with handicaps can participate to some extent in the regular classrooms and regular academic programs.

MS. HANRAHAN: So that the concept of integration is not limited to the nature of the disability?

CHAIRMAN PENDLETON: They can't hear you.

MS. HANRAHAN: My question was whether the concept of integration was limited by the nature of the disability or to the nature of the disability.

MS. LUCKASSON: No. Integration can clearly occur regardless of the disability or the severity of the disability. Now it may be limited in the number of opportunities, but integration can--or the type of opportunities, but integration can always occur and the fact that it doesn't occur is not a function of the person with the disability.

You also asked me about--I'd like to add one other thing about living arrangements. I have recently been looking at movement from one type of community living arrangement, for example, a group home into a less restrictive type of community living arrangement, for example, assisted apartment living and what that research shows is that people with disabilities can move up the continuum from--even after they get out of the institution, from a restrictive group home setting into a less restrictive setting. So a less restrictive environment is a continuum along which we work and a process with which we work. And someone doesn't have stamped on their forehead for all time the level of integration of which they are capable.

In a work environment, it is a tribute to Mrs. Will and to the people in administration and developmental disabilities that they have been working to create transition services and transition programs so that as students leave school settings and grow up and become ready to assume their adult status in the world, they can get job training or employment support. And that their employment and their job training won't focus on the insignificant and often demeaning little jobs that they were trained for or provided in the past, but that their employment will be in integrated settings doing work that has value.

MS. HANRAHAN: I'd like to ask you one last question before I turn over the questioning to Mr. Pendleton, and this is as to the availability and cost of services, particularly with respect to finding employment and with obtaining satisfactory educational rehabilitative services.

Different people whom I have talked to at times have suggested that the services are not really available, that the money is not really there; other people say that the funding is there, it's just a matter of reallocating the funding.

In your experience and from your background--and I understand that you were involved in a fairly recent project that was sponsored by the Organization for Economic Cooperation and Development on transitioning--is it your understanding that services are in fact available if people are able to access them, able to learn to access them, or is there a lack of services that really needs to be addressed?

MS. LUCKASSON: There is a lack of services and there is also--there are also great difficulties in accessing some of the services that are available. It varies around the country by State and by community.

There are certain States and certain localities in this country where people with disabilities have good access to appropriate services and can expect not to be thwarted in their efforts to achieve the maximum independence that they can.

There are other communities in other States where the system seems to be designed to thwart attempts at access, where individuals, particularly if they are poor or if they don't have someone to help them, will have a very difficult time getting access. The prejudices and false stereotypes of local authorities can greatly impair the ability of an individual with a handicap to exercise his right to services and exercise his access to available services.

MS. HANRAHAN: Thank you very much.

Mr. Chairman.

CHAIRMAN PENDLETON: Mr. Roberts.

MR. ROBERTS: My name is Ed Roberts. I'm the president of the World Institute on Disabilities--it's not just a national institute, it's an international institute--I'm also a recent recipient of a McArthur fellowship for work in civil rights and disability.

I'd like to begin when I began to be a principal in physical disability, which was at 14 years of age. I got polio in 1953. Within 2 or 3 days, I went from a child who was achieving his independence to patient and to the label of a helpless cripple, and within 2 days I was in an iron lung. My mother went to a doctor and she asked whether I would live or would I die, and the doctor looked at her and very patronizingly said, "Maybe you should hope he dies, because if he lives he'll be nothing more than a vegetable for the rest of his life."

I am proud to appear here today as an artichoke. It's one of my favorite vegetables and it's a little prickly on the outside but it has a big heart.

I give you that example because that still goes on today. I hear about that over and over the entire country--what a person's potential might be. It's very clear to me what it's based on, it's what we call handicapism, a fundamental prejudice in this country and around the world towards what it means to be disabled. It is a stereotypical response much like the other "isms" and one that is not as well recognized; it's based solely on the disability, has little to do with who the person is.

In fact, we've learned, some of us, that when people come and they look at someone like me, for example, they see my wheelchair, they see my respirator, but if they don't see me they're in trouble, because it gives you a certain kind of power over people. I mean it's powerful--well it is the perception of weakness when you're not at all weak and it can be used, but it's a terrible thing to have to do to people, manipulate your way through life, using the stereotypes against people, it's unfortunate. It follows you around. Decisions are made solely on your disability.

Sometimes people can look in your eyes and they can see anything but that's it, because they're afraid. Disability creates its own stigma, it's own fear; people react to it in different ways, but most of it often manifests itself in prejudice.

And doctors, I think, are among the worst. The medical profession is among the worst in this area; they see the worst. The diagnosis is often the most important thing that they can do, they're excited about their diagnosis. But after they often have no idea what to do.

Maybe we expect too much out of them sometimes, to recognize that people still have--can have quality in their lives, whether they're on a respirator or whether they have been labeled mentally retarded or whether they have been seen as really not whole people.

And I have experienced all of those in my life but I continue to experience them, with the waiter coming up to me the other night and saying to my attendant, Lee Thorn, here, my friend: "What would he like for dinner?" As if I weren't there.

Of course I no longer tolerate those things, I speak up very quickly. And I've learned from experience that you have to be an advocate. You have to advocate for your rights and your ability to live your life the way you want to.

One of the real ironies is when I was about 18 years old, I went to the California Department of Rehabilitation and I asked to be a client, and I was immediately rejected as too severe to ever go to work. Well, I became director of that department 10 years later.

So even our institutions, especially our institutions, are caught up in these fundamental prejudices, feeling that somehow because you have a disability--and the more severe that disability as they perceive it, the more likely you are to be an object and an object of this kind of stereotypical response.

Baby Doe and young children with disabilities--it's interesting--when people got polio in the early days before, there was no hesitation about saving these children. If I would have been 1 month old, 2 months--they'd pour investment after investment into them and we'd often save the children and allow them to take their place in our society.

All of us, family members, doctors, lawyers--unfortunately we don't have enough judges yet; I think we need to move a few more people with disabilities with positive attitudes into the area of being appointed as judges. Let's say judges are conditioned, many legal people have the same prejudice.

I can remember sitting on my father's shoulders when I was a youngster, and there was a public meeting, and there was a young woman there who had cerebral palsy, and she was moving about, she had braces. And I can remember looking and staring at that person and saying, "Wow, now that's a different person, that's somebody kind of interesting." And immediately, I was taken back by my father, told, "Don't stare," no explanations.

Now what do you perceive? You perceive if you can't even look at a person, that must be something to be fearful of, must be something pretty bad. And I think we inculcate these attitudes very young.

And I think Baby Doe and the issues around young people with disabilities are very similar to the ones we're going to get to around aging and disability, and what does it mean to have a quality in your life?

I've been on a respirator now for 33 years and it has not slowed me down; in fact, if anything, it gave me a cause when I was kind of young. Unfortunately, it's not true for all people. People who are fundamentally seen as less than they are often accept that. It becomes very self-fulfilling when you're put away or put in a nursing home; you begin to accept it. And what happens? You're going to begin to hate yourself, the same way blacks and other groups in our society have gone through.

And one has to begin to reshape one's own attitude to take a more positive attitude, and the family becomes critical in that process. I was very lucky and had a very strong mother and father and, despite their own prejudices, they learned that my potential was about as good as anybody's, but they had to be there and they had to be the advocates in the beginning, and hopefully teach me so that I could be an advocate in the future.

Our language, think about the language. Two days ago I was moving down the street in Berkeley and someone came up to me and said, "Oh you're an invalid." An invalid? I looked, I said, "No, I'm not an invalid, I'm a person. I'm a person that happens to have a disability."

And our language: "handicap." My understanding is the cap in the hand, the word for begging. Shut-in. Deaf and dumb. All the words that we use to talk about people with disabilities are prejudicial words. We're trying now hopefully to coin some new words. But when I talk about myself, I talk about people first, people with disabilities later.

The medical diagnosis is so critical to survival of a person and when we have so few people around like Ruth, who actually go into a hospital and serve on the board and have an understanding of what disability may or may not mean, and recognize that we don't know what somebody who's born with Down's syndrome--for many, many months--what their potential might be, and even then we probably don't know.

At first we thought people couldn't learn, but then we recognized we didn't know how to teach. Now we've learned how to teach people. We've also learned to have a lot of sensitivity in living with them, and self-help becomes a critical part. Peer counseling, getting people involved in helping others. It's a very critical part of how well people do and how positive they feel about themselves in their own environment and their ability to change and to work with others around them.

Eight years ago I became a father--which was a little bit of a shock to me because I had been told that that would never happen in my life, not because I couldn't do it, but because everybody around me was so uptight about sexuality that they wouldn't talk about it. And luckily I learned myself. I happened to go to the University of California at Berkeley which is a very free place as I found out; I was as sexual as anybody else, and so much of that had to with loving yourself and caring about yourself, because you have to be positive, obviously, have positive feelings.

Now we're dealing with another issue, not only Baby Doe, but young people who have muscular dystrophy. There are about 50 different disabilities in this rubric of M.D. Doctors diagnose M.D. young, 4 or 5 years old, maybe even before. They tend to tell people quickly that you're going to die, that it's a terminal disability--by the age 15 you'll probably die. Well, the one thing that they're not telling them is that if they use a respirator they might live a normal life. They're not giving people a choice; they're making that choice themselves. And I'm obviously not talking about all doctors, but this is an accepted practice and part of dealing with muscular dystrophy.

I'm obviously going around talking to doctors and letting them see me, as a person that has lived on a respirator for many years with a good quality of life, however we define that. However we define it, I do have a good quality of life.

I'm very upset about this kind of decision that obviously is not only an ethical and moral decision, but it's a civil rights decision, a decision around a person's right to be informed and to know that they can go on living and that, in fact, they have a right to make their own choices, the parents as well as the young person. Often, from M.D. people, this is excluded.

And I think it's another issue that you should add to this growing debate: that it is not only happening with young people. If we allow the kind of thing that happened with Baby Doe, it obviously sets a precedent for people who are a little older; and of course, it's moving very rapidly in the whole debate around what is quality of life for someone who is older and has disability.

It seems to me very clear that unless we can attack this issue of prejudice, then we are going to continue to have these issues around Babies Doe, that people are not going to be well-informed, parents will not--when I got polio, it was like a thunderbolt came into the family, it was like all the protections around you disappeared, and what else could happen. The family almost disintegrated. There were very few people around that had any knowledge of what it meant.

And one of the areas I began to move into quickly was: What's the difference when you're severely disabled and you're motivated? And I remember I was told for years by the doctors I couldn't have a power chair; in fact, it was impossible, I didn't have the kind of muscles.

Well, I fell in love. You know you have a lot to do at times, and it was ridiculously inconvenient to take my attendant everywhere with me, I just couldn't be alone. Well I learned how to drive a power chair in 2 days, even though I didn't have the muscles for it. I was highly motivated to do that.

I think sometimes that's what we forget; we forget the people, that people can do incredible things despite the prejudices, despite the dire predictions, if we give them the help they need. In this case, all I needed was something to adapt the wheelchair for me, to turn the controller around; it didn't cost anything really, and I probably saved the

State thousands of dollars in people pushing me around to my classes and to other places.

Rehabilitation technology today is so far advanced from 20 years ago. We're beginning to develop machines to help people speak; we're developing power wheelchairs that give people incredible mobility. But still, a lot of those things are not available to people when they need them and often, one particular product might be pushed when a person might need another kind of product for his or her particular self, and they tend to sell one product.

So you're not all that well-informed. And I think that one of the real key issues around Baby Doe is information, having people who have raised people with Down's syndrome or neurological problems, because I think that's the next area we're going to move into, where we're beginning to realize that with spina bifida young people can live and live a good life, and even someone with Down's syndrome people are saving now, and they're taking their place in society.

But now we're going to begin to move into neurological issues and they're even more difficult, but we're going to deal with them in the same prejudicial milieu. And unless we can attack these old attitudes--and I think one of the ways we attack them is--I don't care if someone loves me, I just want to be damn sure that my rights are protected and that I do have an equal opportunity to have a family and to do all the things that I can do with my life, despite some of the barriers; I've been able to overcome those.

But I've watched thousands of young people with disability being turned off quickly, their families ruined because they think--predicted that they would be vegetables. Well, what a thing is that to do to somebody in the very beginning? I think we need to turn these issues around.

And one of the ways you do that is by enforcing people's rights and by letting other people know that they don't have to love you, they may not even like you but they don't have to--their heart doesn't have to be filled by the fact that you've been granted a certain kind of right. We'd better enforce the laws we have and we'd better be sure that prejudice around disability is illegal. And the more we do that and we watch it in other areas of the world, the more we do that, the more people begin to blend into the mainstream in our society.

One out of every 16 babies has a birth defect--250,000 babies are born with birth defects in this country. That's a lot. And what we're dealing with are some of the more severely disabled--quote--severe.

I don't know what that means because I'm not sure anymore. I don't look at myself as a person with a severe disability because of the fact that I've learned how to live with my disability, and I think most of us can. I think most of us learn what our own limits are without everyone around us telling us what those limits are going to be before we even know ourselves.

I think maybe we expect too much out of doctors. I have the feeling that we've trained them to be gods, and in fact, they're not. And when it comes to disability, they don't know what the hell to do. And they feel as helpless sometimes as I think parents do and others, but at the same time I think they have to render their judgment.

I would hope to see review teams--more of them--I would hope to see more people with disabilities involved who are living good lives so they're there for information for parents when they make these choices. And if a parent rejects the child because he has, for example, Down's syndrome, there are usually plenty of other people that would like to adopt the child.

I feel personally that that should be allowed to happen. In California we had a landmark case that I was involved in personally, of a young man who was becoming 13 or 14, he was probably moderately to severely retarded. His parents decided--he needed a heart operation--his parents decided it was better that he die rather than live, because they might die. Then who would be there to take care of him? And of course, when he was born, they put him in the State hospital and they hadn't taken care of him anyway, and there was a family ready and willing to adopt him.

And the hype was incredible. Not only within this adminstration, but to be able to allow that to happen. And we finally were able to allow that. The young man is now working, living his own life, and doing it happily and teaching others in the process.

I think we are in the process of developing some good role models, some people who have disabilities of all kinds, who are out there doing it and living their lives in the way they want to live them. I urge us to get those people involved in the process so that they can be the examples, rather than the stereotypical and fearful responses that we have around disability in this society.

I'm obviously very much in favor of integration. I think I was lucky, there was no special school in my community. I couldn't go to one; there wasn't one there. So I went to high school, my regular school. It was a little isolating, but I can imagine what would have happened to me if I had been totally segregated for so much of my life and then tried to be able to move back into society.

It's so much better if we can include people from the very beginning in our educational system; we can understand that diversity is wonderful, that we're not the same. In fact, one of the things that makes this country so unique is how many different types of people there are. Some are faster, some throw better, some are more intelligent; we're all different. That difference is enriching to us, and yet we reject people often because of that difference.

There was a recent case in the State of Alabama, out of Birmingham, where very similar things happened to the case you talked about before, where a young man with cerebral palsy wanted to get on a Delta airliner and fly from Birmingham to Los Angeles. He was rejected because they said he would be offensive to the other passengers. Very similar kinds of words. He sued them based on this, on 504, and lost because of Grove, obviously Grove City, because there's no Federal money on that route. But Delta had a lot of Federal money.

I think its these kinds of things that are really hurting us now, and I think they're temporary because a lot more of us are coming out and we're becoming advocates and we're not going to tolerate it, literally. We're going to help lead our society back into training us as whole people and people who have a right to fulfill whatever potential we have, and we have a right to decide, help decide what that potential is and, in addition, I think we have a fundamental right to protect us from these handicapistic practices. They are fundamental to our society, and they've been there a long time, and they are going to pass.

I think the next 10 years in this field are going to be the most exciting in any rights field because I think we are going to bring people out of institutions. We are going to take them out of nursing homes, and we are going to abolish the segregated schools and bring people back in, and make people understand that we're people and we're a part and we're not going to be apart from.

And I would like to thank this Commission for inviting people like me and others who are very outspoken because I think it's important that we're heard in the field. And I think it doesn't matter, I think we'll be heard anyway, in a lot of ways, but I think the fact that you reached out to us is very important. I think we will remember that, and we will recognize that we're all part of the larger family, I think, that has to learn a lot about each other.

We're all part of this whole civil rights struggle, which includes an issue that just came out around AIDS: whether people who have AIDS are protected by 504. And I disagree with the decision, very vehemently disagree. And I have friends who are dying of AIDS and they are disabled and they deserve the protection of the law. I think what's going to happen is that we're going to see a broader coalition being built.

CHAIRMAN PENDLETON: Thank you very much, Mr. Roberts.

MR. ROBERTS: Thank you.

CHAIRMAN PENDLETON: Do you have a couple of questions?

MR. PASCALE: I had a whole series of questions, but he has pretty much answered them all.

CHAIRMAN PENDLETON: I think we can move on.

[Laughter.]

CHAIRMAN PENDLETON: Go ahead.

MR. PASCALE: I have just one brief question: if you could just describe what the World Institute on Disability is and does?

MR. ROBERTS: The World Institute on Disability is a research and public policy institute. We do action-oriented research, which means that we hope to have changes in public policy. We're involved in working with the Chinese. We're working around the world with governments and especially with individuals, and our basic philosophy is one of self-help and empowerment to help people who are disabled. The issue is the same around the world.

In Africa, for many disabled people, the issue is the right to eat and the right to survive. And the only thing people are able to do is beg.

Here, we're a little more esoteric because we can deal with issues like civil rights and helping people to survive in a hospital environment.

We're, I think, a unique institute because we do come from the point of view of the disabled. We've been involved for many years and I think that makes us a little different in the process. And as we look at public policy, and as we look at new laws and issues like 504, we attempt to put it in perspective: How do we help that person, the individual, as well as the group, attain a higher status in society, that next job, to be able to push for what he or she needs and to organize around the issues?

The first research project we've taken on, for example, is: we've done a national study on the issue of attendant care. Because this guy, Lee Thorn--I wouldn't be here without my friend Lee, who helped me get here. Yet there are thousands of people--blind people need readers, deaf people need interpreters, the mentally retarded folks often need someone to help them move through a complex society of bureaucracy.

What we try to do is to make sure that there is a uniform policy process across countries so people who need help can get up and be independent and get out and work, can really do that.

MR. PASCALE: Thank you.

MR. ROBERTS: Thank you.

COMMISSIONER DESTRO: Just two questions, and, actually, I would like to address them to both of our panelists.

One thing we've been hearing all through the testimony, starting at the beginning up until now, is this notion of the idea of nondiscriminatory medical treatment or nondiscriminatory access to education. All of this seems to be very much tied up with the notion of medical diagnosis. The representatives of the organizations at last June's hearing, some of the representatives of the organizations that were here this afternoon, basically, said, "Look, you know, this really isn't appropriate to talk about as discrimination, really what it is is a medical judgment, it's a range of disability--it's a range of maladies, and the question is to treat or not to treat." I quote Mr. Gerson from last year, in his testimony of last year. How do you respond to the notion that discrimination is not the way that one ought to look at this issue?

MR. ROBERTS: It seems to me that we're dealing in a society that is so highly prejudiced--and doctors are not immune to this, in the sense of the word--because they see us at our worst.

It's so interesting that mostly when doctors see us is when we're in trouble; they don't see the joy, they don't see the zest to life, they don't see our families often, they don't--they get caught up in the, the joy of diagnosis is what I call it, without being able to really understand what might happen next, or what independent living is all about, or how to take people from a state of dependence to a place where they can begin to take care of their own lives.

I'm very clear on prejudice and its place in this. And I think without the enforcement of fundamental rights under 504, we're going to see more. There's obviously a precedent to what's going on here. You heard about the Oklahoma case.

We also know that the first group to die in Germany was the disabled. You go to Germany now--you don't see the disabled around certain ages, unless they've come mostly from being soldiers in the war. And in fact the first group was the people in mental hospitals, the mentally retarded, then the physically disabled people who were institutionalized.

I'm not saying that that's what's going to happen here, but I think that led to other things and I think, in fact, that is the same kind of reasoning here in some ways; not that we're dealing with massive extermination, but in fact we're dealing with prejudice and its effects.

And I think, you know, I want to be clear that there are some young people, babies born, who aren't going to survive; we recognize that. But there are a whole lot of young people being born that would survive if there were intervention and if we could assure better service for their families and for those young people as they grow up to achieve their potential. Now I think that's around rights, too, issues and all that.

CHAIRMAN PENDLETON: Any other questions?

COMMISSIONER DESTRO: Let me just let Ms. Luckasson answer.

MS. LUCKASSON: I think that it is clear that what all of us expect from physicians and what we want from physicians is medical judgments on medical issues. And what we are objecting to are decisions or suggestions or information that are based not on medical judgments but are based on discriminatory and prejudicial views of people with handicaps. And no one, to my knowledge, is suggesting that physicians stop giving us medical judgments when that's what we go to physicians for, is medical judgments.

Quality of life, for example, is not a uniquely medical judgment and that is--the judgments that are not medical and the judgments that are based on their discriminatory and uninformed views of handicapped are what we want to stop.

MR. ROBERTS: I'd like to see this country become a model for the world in terms of enforcement of rights for disabled because I think the world looks to this country around issues of humanitarianism.

COMMISSIONER DESTRO: The last question. We've talked about this in terms of section 504 which is obviously, as we all know, tied to Federal funding.

If you had your druthers, how would you like to see a statement of Federal policy phrased in terms of the rights of the disabled under the equal protection and due process clauses of the 5th and 14th amendments?

504 talks in terms of "otherwise qualified." My own view is that "otherwise qualified" gives an awful big fudge factor, as the Supreme Court used it in the case.

How would you--what kind of a direct statement of Federal policy with respect to the disabled would you like to see?

MS. LUCKASSON: One of the things that happened several years ago when Canada decided to draft a constitution was that they specifically put into the Canadian Constitution an antidiscrimination clause on handicap. And it seems to me that that is--that as a constitutional matter, we want to make sure that individuals with handicaps and disabilities have equal protection of the laws.

MR. ROBERTS: 504 is a very simple statement and there is another--there is a law bogged down right now in Congress that I think would clarify some of that. But I think it's very painful for a person who helped push for 504 to watch what's happened. In the case of the Delta--the Delta case to which I have referred--it was obvious discrimination. There was no question about it being discrimination. Yet because of the narrow interpretation of Grove City, it wasn't applied.

I would like to see us begin to move to take the bite out of Grove City. Because where I thought we were heading, which was equal opportunity for all--and I don't think it has to be a very complex statement. But I think we have an awful lot of education to do of professionals, people who interpret this.

I think we talked about educating physicians; I think we have to do that, as well as judges, and as well as other people, lawyers, who tend to make the laws in this country. And I notice that where there's disability in the family, like with Madeleine Will and others, there tends to be a kind of sensitivity to these issues that there might not be otherwise, and I wish that we could use more of those folks who are clearer about this to educate others.

Because I think in the long run, education in terms of disability comes by having disabled people among all our society: where we work, where we play, where we live, families working together. And that tends to change, I think, people's attitudes. Integration as a tool is a critical part of that because young people growing up have to know there are differences. Some children have disabilities, you know, and others don't.

CHAIRMAN PENDLETON: You know I can't help--as we close the hearings or adjourn for the day, I cannot help but think that my segregated public school environment at a high school level involved a lot of integration of disabled or handicapped people. One of the greatest athletes in this town's name is Gary Mays, and Gary had one arm blown off in a shotgun accident when he was a kid--

MR. ROBERTS: Wilma Rudolph had polio.

CHAIRMAN PENDLETON: --and was probably one of the better baseball players around with only one arm. He was a catcher, as a matter of fact, and he was quite a basketball player. He got into trouble later on, and his name changed to the one-armed bandit because he did a lot of stealing.

I think I'm only making the point of the fact that there are things there that now, hearing you talk, we can knock on integration, that in my time we just took it for granted that here was the guy that could play. And as I said to Secretary Will, he was judged by his abilities, not by his disabilities.

Pete Gray certainly, as he played major league baseball with a smaller bat, and he only had one arm at the time was signed by the Browns, certainly was judged by his abilities, not by his disabilities.

So I guess there are those role models out there, that an integrated atmosphere does begin to work, and if we can look back on some of our own experiences, all of us who--all of us can somehow see that we have been able, if you will, to accept people with disabilities without any hangups at all.

I want to thank you all for coming today, and these proceedings are, void of anything else, adjourned until tomorrow morning at 9:30.

[Recess.]

Friday, June 27, 1986

PROCEEDINGS

PERSPECTIVE OF THE DISABLED

Testimony of John Kemp, Director of Human Resources, National Easter Seal Society, Chicago, Illinois; Adrienne Asch, Adjunct Lectürer in Social Psychology, City College of New York; and Mary Jane Owen, Director, Disability Focus, Inc., Washington, D.C.

CHAIRMAN PENDLETON: We're reconvening the hearings for the second day. I'll now administer the oath to the first two witnesses.

[The witnesses were sworn.]

CHAIRMAN PENDLETON: Mr. Kemp, you may read your statement. Ms. Asch, you may make your telephone call.

MR. PASCALE: Could you please state your name, address, and present position for the record, please.

MR. KEMP: Yes. My name is John Kemp, I am director of Affiliate Relations and Resources, National Easter Seal Society, 2023 West Ogden Avenue, Chicago, Illinois 60612.

MR. PASCALE: Do you have an opening statement?

MR. KEMP: I have a verbal statement I would like to make.

MR. PASCALE: Sure. Go ahead.

MR. KEMP: I appreciate the opportunity to appear before you, Commissioner, and Chairman and the other Commissioners. I would like to at least make some comments regarding the subject in a general fashion, and then answer questions as you wish following the statement.

I apologize for not putting on my coat. It is very warm outside, at least to me it is very warm and so I'm going to try and be as comfortable as I can.

CHAIRMAN PENDLETON: I do not blame you. We'll be reaching you soon.

MR. KEMP: Thank you. The issue before you today is one that I have followed for quite a few years. Prior to joining the National Easter Seal Society in September of 1982, I practiced law and headed a consulting firm based in Kansas City that was a nationwide consulting firming specializing in civil rights issues involving disabled individuals.

I traveled around the country and worked with numerous Federal financial recipients in implementation of section 504. Specifically, we had a contract with the United States Department of Education and another contract with the United States Department of Health and Human Services to provide training and technical assistance to recipients of their various Federal funds.

Under the HHS contract, our consulting firm, Kemp and Young, Incorporated, had as a subcontractor the Tennessee Hospital Association, and participating with the Tennessee Hospital Association were two specific hospitals: Baptist Memorial in Memphis and Williamson County Hospital in the Nashville area.

Our purpose was to provide training and technical assistance to all members of the Tennessee Hospital Association on all aspects of 504. We covered, over an 18-month period of time, a significant amount of work and the subject matter regarding services in the hospital to a variety of disabled people who were coming there for services. The education that was imparted, we feel, was terribly significant, was helpful and meaningful to them. And their participation as a member hospital association was critical to their membership in understanding their obligations under 504.

Many of the responses that we received following the training and evaluation addressed the subject of new issues being raised by virtue of 504 and dealing with not only disabled infants, but disabled individuals, hearing impaired individuals in the emergency room, and a variety of other situations found in hospital settings.

So we felt, and I think I can conclude safely that, with the participation of the Tennessee Hospital Association, we imparted a significant amount of information to them. It was crucial to their understanding of 504, and I think this particular subject that's before you was addressed meaningfully with them, and they understood their obligations to provide services and recognize the civil rights of children with disabilities and infants with disabilities.

In addition, since that time, the National Easter Seal Society--after my joining the National Easter Seal Society has adopted the Principles for Treatment of Disabled Newborns. I don't know if it has been introduced into the record, yet but the Principles were endorsed by nine national organizations in late '83 and early '84, and those Principles of Treatment were approved by the National Easter Seal Society in February '84, and I will be providing that as written copy to you for inclusion into the record. In it, I think you will find that the issues before you have been addressed in a policy manner, and there is recognition of the civil rights of children with disabilities.

In general, my specialty has been looking at attitudes towards disabled people, and I think what we're faced with is recognizing and hopefully endorsing the civil rights of infants with disabilities. I realize that there's a crossing over and a confluence of issues here where you have parental rights that are usually recognized and enforced at a State governmental level, and civil rights usually reserved for the Federal domain to protect. And I think that is a critical issue before you today and throughout these hearings, and hopefully you will come forth and recognize that, I think, there are overriding civil rights issues that have to be recognized regarding disabled newborns.

I want to make one final comment, that is, regarding the attitudes of the society and the medical community, anecdotally. I was born without arms or legs, some 36 years ago, and my parents were told--and my dad frequently speaks of this--that I should be--he was told this by the doctor that delivered me--that I should be taken home, taken care of, and that the best I could hope for would be a life of, hopefully of comfort, but certainly not of any kind of achievement. My dad resented the heck out of that kind of a statement. My mother died 15 months after I was born, and he raised three of us kids. I'm the only disabled child. But I think he feels reasonably satisfied that he made some good decisions about mainstreaming me into society, creating opportunities for me.

I would let you know that there are a lot of other people like me, maybe other people with more severe disabilities, who are born, who are in need of recognition of their civil rights and the responsibility of the Federal Government to enforce those civil rights on their behalf.

In a volunteer capacity as chairman of the Board of Access Living, an independent living center in Chicago, I work very closely with the CEO of that organization, who is a quadraplegic female. We regularly conduct training programs for the University of Illinois Medical School for the doctors and to-be doctors there, and we are continually astounded at the naivete of the medical profession regarding the rights of and services for disabled individuals. Her problems, if they are female in nature, are usually referred to a physical medicine and rehabilitation person only because of her quadraplegia, and this phenomenon continues to astound her and infuriate her. That is symptomatic of the medical community, and I would say I have heard this comment on numerous occasions dealing with people who are disabled, that the disability becomes the primary focus of the medical attention, when, in fact, they may be in need of medical services unrelated to their physical disability or mental disability.

Those are general comments I felt would be helpful, and I would like to follow up with written comments that amplify on all these aspects.

CHAIRMAN PENDLETON: Without objection we would so accept your written comments.

Ms. Asch, are you ready to enlighten us?

MS. ASCH: I hope so.

MS. HANRAHAN: Ms. Asch, would you please state your name and address and occupation for the record?

MS. ASCH: My name is Adrienne Asch. My address is 316 West 104th Street, New York, New York 10025.

MS. HANRAHAN: Thank you. You can be seated for the testimony if you would like.

Do you have any opening remarks you would like to make?

MS. ASCH: Yes. There are five points that I would like to make. First of all, people with disabilities see themselves and are now seen as members of a minority group. Section 504 and its companion sections in Title 5 of the Rehabilitation Act of 1973 were the first statements of Federal policy and Federal law recognizing people with disabilities as a minority group.

Section 504 is patterned after Title 6 of the Civil Rights Act of 1964, Title 9 of the Education Act of 1972 to protect members of racial and ethnic minorities and women against kinds of discrimination. We're also concerned about people with disabilities.

In the situation of children, and especially infants who are members of other minority groups, they usually are born into families where one or both parents share the same minority characteristics, whether that's ethnicity, race, or gender. Children with disabilities, including infants with disabilities, are rarely born into such families. And in this important way, they differ from members of any other minority group. What that means is that people with disabilities as adults are important activists and advocates for those infants with disabilities.

I'm here, as are other people, to give a perspective of adults who have disabilities because we feel that we are at least as important advocates for those infants as are any professionals or even the infant's parents.

In fact, because parents of disabled children, and especially disabled newborns, rarely share this minority characteristic, especially when they have just discovered the fact that their infant has a disability, they are in an extremely difficult position to advocate for that infant. The parents of other children with minority characteristics can do this much better. They know what life holds in store for that infant and their child. They can advocate against those who would hurt their children for those minority characteristics, because even though they may know that life is fraught with problems, it is also going to contain various joys.

But the parents of a disabled infant, moments, days after its birth, have very little such information. In fact, they are likely to have been given information by physicians, by social workers, by any other professionals, by clergy, that reinforces whatever stereotypes they have about the limits and deficits and tragedy of so-called defective, deformed, damaged infants.

It is very important to understand that there is a disability perspective, an adult disability perspective, to advocate for children. The news media has never understood this in its reporting on Baby Doe and similar cases. In commenting on the Bowen decision, The New York Times, in an editorial of June 12 referred to the relief for beleaguered families of the court decision. It talked about the unfortunate children.

The Times is representative. It has never understood that these unfortunate children, first of all, may not be anywhere near so unfortunate as nondisabled people think; and second of all, regardless of the severity of their impairments, those children have interests, quite possibly different from and possibly at odds with, those of the parents. They are separate people. They must be thought about as separate people.

The reason to cover the problem of medical discrimination, whether it is against disabled infants or disabled people is that those people, as born, existing people, have separate interests and civil rights apart from any family, societal, economic, social, or emotional burden that they might cause. Other people cause burdens, too, but we don't consider whether they should be alive, if it is all right with someone else. We do. We talk about the burden that disabled people will cause to their families, to their siblings, as though it means that the only way that disabled children should be allowed to live is if it is all right with someone else.

When we talk about medical discrimination against people with disabilities, we have focused a lot on infants, for good reason, because perhaps those infants are in the least good position to advocate for themselves. But medical discrimination is pervasive.

We know, of course, of the Oklahoma case, a major lawsuit now being brought against discrimination not only against disabled infants, but within the class of disabled infants, discrimination by economics and by race. There's the case of Phillip Becker, which I'm sure all of you are familiar with, whose parents refused the opportunity for him to have surgery. In a paper by Ann and H. Rutherford Turnbull on the ethics of early intervention, the authors talk about the parents of a profoundly retarded young man of 15 who were frequently asked by the physicians who were working with the child, youngster, whether they really wanted to continue with kidney dialysis or blood transfusions.

Would those physicians have asked such a thing, even dared ask such a thing of the parents of any other 15-year-old minor child without a disability? Of course not.

To show how much the media does not understand this, in October of 1985, to mark the effective date of passage of the Child Abuse Amendments of 1984, there was to be some TV coverage of the Baby Doe case and all that led to the creation of the Child Abuse Amendments. As someone who had written and spoken on this topic, I was contacted and asked if I would appear on a CBS TV News show to discuss the question.

When called by the CBS TV News people to find out what my interest in the case was and what my expertise was, they said, "Well, do you have a disability?" and I said, "Yes." They said, "Well, are you the parent of a child with a disability?" and I said, "No, in fact, I'm not." "Well, what is your stake in this case?" And I explained that I thought there was a disability perspective that needed to be. involved, needed to be aired. CBS folks said, "Well, but this is not a matter of discrimination. We're not talking about job discrimination, we're talking about medical care for children and infants and family rights." I said, "What do you mean, this is not a matter of discrimination? If this infant did not have a disability, we would not be here having a discussion whether she or anybody else should have surgery. It would be an open and shut case." The man said, "Gee, I never thought about it that way." However, it is interesting to note that whether I persuaded him or not, either he or his supervisors refused to have me or this perspective aired.

MS. HANRAHAN: Excuse me, Ms. Asch, for interrupting for a moment. We Would like to leave a little time for Commissioners to ask questions, and what you have said is very interesting. I think there are plenty of questions they would like to ask.

MS. ASCH: I will try to be brief. I have a couple more points that are important that I would like to make. We know of other medical discrimination. Sterilization abuse for people with retardation and for people with other disabilities. And there's professional support for it. Furthermore, anecdotal and a certain amount of documentary evidence has been amassed by women with disabilities.

If reproductive freedom includes the right to bear children as well as the right not to do so, women with disabilities, unlike most other women, are often forced by professionals to have sterilizations, to be refused reproductive health services. In fact, family planning agencies have recently had to set up special programs so that their policies no longer included refusals to serve women with disabilities.

Women who choose to bear children are often unable to find proper obstetric and gynecological care because physicians do not believe in their capacity to become effective mothers.

There's an enormous amount of attitudinal evidence that's been amassed to show that people with disabilities are not wanted as family members by people without them. Even when people without disabilities are willing to accept disabled people as coworkers, that does not go over into willingness to accept them as family members.

We have unpublished data that I will be happy to provide, if you want more detail, to show that nondisabled people no matter how good their attitudes are about disabled people, on lots of other scores, are far less able than are people with disabilities to accept the notion that newborns who have disabilities are entitled to medical treatment.

Furthermore, the more time that people spend around those with disabilities, the more willing they are to assume such a posture, that disabled people, like others, are entitled to medical treatment. Therefore, it is clear that the matter of medical care for disabled infants is not a matter of professional judgment but of just plain discrimination and prejudice, and that's why it needs to be covered under a civil rights statute.

The Department of Health, Education and Welfare, when it enacted the regulations signed in 1977, would never have enacted those regulations if the Department had not believed there were medical discrimination and problems in obtaining medical services, or else it would never have adopted Part F of the section 504 regulations.

Now last, I want to make a comment that has to be--about how this case and the Reagan administration's championing of the rights of disabled newborns must be seen in the context of a thoroughly disgraceful record of the Reagan administration on civil rights for all people, including disabled people in every other area of life. There's the Grove City case. There's the cutting off of disabled people from SSDI rolls.

There's the cutting of civil rights enforcement and of programs of service for people with disabilities that could help people get off rolls and into employment.

There's the cutting of health care funds for prenatal care and maternal and child health, increasing the incidence of disability for infants and children, especially those of low birth weight, often infants of poor women.

There's the cutting off of funds and--or not cutting off of funds, but there's the cutting off of support for regulations for health and safety in the workplace and that means that there's an increase of disability in workers.

Furthermore, families and children and adults with disabilities are further from public support for health care than they have been in the last 50 years. There's no possibility now for national health insurance or even for catastrophic coverage for catastrophic illnesses that might help parents of children with disabilities take those infants home less grudgingly, with more confidence that they would be able to care for and pay for the care that those infants need.

There's no family support, financially, servicewise; and the Reagan administration has done nothing to assist parents, newborns, or disabled people or anybody else in need of civil rights protection.

Last, we talk about how the Reagan administration supports the rights of disabled infants. What about its support of the rights of those same adults with perhaps retardation and other developmental disabilities who sought housing in Cleburne, Texas? Where was the Reagan administration's Justice Department then? The Reagan Administration, at least in part, sided with the city of Cleburne, not on the side of people with retardation challenging the discriminatory ordinance.

I think we can comment on the Reagan administration and its being exclusively pleased with its championing of the rights of disabled newborns has to be seen in context. It is whimsical, it's hypocritical; it is disgraceful, and if we're going to have real rights, real civil rights for newborns or anyone else with disabilities, those rights have to be seen in a context. It can't just end with birth in the neonatal unit. Thank you.

MS. HANRAHAN: Thank you, Ms. Asch. I have only one question. How do we go about changing society's attitudes towards the disabled? Are they based primarily on ignorance or is there a prejudice and a stereotype and a bias that's independent of ignorance and can it be cured by ignorance? How do we go about creating a society that wants reflected in its laws equal protection for the handicapped?

MS. ASCH: There are other people who will talk about attitudes further later this afternoon. I'll give you the understanding that I have from reviewing social science data on attitude change for people of other minorities. Strong laws make a substantial difference.

The legal climate has made an attitudinal difference. Knowing that one cannot discriminate, although it doesn't necessarily change one's heart, certainly changes one's behavior, or can; and possibly behavioral change will ultimately change the hearts and minds.

Furthermore, contact, the sort of contact that appropriate enforcement would guarantee for disabled children and adults in schools, in workplaces, in community facilities, in recreational facilities, sustained positive contact in a range of social situations that these civil rights laws are designed to guarantee is in fact the best way to change public attitudes. And that's why we need stronger and better and more vigorous civil rights enforcement: to insure that the society that is fearful and ignorant and terrorized doesn't have a chance to operate on that fear and ignorance and terror.

MS. HANRAHAN: Thank you very much. Mr. Pascale?

MR. PASCALE: I just have a couple questions for Mr. Kemp. When we talked earlier, you mentioned that physicians seemed to have a paternalistic attitude towards persons with disabilities. Could you elaborate on that?

MR. KEMP: I touched on it briefly in my testimony. The aspect that I'm focusing in on is that the doctor or the medical community seems to know best what we need and what we want, and many times these kinds of decisions about what is appropriate care, what's the best treatment methodology are usually made with little input from the disabled individual. And that kind of attitude, it seems to be pervasive and has been so for 20, 30 years, as long as I can remember, as long as my dad has been telling me this has been going on, and other people have dealt with it. The doctor always seems to be able to take charge of a disabled person's life and know what's best for that disabled individual, instead of the locus of control being within the disabled person or the family to decide what's best.

MR. PASCALE: Do you feel there are attitudinal barriers between those persons with disabilities and those who don't have them?

MR. KEMP: Absolutely. I think you are just starting to hear about it in previous testimony and the answer to the question: How do we overcome ignorance through education. What you are talking about is an attitudinal problem that is pervasive towards disabled individuals. To elaborate and to amplify on the previous comment, a study done by high school students in Canada in 1982 asking them to assess their attitudes toward disabled individuals and how to overcome the attitudinal barriers they had towards disabled individuals; the conclusion after a long, long study was that extended, close contact among equal status peers was the best way to achieve acceptance, understanding, and equality among nondisabled and disabled individuals.

This kind of simple logic is based on a recognition of civil rights and an enforcement of the civil rights so that the participation is guaranteed and the extended close contact is ensured. Truly, a statement that disabled individuals are handicapped by the negative attitudes of other individuals is a very true statement.

I think terminology places a great role in what we are doing. I'm interested in what Mary Jane is going to comment on because I know Mary Jane very well. I know she might say things like "terminology is very important in calling people 'the handicapped,' calling children 'defective.'" The absurdity of calling disabled people of any age defective is like calling us cars and that there's a limited warranty and the warranty expired or there is an implied warranty that's been breached in some way.

We're not products or appliances, we're people, and I don't think we're defective. It is an attitude that is pervasive in literature and language and it offends me and I'm sure it does many disabled people as to how we are called and how we are regarded.

CHAIRMAN PENDLETON: Let me swear Ms. Owen in.

[The witness was sworn.]

CHAIRMAN PENDLETON: Now you are official.

MS. OWEN: Thank you. I apologize for being late.

CHAIRMAN PENDLETON: Quite all right.

MS. OWEN: I'm particularly pleased to be invited to testify.

MR. PASCALE: Could you state your name and address and present position for the record?

MS. OWEN: I'm Mary Jane Owen, appearing as director of the Disability Focus here in Washington, D.C. I am employed by the Federal Government, working for the President's Committee on Employment of the Handicapped, and I am also a writer, being a contributing editor at the present time to the two major disability publications, Disability Rag and Mainstream Magazine. The offices of Disability Focus are at 2032 Belmont Road, Northwest, Number 226, Washington, D.C. 20009. I did bring copies of several supporting documents here.

CHAIRMAN PENDLETON: We'll put those in the record if you want us to do so at this time.

MS. OWEN: Fine.

I do feel that I have a true perspective of what disabled people around the country are thinking about this issue. I first began writing about Baby Doe as one of the first of the disabled people to do so and have continued to do it over the last few years.

As I say, I do write for Disability Rag and I also write for Mainstream Magazine, as well as mainstream publications and professional journals. I get a lot of feedback, and I am in an invaluable position in terms of getting a sense of what's going on around the country.

I would like to suggest, first of all, that we have real conceptual problems in looking at the issue of discrimination at best. I'm talking to the right people when I talk to the U.S. Commission on Civil Rights, when I talk about the problems of confirming what discrimination is. And for the most part, it is something one feels. I know as a formerly sighted woman, a professor, well on my way to a very successful career as a researcher and an evaluator, professor of methodology and human services, I know what happened when the only change was suddenly the loss of sight. I experienced discrimination as I had never anticipated I would.

Now when it comes to documenting what is happening around one, lawyers' wits and moralists' wits are taxed. I have a very difficult time confirming my difficulties in being deprived of my equal access to the benefits and the challenges of life in America today.

What of a small infant who is not yet equipped to deal mentally with the process? I think our conceptual frameworks need to be examined a bit, and I would like to go on with that.

In terms of the perception of disabled people on the decision of the Supreme Court and the media coverage and the man on the street and the woman on the street's response to the Baby Doe situation, I think there is a shock, disbelief, a feeling of having one's hopes dashed that the right to life of a child that is seen as flawed is not considered covered by the Constitution.

I think that sometimes in our scientific desire to develop researchable questions that we can understand and trade back and forth, we begin to so simplify the question that we miss the picture that we were trying to focus on. And I think that that is what is happening in this instance.

I was so touched by Connie Martinez's testimony yesterday when she talked of her "familia". I was sorry that she was not questioned more because I think that you would have found laid out before you a very concrete mind. Those of us sitting in this room are burdenened, if I may suggest so, by our conceptual frameworks which blind us to many of the realities that, in a simpler age, may have seemed crystal clear.

Not only do I think there is a constitutional issue involved, there is a moral issue involved that precedes even that. Whenever we as human beings decide upon the value or the lack of value in one other person's life, I think that we have bypassed common sense. Connie spoke of "familia." I speak of family. To be humorous for a moment, there is a saying going around that disabled people procreate by accident. I would suggest that that is not just a humorous saying fit for a bumper.

I would like you to think about it for a moment. Disabled people, whether we are adults or children, are created by accident. It was not something that was intended. Those babies that are being killed are my children. They are a part of my community.

I used to say when I first began to address this subject, that I had a gentle need to know what was happening in the nurseries. That I had a gentle need to know about the decisions that were being made on the part of harassed doctors and upset parents, bereaving parents, and I didn't want to intrude upon the agony of the decisions that were being made.

I think that I, as well as many other disabled people, have become a little weary of our own gentleness. Because the pattern has persisted, and now we are confronted with a Supreme Court decision that would appear to raise serious questions about whether we, who are concerned about our little brothers and sisters, do have a right to know what is happening.

I am not in favor of big State government intervention into the lives of families. I am not. But I would suggest to you that there are times when there needs to be a big brother holding the hand of little black children as they go by people that are spitting in their faces, and there needs to be a big brother that somehow oversees the destruction of what I consider to be valuable human life.

Connie is an important symbol to me because I find her an articulate, concrete, self-confident, productive person, severely mentally--moderately mentally retarded.

I would submit to you that we as a society need a few more people with a concrete frame of mind.

It was not too long ago that I got into a discussion with a genetic engineer. He wants to fool with the genes. He wants to eradicate those things that he considers to be less than perfect within the human race. That will certainly be me. I carry a "bad" gene. I put "bad" in quotes. My daughter inherits, perhaps, that gene. When she was born, she was very premature. Very underweight. I was told the first day of her life that she had 1 percent chance of survival. I was later told at one point that she was mentally retarded.

I'm very pleased that she graduated cum laude from Harvard. She may face blindness, but I'm here to tell you that blindness has given me many opportunities to explore things that I would not have been able to explore if I had continued as what I would call an intellectual, abstract-thinking bigot within an academic setting.

God strikes us in odd ways to teach us the lessons of life. I am very concerned. I am very concerned, and I believe I reflect the concern of other disabled people when disabled infants are judged as not having value.

You might ask me why I feel so confident in talking about the disability community. I don't know if the other panelists have referred to the Harris Poll. I have not had a chance to review the final report, although I have done several analyses of the preliminary report that was given to Congress back in February.

I have addressed the emerging minority mindset within the disability community in one of the articles I have attached to this material. Many disabled people find it difficult to identify as disabled because they know of the odious associations and the need to disassociate themselves from that title as disabled. If they are to work, to get benefits in the current system that we have devised as rational human beings, a disabled person who wishes to be productive but needs additional help, whether it is an attendant, whether it is a reader, whatever that might be, is also called upon to jeopardize the coverage for medical care into the future.

When they take the risk of dissociating themselves from the Social Security system--I myself have experienced that. I was on Social Security Administration programs, and have on several occasions had to assert that I was unemployable. So there are many reasons why confident disabled people wish to disassociate themselves from the name.

However, what is truly significant is that almost half of the individuals interviewed do identify as a member in some way of a minority, and 75 percent of those individuals do think that minority protections apply to disabled people. That number goes up to, I believe, 82 percent, when you are talking about younger disabled individuals, which implies to me that there is an evolving sense among disabled people that we do constitute and should be considered a minority.

There were 200,000 flawed, disabled people who were subjected to negative population control methods as the principal and respected physicians within the Third Reich attempted to evolve toward the ideal society. Two hundred thousand disabled people were killed to answer a problem. This began in 1939 when a Nazi Party member from Leipzig was distressed about having a blind daughter who was born with one limb missing, and she was evaluated, apparently only from an exterior point of view--was evaluated and declared incurable; and she was the first to be mercifully put to death.

MR. PASCALE: Excuse me, could you sum up? We would like to have some time to ask some questions.

MS. OWEN: I apologize. It is obvious I have so much I want to say. Let me say that I do feel I am reflecting deep concern on the part of the disabled community about this situation. I am pleased that you are listening to us, and I hope you will continue the dialogue. We need you. We need you on our side.

MR. PASCALE: I just have one question. You have talked about the problems and the attitudes of society towards persons with disabilities. Do you have any recommendations about how we can start changing those attitudes?

MS. OWEN: Yes. Number one, we need to have strong protective legislation. As every other minority has faced discrimination, it has needed that. In addition, we need to do what I have called "grind new conceptual lenses." People who are in acute medical need of treatment must be treated as patients, and a medical model is appropriate. It is not appropriate to use that model when thinking about disabled people. And we need, as a society, a new way of viewing disabled people, and that is what I am about with my work--grinding new lenses through which society can view its people that are limited in some way in terms of function.

And incidentally, that is very pervasive. It is a very normal process to develop flaws. As a matter of fact, I believe it was--is it--E.F. Hutton, in selling disability insurance in one of its brochures, mentioned that a man of, I believe it was 43, faces a 50.3 percent chance of becoming significantly disabled at some point in the future, and half of those will be for a period of years. So I would suggest to those of you who are approximately that age in the room, that that might make you reevaluate the normality of physical, mental, or emotional limitation.

CHAIRMAN PENDLETON: If I could--you got another question? Just to make a point, Ms. Owen, we could not question Ms. Martinez as a public witness by the rules of how the Commission operates. We are prohibited from questioning public witnesses, but certainly they are able to come and give us their testimony. That becomes a part of the record. If there's something to be asked later on, that's okay, but I want you to know that while we wanted to, we really couldn't.

We did get one kind of question of identification but not one of substance, which I mentioned is impermissible by the rules of our hearings.

Let me just ask a question. I forgot to ask it in the beginning, to show my own, I guess, insensitivity or maybe I'm having some other problems with age, but is there anyone here who is hearing impaired? I should have asked that earlier.

MS. OWEN: I do have ear difficulties, but I'm not hearing impaired.

CHAIRMAN PENDLETON: I apologize for not making the announcement earlier. Thank goodness I'm not too much in error.

Mr. Destro, you have a couple of questions?

MR. DESTRO: Yes. I would like to address this to anyone on the panel who would like to tackle it. I had a--I think one of my introductions to this whole area of the interface of medical care discrimination and disability was a number of years ago when I first got involved with the Phillip Becker case in California. It struck me that those who have certain disabilities are caught in a multiple bind: the medical bind of describing all of these problems as purely medical, and it seems that that's what the Supreme Court has done in the Bowen case; the societal bind that you talk about, which affects the parents' judgments as to whether or not the child is worth saving; and I think a general prejudice toward the disabled which is reflected, I think, in a lot of the laws; the way the laws are structured is the way you put it, and some of the court decisions going back to Buck versus Bell and before.

To get to my question--the title of this hearing deals with handicapped newborns and the coverage of section 504. The Supreme Court decision picked up on the term "otherwise qualified," and essentially, you know, opened up the barn and let all the horses out. And it would seem to me--I would like to get a sense for what would you like to see the law--how would you like to see the law restructured so that those kinds of fudge factors are no longer in there?

The Court said--the legislative history--it said they never contemplated handicapped newborns; as I read the opinion, it says they haven't contemplated them because they didn't want to get into medical things. I won't continue to blather on. I would like to hear what you have to say about that.

MS. OWEN: May I respond to that? I do think that that was a misuse even of the concept of "qualified." Unfortunately, handicapped infants are born into alien families, families that have already probably stated the only requirement they have of a child was that it must be perfect, so I think that--I as a layperson, I have no right to question the judiciary wisdom--

MR. DESTRO: Oh yes, you do.

MS. OWEN: --of those people that made such a profound mistake, I suppose. I am appalled at the concept that parents who are a part--disabled infants are born into alien families. Black families have black children. White families have white children. Asian families have Asian children. And the enemy, those individuals who fear us most, may be the parents of a child. It is a shocking experience for them to put the decision of life and death on the basis--and whether those children's--those infants should be protected or not, whether they are qualified to be protected or not, on the basis of a parental decision, or going along with a medical decision, is just to me the height of hypocrisy.

MR. DESTRO: Ms. Asch?

MS. ASCH: I have a couple of comments. Not being afraid to question the judiciary, no matter what minority that puts me in, perhaps a majority in this case--

MR. DESTRO: I don't believe they have declared themselves infallible yet.

MS. ASCH: It seems to me that the "otherwise qualified" phrase is a problem throughout section 504. Blacks who are fighting discrimination don't have to prove--they may have to prove they are otherwise qualified, but there's is nothing in the law in Title VII, about otherwise qualified blacks or women. It is a paternalistic, insulting, condescending statement no matter what part of section 504 it applies to, whether its newborns or job discrimination. My lawyer friends can tell me all the rationales for putting it in, but--so that's the first problem.

CHAIRMAN PENDLETON: Ms. Asch, in your answer, could you somehow--I like what you are saying. Can you tell us what makes somebody unqualified?

MS. ASCH: What makes somebody unqualified?

CHAIRMAN PENDLETON: We hear "otherwise qualified" and "qualified," but is there a category of "unqualified"?

MS. ASCH: Sure. If I apply to medical school having taken no biology courses, I don't think they should let me in.

CHAIRMAN PENDLETON: What about in the treatment process? Or the protection process?

MS. ASCH: It seems to me that in terms of medical discrimination, one can't be unqualified. The fact is, once one is born, one is qualified for the medical treatment that will assist one to live. It is ludicrous to say that one is unqualified for medical treatment.

MR. DESTRO: Well, isn't this--and I don't want to get off on a tangent--but this really seems to be the crux of the difference of opinion between the medical community and even--I read the Bowen opinion with a great deal of frustration, where Justice Stevens and I quote says the Secretary has not even enumerated a theory of discrimination remotely resembling anything invented by the dissent. Basically, the majority is saying, "Well, if the child--if nontreatment for the disabled becomes a treatment, and it seems to me we have a doublethink going on here and I'm not sure how to break that. I wonder if you have suggestions on how to rephrase the law to get around that.

MS. ASCH: I would take "otherwise qualified" out, not only in terms of medical discrimination only, but throughout section 504. That's one thing I would do. I would make explicit within the regulations of 84.51 and following, that if section 504 applies to discrimination in the receipt of health services by providers of particular facilities, it has to include receipt and information about the types of services that would be given in a particular medical situation if there were no otherwise presumably not reparable disability in question.

I mean, if, for a child without Down's syndrome, you take care of an esophagus that needs surgery, then you take care of it for the child with Down's syndrome. To fail to do so is clearly discrimination. It is nonsense to say that's a unqualified disabled child. I think it may be that the regulations in subpart F need to be strengthened, but I don't even really understand why there's some discussion about reshaping the statute. It might be that the regulatory process needs some work. Some lawyers might be better at commenting.

I would like to make two quick points, though. Because of the medical model and its pervasiveness within the hospital and within the neonatal unit, one thing that the Supreme Court's decision did somewhat support is a hospital ethics committee or an infant bioethical review committee as it is sometimes called. A disability perspective must be on those committees. And that's not a disability perspective provided by the orthopedic surgeon or the director of a rehabilitation hospital or a rehabilitation unit. It is a disability perspective provided by people who are working as advocates in disability political education and civil rights issues within the community. That perspective is virtually never represented on hospital ethics committees.

Furthermore, if we took disability civil rights out of a whole rehabilitation medical framework and put it into civil rights laws where it properly belongs, we might be better able to show how much these are civil rights issues and not medical issues, rehabilitation issues, and service issues.

MR. DESTRO: Mr. Kemp, did you have a comment on that?

MR. KEMP: Adrienne is hitting the points exactly as they should. The question revolves around "otherwise qualified," and it ought to be removed. In the regulatory process it has been misapplied. In the civil rights concept it has been misapplied. When it comes to treatment of disabled infants, there's no question--why even have a qualification for it?

The laws that defined qualified handicapped individuals as, for employment purposes, people capable of performing essential functions of jobs, and then it gets into eligibility criteria for health-related matters. What does it take to be eligible to receive health care services? It should be removed from that part of it. I concur with the rest of her comments.

MR. DESTRO: Let me ask you from your perspective of dealing with the Easter Seal Society: Do you have a lot of dealings with people at the State and local level on care and treatment kinds of issues?

MR. KEMP: We have some dealings. Not a lot. We are slowly moving out of the medical rehabilitation business. We still have some medical rehabilitation facilities, but we're more into other kinds of services now.

MR. DESTRO: I'm interested in looking at again, across the board in terms of the State attitudes, the official attitudes, more so than the doctors' attitudes now. And the question that I have is--it goes somewhat to the question of the Child Abuse Amendments and whether or not they are sufficient, but it seems to me that a lot of reliance has been placed on State agencies to enforce the rights of the disabled infant against the parents. And that's really where all this takes place, it is done, in the context of child abuse, and as many witnesses have said so far, none of these questions would even come up if the child was not disabled. My question is: In your experience with State agencies, are the State agencies affected by the same kinds of prejudice that people say the medical profession is?

MS. OWEN: May I address that? I did do a review of the professional literature in social work education, MSW programs. In my review of the literature, I found no material dealing with the positives of life as a disabled person. There were several that helped what were so-called healthy families deal with the tragedy of having a flawed infant or child; and at the other end of life, there were some that attempted to help families deal with an aging member. There were some references to emotional disabilities in the working years of life, but this professional group literature does not reflect in any way, any of the productive potential of disabled people, and I would submit to you that that is not unique to that particular professional group.

There needs to be curriculum revision as people begin to prepare themselves to make life and death decisions that deal with a group of people about whom they have been ill-prepared.

MR. DESTRO: Do you have a copy of your review of the social work literature?

MS. OWEN: I didn't bring that with me, but I could submit that.

MR. DESTRO: Would you please do that, because the question, and this really is my last one, is: Could you draw a little better connection between the attitudes in the literature of the social work profession and what goes on in the State agencies? Why do you consider that to be a relevant connection?

MS. OWEN: I think that it is based on the history of the emergence of that particular professional discipline, just as it is with the rehabilitationist in various transformations. Those helping professionals grew out of a period of time when the medical profession was developing oaths and professional protections that eventuated their currently being next to God. Now, it was probably wise from a professional point of view to adopt that medical model as the way they would go, and I would suggest to you that many social workers see themselves as junior medical people, as do other caretakers, so that the mindset--the way to begin to conceptualize people out there is to divide them in--I call it a tyranny of the bell curve, an idea of normality, which, of course, is a mathematical formulation.

MR. DESTRO: I guess my question was a little more simple than that. I didn't want to put words in your mouth, but I would like to get it. Ms. Asch, you can address that in a second. I wanted to finish the question, which is, you know; Are most of the people who work in these child abuse agencies social workers?

MS. OWEN: Yes, and they have been trained not to think about disability in a positive, productive frame of reference.

MR. DESTRO: Ms. Asch?

MS. ASCH: Basically that's what I would reiterate. Social workers are trained as social workers. When they have anything about disability in the curriculum, it is disability from the tragedy framework, and there is certainly no positive view about how families could live with the disabled child in anything but trauma and distress.

The child abuse agencies are staffed by social workers. They have no reason to think otherwise. It has been very difficult for people with disabilities to get into the social work profession to get trained, or to take positions of responsibility and change it.

So social workers, like everybody else, are brought up in a culture that devalues people with disabilities. And there's no reason to think that they're not going to bring that devaluing right to their work and they say, "These poor parents, I really understand why they don't want to treat this child. It's not really child abuse. I don't care what the law says. It is really understandable. The child is going to be a great burden."

If you think about clients as people who need help and are below you, and that's certainly how social workers are unfortunately taught to think, you are certainly going to think that about your disabled infant who is the lowest of the low and the most vulnerable of the vulnerable.

CHAIRMAN PENDLETON: Ms. Asch, I can't let the opportunity go by. I think it is important that we know--we have to give some guidance and make some recommendations on many things. Your comments about the administration with respect to a lot of things prompts me to ask you what specifically in the area of civil rights protections for handicapped newborns would you want us to transmit to the administration? The adjectives you use, I can understand those, but what is it you specifically want us to transmit?

MS. ASCH: Two things. You can't deal with the rights of newborns with disabilities, and as you will notice, I have been referring exclusively to newborns as newborns with disabilities. If there are disabilities, there are diagnoses that are a biological problem. The handicaps are a social problem that we create for them. We have to do two things, I think. We have to make sure that the regulations of subpart F are strengthened, or that the statute, section 504 itself, is strengthened, if that's really the way it needs to go. Somebody else can talk about that.

The other thing is that those civil rights have to be in a full context. That means the passage of the Civil Rights Restoration Act to get rid of the horror of Grove City. It probably means reintroduction of civil rights legislation that would put people with disabilities in Title VII of the Civil Rights Act and getting us out of a rehabilitation model and a medical model where we don't belong.

CHAIRMAN PENDLETON: Just one other question. Anybody can answer this. What is it--is there something magical about having to be designated a minority to get protections and attention? Isn't that also a kind of doubly demeaning situation? The government somehow designates in order to treat groups of people, whether by race or gender or physical condition; you have to be somehow designated as a minority, and then we can do something about it. Is that fair?

MS. ASCH: I want to get my crack in about it. There's a piece I wrote entitled "Personal Reflections," which, if you want, I'll submit.

CHAIRMAN PENDLETON: I would love you to submit it.

MS. ASCH: In it I comment that were it not for what society does, we wouldn't have to have topics, meetings, studies, reports or laws about people with disabilities or any other group; but the fact is, if society is going to define you some way, you had damn well better do something to get out from under the problems that that definition imposes for you.

As I once put it in this article, when someone asked me why I stood under a particular sign for disability, I said I had not decided whether I wanted--this was a group exercise--whether I wanted to stand under a disability sign or a sign for woman. And an acquaintance commented, "If you hadn't stood under the disability sign, I would have said you were denying it." I said, "It is you and your attitudes that put me under that sign, not my disability. You put me under that sign. You and society make it necessary for me to declare myself a member of a protected class because you do things to me because of your assumptions about my class membership. Then I need protection. I'm happy to be just an ordinary person. But if you are not going to treat me that way, I had better do something to get you to stop doing what you are doing."

So when we have a time when there's no discrimination based on class membership and people are viewed as individuals, we can get rid of all these laws, but we are far from that time.

CHAIRMAN PENDLETON: I'm sorry. I wasn't trying to talk about getting rid of laws, I'm just trying to find out the--designations do have problems for people, and I just wanted to hear you answer that.

MS. ASCH: But without them we are in worse shape.

MS. OWEN: I would like to mention an article included in this packet that is called "One Last Bastion of Segregation." In it I suggest that this is the last civil rights battle that needs to be fought because if, as a nation, we can create an environment, whether it be physical or social, that is accepting of the range--doesn't concentrate on the bell curve, but accepts the range over which human beings are spread, then there is no need for further civil rights efforts. We will be treated as individuals. It will be a world of dignity. We may disagree on the time frame in which that can transpire, but I think that is all our goal. All of us.

CHAIRMAN PENDLETON: Mr. Destro?

MR. DESTRO: Ms. Asch, I wanted to ask you a favor for the record. You recounted some cases of other medical care discrimination against adults and women in access to medical care. Do you have any kind of a summary of those cases that you could submit for the record? Because I don't want them just noted on the record. If you have some specifics, we would certainly appreciate them.

MS. ASCH: Let me ask you whether the kind of material I have will do as a summary. First, I do have some unpublished dissertation research data that I can put together, and I cite sources. Unfortunately, for a lot of the adult discrimination and medical discrimination, particularly as it applies to women, there are few written documents. There are enormous amounts of evidence that have come to me in my research. But I can note names, I can note numbers. What would you like?

MR. DESTRO: Whatever you think is going to be relevant for the record. I guess I don't want to throw it back in your corner in that way, but I keep coming back to the statement of Justice Stevens in the Bowen case, that there wasn't any evidence. What I would like to see--I think the interesting things in most of the civil rights is the connections between them and the ways you might deal with them in a consistent basis across the board. I tend to think handicapped infants are just the tip of the iceberg and I would like to see a connection made in this record, so whatever you think is going to be the most persuasive--

MS. ASCH: I think what needs to get on the record is that a lot of those instances of medical discrimination are extraordinarily painful and private. Not only are they often physically devastating to people and women, but they are psychologically devastating. It is not necessarily easy for people to go public with denials of obstetric care or disgraceful comments from gynecologists about, "get your tubes tied, you can't take care of a child." Those are very painful matters that people don't necessarily want to go public about. They will report them in private groups, but you have to understand why it is difficult to collect that data and put it in a form that will be a document for the record. I will do my best.

CHAIRMAN PENDLETON: I thank the panel very much. We'll have a short break and have Mr. Bopp. Thank you very much.

[Recess.]

ADEQUACY OF THE CHILD ABUSE AMENDMENTS

Testimony of James Bopp, Jr., Brames, Bopp, Haynes and Abel, Terre Haute, Indiana

CHAIRMAN PENDLETON: Mr. Bopp, could you please raise your right hand?

[The witness was sworn.]

CHAIRMAN PENDLETON: Counsel?

MR. PASCALE: Thank you. Could you please state your name and address and current position or occupation for the record?

MR. BOPP: Yes, I'm James Bopp, Jr., B-o-p-p. My business address is 191 Harding Avenue, Terre Haute, Indiana. I'm a partner in the law firm of Brames, Bopp, Haynes and Abel. I'm a member of the President's Committee on Mental Retardation and president of the National Legal Center for the Medically Dependent and Disabled. Also, I am general counsel for the National Right to Life Committee in Washington, D.C. I have been involved in several of the major cases that have related to this issue. In 1982 I represented a couple from Evansville, Indiana, who sought to adopt Infant Doe while Infant Doe in Bloomington was still alive, and I filed on their behalf, pleadings in the Bloomington court that were the subject of a hearing. That attempt for temporary guardianship was unsuccessful and the child died that evening.

I'm also counsel for Carlton Johnson and his mother and others. Carlton Johnson, whom I describe in my testimony, is an infant who was born with spina bifida and was refused treatment at Oklahoma Children's Memorial Hospital based on nonmedical social, economic, and quality of life criteria. I'm representing him and his mother and others similarly situated in seeking to redress that denial of treatment. I've authored briefs in the United States Supreme Court in the Bowen case on behalf of Carlton Johnson in one brief, and in a second brief, on behalf of Senator Orrin Hatch and Representative Austin Murphy, the chief sponsors of the Child Abuse Amendments of 1984.

MR. PASCALE: Do you have an opening statement you would like to read?

MR. BOPP: Yes. In 1984 President Reagan signed into law the Child Abuse Amendments, which went into effect in October of 1985. In general, the Child Abuse Amendments of 1984 require States that receive Federal funds for child abuse and neglect agencies to regard withholding of medically indicated treatment from disabled infants with life-threatening conditions as a form of child abuse.

States must require prompt notification of suspected instances of such withholding by individuals designated by each health care facility, and provide for an appropriate investigation and pursuit of legal remedies by the State child abuse and neglect agency as needed to prevent withholding of medically indicated treatment.

It establishes grants to improve the provision of services to disabled infants with life-threatening conditions; it establishes national and regional clearinghouses, and required the issuance of regulations by the Department of Health and Human Services which, on May 15, 1985, were promulgated by the Department.

Prior to the passage of the Child Abuse Amendments of 1984, unfortunately, the record of child abuse protective service agencies in infanticide cases was not a good one. In the case of Infant Doe in Bloomington, Indiana, the child neglect and abuse agency took no action even after it was appointed guardian ad litem for the purpose of appealing a judge's order which denied the child medical care, food, and water.

In the case of Kevin of Robinson, Illinois, the child abuse and neglect agencies in Illinois were aware that this child, who was born with spina bifida, was not receiving appropriate surgical treatment, and the authorities did nothing. It was not until the Department of Justice and the Department of Health and Human Services threatened to sue State and local authorities and to terminate Federal funds, that the State child abuse and neglect agency acted to protect Kevin. And Kevin now walks with braces and has normal or higher than normal intelligence.

In the Baby Jane Doe case in New York, the New York Attorney General's office defended the decision of the physicians of Baby Jane Doe to deny that child medically indicated treatment. Baby Jane Doe was in a State hospital, and the Attorney General represented the hospital's interests, which were evidently conceived to be served by the withholding of necessary surgical care for a child born with spina bifida and hydrocephalus.

I think the intent of the Child Abuse Amendments of 1984 was to remedy this failure to act by State child protective service agencies and to help marshal State resources and expenditures to implement the Federal policy protective of handicapped infants.

There are several reasons, though, why we need to be concerned about the willingness of State child protective service agencies to act in appropriate circumstances, as required by the Child Abuse Amendments of 1984. There are no doubt many instances in which agency personnel in child abuse and neglect agencies agree with the quality of life judgments that underlie many nontreatment decisions for children born with disabilities, even though this is not a proper legal criterion under the Child Abuse Amendments of 1984. I do have a particular perspective on this for members of my law firm, both in Indianapolis when I practiced law there and now in Terre Haute, have represented respectively the Marion County Department of Public Welfare, which is in Indianapolis and the Vigo County Department of Public Welfare in Terre Haute. In addition, my wife was a supervisor at the welfare department in Vigo County for 5 years and currently serves on the board of the welfare department in Vigo County.

Unfortunately, the way that child abuse and neglect agencies customarily operate means that actions to protect disabled infants with life-threatening conditions who are denied medically indicated treatment is quite unfamiliar territory and involves expertise and time that child protective service workers do not have.

Because of this, the organization representing social workers opposed the Child Abuse Amendments because they would force them into unfamiliar territory. In addition, there is an ongoing relationship between hospital personnel and the child abuse agencies in the other cases with which they deal. Child abuse agencies rely heavily on reporting from hospitals and physicians about instances of abuse and neglect which they would see in their emergency room, and of course in those circumstances, the hospital personnel and the physician are acting as an ally of the child protective service agency.

In these cases, however, the child protective service agency is in an adversarial relationship with the hospital and the physician, and it involves the case worker determining whether or not the physician has acted appropriately and made appropriate recommendations of treatment. So this is not only an unfamiliar but a quite uncomfortable adversarial relationship for an agency whose job normally depends upon the cooperation of these very same individuals.

Now the case of Johnson versus Sullivan, the case of Carlton Johnson in Oklahoma, is a good example of both the conflict that can arise between the responsibilities of the child abuse and neglect agencies under the Child Abuse Amendments of 1984 and the problem of medical treatment decisionmaking which underlies all of this.

In the Oklahoma case, for instance, the Oklahoma child abuse and neglect State authority is the very same State authority that operates the hospital at which the children were denied medically indicated treatment. You then have a situation in which the two agencies which may be involved, one in denying medical treatment and the other in enforcing and insuring that medical treatment is provided, are within the same department of the State government. It is difficult to believe in that circumstance that child abuse and neglect agencies would take enforcement action against a hospital that is a member agency of its own State department.

In addition, the decisions that were made at Oklahoma Children's Memorial Hospital, I think, point out the reality of medical treatment decisionmaking which unfortunately, as demonstrated in the Bowen case, is not properly understood. The Oklahoma experiment was reported in an article in Pediatrics Magazine in 1983. The article described a selection process that began in 1977, and the reported period ended in 1982 in the article, where the selection process for determining which infants presented at this hospital with spina bifida would be treated and which would not be treated.

Treatment of spina bifida involves the closure of a spinal lesion in order to prevent infection and to prevent further disability as a result of the condition. It is also that closure that often prevents the death of the child due to infection.

Secondly, if the child has hydrocephalus, which is a frequently associated condition, the medical treatment involves the insertion of a shunt in order to drain the spinal fluid and prevent damage to the brain. At Oklahoma Children's Memorial Hospital, there was a team of physicians, social workers and others, many of whom were employees of the hospital and thus acting as its agents, who employed explicit quality of life criteria in making a decision about whether or not a child would be treated or not treated.

The team used a formula which was QL equals NE times the sum of H plus S. The formula is: quality of life equals NE, which represents the patient's natural endowment, both physical and intellectual--now at this point in the formula, they would call up their predictions of the future ability of the child with treatment to have a full intellectual capacity, to be able to ambulate, and other predictions that they would make about the child's personal quality of life. And then they would add to that H, which is contributions from home and family, and in this case they mean the financial and intellectual resources of the family, plus S, which is the contribution from society, and this is whether or not they consider appropriation levels by government for programs that assist persons with disabilities to be adequate.

They used all of those considerations, nonmedical social and economic criteria, to decide whether or not they would recommend what is otherwise medically indicated treatment for these children. They did not recommend--they recommended against treatment in some 48 percent of the cases. Twenty-four of these infants were eventually not treated, and all of them died within 189 days.

They were not--if not treated, in addition to not being provided surgical procedures, they were not given antibiotics for the inevitable infections that would rage up and down the spine and into the brain of these children, nor were they given sedatives to control the pain that would flow from it.

They describe in their article, and of course this raises the critical point, that in the way that they recommended treatment to the parents--they did not disclose the nonmedical social and economic criteria and prejudice against the handicapped that they utilized in coming to their decision about whether or not the child ought to be treated. They presented their recommendation in a very pessimistic way, often masking it as an actual medical treatment decision in saying things such as, "the child is going to die anyway with treatment."

Indeed, Ms. Johnson, one of the plaintiffs that I represent, the mother of Carlton Johnson, said, and I quote, "The only thing they told me was about a shunt, and this, you know, after they told me about six months, that he would live six months without it, and with it a year. I just figured, what's the sense? He already suffered, so why should he suffer any more?" Obviously, Ms. Johnson was not informed correctly about the medical prognosis of closing the spine of this newborn infant, and indeed he is still alive today, one of the biologically tenacious survivors in what has been otherwise a very lethal experiment at a major hospital in our country.

It is not surprising that Carlton Johnson was selected for no treatment. His mother was on AFDC, was unmarried, she is black and uneducated, and the child was born out of wedlock. These are the very criteria they say they take into account in determining not to provide beneficial medical treatment for such children.

A suit has been brought both by attorneys of the National Legal Center and also attorneys of the American Civil Liberties Union and others in this case, alleging a whole variety of Federal civil rights and constitutional law violations.

I don't think there's any question that this case represents the application of a wide variety of Federal statutory and constitutional law protections that apply in cases of denial of medical treatment to disabled infants. I don't think that it is a question of whether or not there is--it is going to be or is not going to be a Federal role. There already is a Federal role by the application of a wide variety of statutory and constitutional protections that protect infants such as Carlton Johnson when they present with a medical problem and present at a State-run facility at which decisions, discriminatory decisions, are made about medical treatment.

So the question of the sufficiency of the child abuse and neglect law, I think, can be readily understood when we understand its limited application. The Child Abuse Amendments of 1984 only apply to State child protective service agencies, only require them to take action. They do not--and the penalty for failure to take action would involve then only a denial of Federal financial assistance to the State child abuse and neglect agency. There is what I consider to be a very good substantive law standard adopted by Congress in the Child Abuse Amendments that does not apply to hospitals or physicians as State actors who are the actual agents of discrimination.

In addition, the Child Abuse Amendments do not provide a private cause of action for an infant like Carlton Johnson either to obtain treatment that he is being denied or to compensate him for his injuries. I think the analogy would be if someone came before you and said that all we need in terms of Federal civil rights protection for blacks is that we will give Federal financial assistance to a State-appointed and State-run agency whose job will be to run around and seek out people who are discriminating, and if they fail to take appropriate action, we'll just simply withdraw the Federal financial assistance.

If that was the approach that was taken in 1964 in the Civil Rights Act of 1964, with the types of protections that blacks needed, you can imagine the simple response of many States, and that is: They would decline the Federal financial assistance, which would therefore remove the obligation of any State agency to act to protect the rights of persons who are black.

That is the apparent approach that some would argue is the appropriate approach in this circumstance. I would argue, however, that the Child Abuse Amendments are quite limited in scope, in application, and in projected enforceability, and that what we need are substantive law standards that apply to the actual persons who are discriminating, and that would be physicians and other health care providers at hospitals that make discriminatory recommendations to patients about medical treatment.

So I think that there are quite substantial limitations on the Child Abuse Amendments, even though they do represent a step forward in this area.

Now to supplement my oral statement, I would request permission, Mr. Chairman, that the following documents be submitted for the record. First is my written testimony, which I have prepared, and parts of which I have just summarized. Second is an article entitled "The Child Abuse Amendments of 1984 and Their Implementing Regulations, a Summary," which is an article that I coauthored concerning the Child Abuse Amendments and that was published in *Issues in Law and Medicine*. Third is the *Pediatrics* article I just referred to, published in October 1983, entitled, "Early Management and Decision-making for the Treatment of Myelomeningocele," which concerns the Oklahoma experiment.

Next is the brief amicus curiae of Carlton Johnson, the plaintiff I represent in Oklahoma, submitted in *Heckler* versus *American Hospital*

Association, which gives many more details about both the Oklahoma case and the need for Federal substantive law protection. The next is the brief amicus curiae of the Honorable Orrin Hatch and Austin Murphy who were the chief sponsors of the Child Abuse Amendments of 1984, that addresses an issue that was raised in the hearings last year. There were repetitive statements by medical and hospital personnel claiming that Congress intended, by the adoption of the Child Abuse Amendments of 1984, to preclude application of 504 or other Federal law protections in this area. The two chief sponsors of the Child Abuse Amendments in this amicus brief point out quite clearly that that was not the intent of Congress.

Finally, are two articles that address what I consider to be the most important problem or question that needs to be addressed in this area, which is the ability of physicians in using nonmedical social and economic criteria and prejudice against the handicapped to determine, in fact, what parents will consent to or not consent to.

The first of these two articles is one by Thomas E. Elkins, who is at the University of Michigan Medical School, and the name of that article is, "An Approach to Down's Syndrome in Light of Baby Doe." He and his coauthor review the immense emotional and psychological burdens that impact on a parent at the birth of a child with disability.

The second is the article, "Medical Authority and Infanticide" by Patrick Molen, published in the Journal of Law and Health, which discusses the power that physicians have to determine parental or patient consent to medical treatment in looking at the position that physicians have. I would request that these items be included in the record.

CHAIRMAN PENDLETON: With no objection, they will be included in the record. Mr. Pascale?

MR. PASCALE: Thank you.

Do you believe that the remedies provided by section 504 are superior to those in the Child Abuse Amendments; and if you do believe so, could you specify those differences?

MR. BOPP: I think the remedies available in 504 are superior. The Child Abuse Amendments of 1984 require, at the pain of loss of Federal funds, State child protective service agencies to act. That is quite in contrast with the application of 504, which provides a substantive law standard for the entities that are discriminating against persons with disabilities in the delivery of medical care, which are hospitals and hospital employees and others who are recipients of Federal financial assistance. So the Child Abuse Amendments are quite indirect in their ability to influence the discrimination that is occurring within hospitals.

Second, section 504 provides for private remedies, remedies where a child who is denied treatment can go to Federal court and insist upon treatment if a hospital would deny treatment or, second, may seek damages to compensate him for his injuries.

Third, actions by State child abuse and neglect agencies only occur on a case-by-case basis. Section 504, in contrast, can be the subject of a class action; it can also be the subject of declaratory and injunctive relief to protect infants in the future from an institutionwide program of discriminatory denial of medical treatment, such as occurred in Oklahoma. The Child Abuse Amendments only would involve a case-by-case protection of then-alive infants that are denied treatment, whereas under section 504 you can get injunctive relief to prohibit the hospital from using this form of criteria and protect all future infants.

I think there's an appropriate role for Federal oversight available through 504 that is not available through the Child Abuse Amendments. That is, the people we're talking about are hospitals and health care providers. Those are the ones that need the Federal oversight, not the child abuse and neglect agencies which are not in and of themselves denying treatment.

I think, with the reservations I have described about the willingness and continued willingness of the child abuse and neglect agencies to act in this area, that there needs to be strong Federal oversight order to insure proper medical treatment for these children.

MR. PASCALE: In the last year or so, since the Child Abuse Amendments have been in effect, have they had, in your opinion, any beneficial effect on the problem?

MR. BOPP: I think that they did have some beneficial effect because the Child Abuse Amendments incorporated two, I think, very positive principles. The first principle was that medically indicated treatment should not be denied to an infant born with disabilities, and it established three clear standards on that.

Number one is that food and water shall be provided to a disabled infant in all circumstances. In other words, provisions of food and water are not optional. It is not a form of medical treatment. It is minimal care, comfort care that's required to be provided to all human beings, including disabled infants. The second standard is that quality of life considerations may not be taken into account in making what should be a medical decision about treatment. The third standard is that the only exceptions to the requirement of medically indicated treatment are when the provision of the treatment would be futile in correcting the physical abnormality, life-threatening abnormality that the child has; when the child is born dying; or when there is no available beneficial care available for the child.

The second principle that the Child Abuse Amendments incorporated was that parents' decisions about this do not enter in the inquiry. The State child abuse and neglect agencies are required to go to court to override a parents refusal of medically indicated treatment for a disabled infant. Thus, the State government is required to act to override parental refusal to consent to provide care to the child that the child needs. So I think to that extent, that the Child Abuse Amendments many times are a very positive contribution to the law and have established an appropriate standard that ought to apply to medical treatment decisions.

I think that the Bowen case, coming about a year or so after the Child Abuse Amendments went into effect, has negated some of the value of the Child Abuse Amendments, not because the Bowen case has anything to do with the law, what the Child Abuse Amendments would require, but because it is giving the wrong signal. The signal is--as opposed to the substantive law requirements of the Child Abuse Amendments, the signal now is, and you read in medical journals, if parents refuse treatment, then that ends it; the Supreme Court has said that, there's no discrimination if a parent refuses treatment. That just throws us back to the same conceptual framework we had before.

In other words, before the Child Abuse Amendments, all the physician had to do was to present the information in such a pessimistic light that they know that almost invariably, if done in that way, and because of the authority they have over parents and patients and because of the emotional state of parents when a child is born with a disability, they can manipulate and guide and determine what parents will consent to or not consent to.

So now we're back to the old problem, which is that that's all they have to do, and that is something they are quite adept at accomplishing, too often using nonmedical social and economic criteria or prejudice against the handicapped to do that. So I think some of the positive effects of the Child Abuse Amendments have now been, well, not directly impacted in terms of a legal analysis, but certainly diminished in terms of public perception. And our hope is that the medical profession will incorporate within its own activities the notion that it ought not to use this type of criteria to guide medical treatment decisions.

MR. PASCALE: Thank you. I have no further questions.

COMMISSIONER DESTRO: Mr. Bopp, do you have any information regarding the number of times, to your knowledge, that Federal funds have ever been withdrawn for noncompliance in any area of civil rights law?

MR. BOPP: I don't--

CHAIRMAN PENDLETON: I just want to caution you this is a good question. In any area of civil rights law, do you know of money being cut off, Federal money being cut off?

MR. BOPP: I personally don't know of any. I'm not an expert on Federal financial assistance in all areas, but I would expect that government agencies whose job is to distribute Federal funds would be quite reluctant to withdraw funds even in circumstances in which there is gross noncompliance with the provisions of the act. I think there's a natural and understandable reluctance to do that; quite particularly in this area when we're talking about the Child Abuse Amendments, it is not of much effect. The vast majority of funds that fund child abuse agencies, such as in the State of Indiana, are from county and State funds. Indeed, Indiana does not even receive funds under the child abuse prevention and treatment program, and it was in Indiana where the paradigm case occurred. And so fortunately, we have changed our own State law to protect future Infant Does in Indiana, but without that, the Child Abuse Amendments would, of course, have no effect.

CHAIRMAN PENDLETON: If you will allow me to follow up with a question. It does seem to me--here we have a situation where the Federal Government imposes policy without dollars, and it is incumbent upon the State governments to take on Federal obligations, and there's talk about the Federal Government not providing enough money or--it is not that the Federal Government is not providing the money, it is that those that represent people at the State government levels have decided that's a State responsibility. And if that's the State responsibility, then how do you see us, this Commission, if you will, making some statement about how the funding process should occur?

MR. BOPP: Well, I think that I would focus the attention a little bit differently because I think the Child Abuse Amendments of 1984 was a good law to adopt. I think it incorporated appropriate standards, and it is appropriate that State child abuse agencies treat denial of medically indicated treatment to infants as a matter of medical neglect, as it truly is.

I think the proper Federal focus, though, is not to treat this matter as a matter of child abuse and neglect which is properly and primarily a State function, but as a matter of civil rights protection. The proper focus is on protections afforded by the 5th and 14th amendments to the Constitution, where persons with disabilities are being denied equal protection of the laws even under the Cleburne standards. The Medicare protections that apply, requiring equal treatment, also provide

Federal law protections, and there needs to be positive civil rights legislation that provides a substantive law standard on health care providers to prohibit them from using nonmedical social and economic criteria and prejudice against the handicapped, in providing medical treatment. So I think this is properly considered on a Federal level as a civil rights matter, and that it is not exclusively a State matter of concern but is a proper Federal matter of concern.

CHAIRMAN PENDLETON: You're saying there's a compelling Federal presence that needs to be handled here?

MR. BOPP: I think there does need to be that. I think that discrimination against persons with disabilities is properly considered a denial of civil rights when it is done by State entities or State-financed entities, when it is done by government. And in many cases we're talking about people either receiving Federal financial assistance or who are in fact State employees, physicians, social workers, and others making these decisions and recommendations about treatment, and they are using discriminatory criteria.

COMMISSIONER DESTRO: Is that why you see a need for a private right of action here instead of a funding withdrawal?

MR. BOPP: Yes. I think the proper focus of civil rights, although it has an important Federal enforcement component--I don't see that as the primary value of Federal substantive law civil rights protections. I think this is a matter in which private parties, those who have been the victims of discrimination or who represent persons where State entities have adopted discriminatory criteria, can enforce their own rights. And although I think it is important to have a Federal oversight responsibility and involvement in the Justice Department and others in appropriate cases, there needs to be a private cause of action for people like Carlton Johnson.

I think there was and still is, even under the Bowen rationale, a need for appropriate Federal substantive law protections that they can enforce themselves. I think the great victories in other areas of civil rights have come from litigation by private parties representing the victims of discrimination who have caused changes, appropriate changes, in discriminatory activities of government, and that's an important component of civil rights protection.

COMMISSIONER DESTRO: Isn't what you are saying, though, that in the absence of a private right of action--and I think that's still an open question; that's part of the question I think you are asking in the Oklahoma City case, isn't it, whether or not there's indeed a private right of action for a child under 504 in one of these cases? As I read the Bowen case--I'm not sure what the plurality of the Supreme Court said about the application of 504 to handicapped infants, but isn't the alternative turning a 504 case into a medical malpractice case, and isn't that what we're really teetering on the brink of, that the only alternative you have is a medical malpractice case where the standard of care in the community becomes the standard by which the case is judged?

MR. BOPP: That's right. If these matters are not judged as civil rights cases, and there are not Federal civil rights protections that are available, the only remedy is through State medical malpractice causes of action. And when you are talking about medical malpractice, you are talking about the standard of care that is provided by physicians within the locality in which this child is treated. Well, in Oklahoma City, at Oklahoma Children's Memorial Hospital, which is the proper place to look to to determine whether or not there is malpractice, or may be the proper place, arguably anyway, what you have is a standard of practice in that locality which is to deny medically indicated treatment to infants born with disability, specifically spina bifida, based on nonmedical social and economic criteria and prejudice against the handicapped.

You have physicians who have adopted a standard of practice of discrimination that cannot then be redressed by a medical malpractice cause of action. I guess my point is: These matters that we are addressing cannot be left to physicians to decide what criteria they are going to take into account in what ought to be a medical treatment decision. They are not making medical decisions based upon medical criteria, like if you have a blocked esophagus, are there available therapies, surgical procedures, that can unblock the esophagus and allow normal feeding and relieve the child of a life-threatening condition.

What they are doing in these cases is: they know that that's available, but they are saying, "We ought not to provide medically indicated care because the child has Down's syndrome, because the child has a potential for mental retardation, because the child may not walk." These are all nonmedical social and economic criteria, discriminatory criteria based upon handicap. If they would just not adopt other roles for themselves in doing this, but stick to their training and their job, which is to talk about medical treatment when there are physical problems and other problems that can be addressed, then we would be in a position in which there wouldn't be the problem of discrimination or denial of treatment that we have. But unfortunately, as other witnesses have indicated, particularly Professor Turnbull, there are, pervasive within the medical community, attitudes and approaches that use this type of criteria.

COMMISSIONER DESTRO: Are there other cases, to your knowledge, of medical care discrimination out there besides Oklahoma City that either the National

Legal Center is looking into or other agencies like yours are looking into?

MR. BOPP: Yes. And it cuts across the age spectrum. There have been--and several of which have been mentioned in articles that describe denial of medically indicated treatment based upon disability that has been published in other medical journals. I think Professor Turnbull mentioned there are six articles other than the pediatric article, just on the neonatal circumstance, which describe what happened similarly to what happened in Oklahoma.

But equally so, there has been a growing number of court decisions that have allowed the withdrawal of beneficial medical care or therapy or even food and water from persons, based upon their degree of disability. The seminal case in this area is the Quinlan case, where the New Jersey Supreme Court decided that Karen Ann Quinlan could be denied a respirator. This they thought was a life-sustaining treatment, not because the respirator didn't provide--wasn't beneficial to Karen Ann Quinlan in aiding her respiration, but because they said that Karen Ann Quinlan did not have the prospect of returning to a sapient state. Therefore, because Karen Ann Quinlan might not fully recover and be fully functioning mentally, then you can deny medically indicated treatment to her.

And there's been a whole series of cases involving people ranging in age from Phillip Becker at 13, to 87, where the criterion that the courts are beginning to use is degree of recovery or mental incapacity or physical incapacity of the person: judging whether or not their lives have value, the lives of these persons, be they Nancy Jobes or Paul Brophy or Baby Barry or many others, looking at the value of the patient's life, rather than the beneficial things that either the treatment or even food and water can provide the person.

COMMISSIONER DESTRO: Last question. I think you have covered most of the issues I wanted to cover. On one of the panels this afternoon, we're going to be talking to some medical people, and we have some of the articles that they have written. In your experience in investigating these cases, who generally initiates the idea of not treatment or nontreatment or withdrawal of treatment? Is it the parents or is it the doctors?

MR. BOPP: Not in every single case, but in almost all cases, that question is raised by the physician, and he raises it based upon disability. He raises a question that involves a disabled child that he would never raise involving an otherwise, quote, "typical," end of quote, child.

COMMISSIONER DESTRO: In the Carlton Johnson case, did the doctors raise it first or did the mother raise it first?

MR. BOPP: The physician raised it first in the case of Carlton Johnson.

COMMISSIONER DESTRO: How did they raise it?

MR. BOPP: In making the recommendation to Ms. Johnson that she ought to refuse medical treatment, they said that the child is not going to live even with treatment, that she has an option to refuse treatment that is available, that they would perform if she consented to it, but if she refuses to consent, they won't perform, and that she has no obligation to consent to it. And of course, this is unthinkable in the case of an otherwise typical child, that this question would even be raised, that you can deny medically indicated treatment to a, quote, "typical child," end of quote; raising the question in and of itself is discriminatory. They are raising that option of denying medically indicated treatment for a child because the child is disabled, as opposed to an otherwise typical child;

that in and of itself is discriminatory and imposes extraordinary burdens on patients.

COMMISSIONER DESTRO: Again I just want to finish this; that point has been made. I guess the real point that I'm looking for is: Does the doctor leave the parent, in your experience, with the impression that the withdrawal of treatment is the medical treatment of choice and that to choose treatment is either worthless or not in the child's best interests? That's really what I'm getting at, because we've already established that the view is that they wouldn't do that for a nondisabled child.

MR. BOPP: That's precisely the way it is normally put, and that is, it is put to the parents as if it is a medical decision based upon medical criteria, and that it is the physician's recommendation that they pursue a nontreatment protocol, where there is available beneficial medical care for the child, and they will even go so far, as one physician on McNeil-Lehrer a week or two ago said, they even go so far as saying, "If it were my child, I wouldn't treat my child."

Now, a parent hearing this assumes the physician is making decisions based upon medical criteria, and the physician is not disclosing to them that they are basing this criteria on nonmedical social and economic criteria. So they assume that the physician is acting based upon medical, a truly medical recommendation, and they couch it exactly that way, and they would hardly expect that a physician would refuse treatment that would be beneficial for their own child. And they don't understand that the physician is basing it on the value or worth of the child, or in some cases, the value or worth of the parents, in making this recommendation.

CHAIRMAN PENDLETON: Thank you very much. This session is adjourned until 1:15, rather than 1:00.

[Recess.]

AFTERNOON SESSION

PERVASIVENESS OF DISCRIMINATORY ATTITUDES

Testimony of Irving Kenneth Zola, Professor, Department of Sociology, Brandeis University; and Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc., Johnstown, Pennsylvania

CHAIRMAN PENDLETON: This is the afternoon panel, panel 7, Pervasiveness of Discriminatory Attitudes.

Professor Irving Zola--and I understand that Ms. Schwaninger will not be here, is that correct?

MR. PASCALE: Yes.

CHAIRMAN PENDLETON: And Ms. Darling. How are you? If you would raise your right hand and take this oath we would appreciate it.

[The witnesses were sworn.]

CHAIRMAN PENDLETON: Counsel?

MS. HANRAHAN: Thank you. I'll start with you, Ms. Darling. If you could state your name, address, and occupation, please, for the record.

MS. DARLING: My name is Dr. Rosalyn Benjamin Darling. I am director of Early Intervention Services at the City Council Clinic in Johnstown, Pennsylvania. Thank you.

MS. HANRAHAN: Professor Zola, your address and occupation?

MR. ZOLA: Professor of Sociology at Brandeis University, executive director of the Boston Self-Help Center; editor and publisher of the

Disability Studies Quarterly. I live at 43 Waban Road Hill North, in Newton, Massachussets.

MS. HANRAHAN: As soon as you get settled, I understand you have an opening statement, Professor, so if you would like to start with that.

CHAIRMAN PENDLETON: We have Professor Darling's statement, and without any objection, it is so entered into the record.

MS. DARLING: That's fine.

CHAIRMAN PENDLETON: Mr. Zola, do you have an opening statement that's written?

MR. ZOLA: Yes, it is not written.

CHAIRMAN PENDLETON: If you want to submit something later for the record, please feel free.

MR. ZOLA: Trying to take advantage of what has gone before, I just wish to set out several points that we may want to be questioned on later. First, the panel is appropriately entitled "Pervasiveness," and I wish to say unqualifiedly that the pervasiveness of negative attitudes toward people with disability is indeed almost all-pervasive, and to some extent in all of us in society.

In the sense that sexism and racism have become parts of our society, the depth of what some of us call "handicapism" is also similarly rooted in many of the social conditions in our society. And as in favor as I am, and I'm sure many others are, of strengthening the civil rights of people with disabilities, we have to be continually aware that it is only a piece of a total problem and of many other issues, including resources, that it has to be part of.

The issues of discrimination in disability and the negative attitudes are all about us. They are parts of the media image that continually assault in many ways all members of our society, and they are part of the daily life of anyone with a disability.

Were it relevant, I could talk about, from the moment that I decided to come here this morning, the kind of subtle discriminations that I encountered as I came from the airport ultimately here.

It is appropriate in many ways that we're dealing with aspects of children, because one of the dilemmas of anyone with a disability is that, far too often, they are treated as if they were a child, which is kind of the experience that I had this morning in coming here.

Second, I wish to note that the issue again of discrimination, and in terms of whom we are considering, goes far beyond children with disability. In fact, in many ways it goes beyond--I'm ambivalent about the term "minority," you had mentioned it earlier, because one of the issues is--there is no doubt in my mind that in many ways we are a perceived minority, but in other ways I think we are a statistical majority.

Building on the comments made this morning, there really is an issue in which, if we try to overdefine ourselves as a particular group with particular diseases, we lose focus on many of the issues facing anybody in our society. Though there may be a figure that is agreed upon at a given moment in time of 36 million people with disabilities, rest assured that everyone in our society, including the people here, is at very least, "at risk." And if you survive beyond the age of 50, you live under the virtual certainty that you will have one or more disabilities for many years and decades of your life which will indeed interfere with your full participation in the society.

My third point. I have no particular great confidence in the medical profession per se as being the repository of wisdom in terms of what is quality of life. In fact, were I pushed, I might even be able to make a case that I think the medical profession may be less well-equipped than other segments of our society to make judgments as to what is the quality of life. This is based on at least a quarter of a century of experience of teaching at medical schools and looking at, indeed, who ultimately becomes a physician and the training to which they are exposed.

A comment may also reflect on other health care professionals. On the same theme of medicine, I would ask you to be very wary of any statements that come forth that the nature of this guarantee of rights will in any way interfere with the hallowedness of the doctor-patient relationship. That is a theme that was heard nearly 30 years ago when medicare was first on the scene, that indeed if funds are paid for that, that third party will interfere.

There have been many complaints about the practice of medicine, but not that medicare has interfered with the nature of that relationship. I see nothing in studies that have been done that would lead me to believe that, indeed, if there is this other form of regulation, that would itself sound a death knell of the privacy of the doctor-patient relationship. That's all I have.

MS. HANRAHAN: Professor, I would like to pick up on something you were just talking about and earlier talked about with respect to everybody being at risk to become a disabled person. Do you find the attitudes vary according to the nature and extent of the disability?

MR. ZOLA: I don't think it does, if by "extent" we mean the seriousness. Often, it has been argued in the Sociological literature--is it worse to have a disability when you're young versus when you are old. To the degree to which it is worse, it has more to do with the fact that given that society makes many decisions that have a permanent quality to them, and they make those decisions tracking young babies and infants at an earlier age, then that would be one reason why the younger you are, the more you are likely to suffer, if you will, the slings and arrows of a society that has negative views toward disability. You may find that, at a moment in time, as the Louis Harris Poll has shown, younger people are more aware of many of the issues of rights and feel a more common identity with fellow men and women who also have disabilities. But I feel that that's a moment in time; the older the population, the more likely they have been sucked into the view of disability being a purely medical problem and thereby left to medical authorities. The idea of rights is in many ways a recent phenomenon in terms of the application to what we're speaking of.

MS. HANRAHAN: Along those lines, is that something that you can draw into people's attitudes--where my question is coming from--there's a gentleman named Paul Wehman from Virginia Commonwealth University who has done some work with vocational rehab for what are considered the unemployable, people that are past the point, almost medically fragile, and severely disabled. And he apparently has a slide show that I am told is very effective because, in the abstract, people can more readily accept that you can have people who are articulate and may be able to get around and speak in their own defense. And people can understand that these people can lead productive, happy lives. But when you get to the severely, severely disabled, is there a difference in the attitudes?

MR. ZOLA: I think that's where we've gotten hooked on the wrong end of the continuum. I would rather start from the position that there is no one who cannot lead a full life in our society, including a piece of it, being a vocation, and let it be proven, if you will, that there is a circumstance in which that doesn't fit. In other words, I want to start with the point of view of guaranteeing the opportunities and trying to alter the nature of the working, the social, if you will, the attitudinal environment, and then let it be, "Oh, this is a case where it doesn't happen to work." Whereas when we start at the other end and start to exclude, "No, these it won't work with," then you have many stories like the ones you have heard the last few days, from people like me. What do I mean? You heard Ed Roberts the other day, and I'm sure as you listened to his testimony, you said, "Oh, my God! They rejected him for rehab, what a waste!" But maybe somewhere down deep, a little voice said, "But you could understand it." You could understand why they might have that feeling. Here he is a respirator-dependent individual and you might think--the prejudices that exist are tied into what people don't know about in terms of really severe.

I'm a contemporary of Ed, and while Ed was in the State of California, I was in the State of Massachussets. I was approaching my vocational rehab around the same time that he was his, meaning the fifties. Both of us were post-polio and I, relatively speaking as you see, aside from the weight and the gray hair, was pretty much like I am today. Long leg brace on one leg, knee support on the other, back support, use two canes. That was essentially what I was.

At that point, my school, my rehab agency, etc., even though I, unlike Ed, had already shown that I was in the top 10 percent of my class at Boston Latin School, the view of what disability could do was so pervasive, that they advised that I go maybe to a vocational high school and were upset when I was accepted at Harvard University.

So in other words, we would like to think that it is totally in the seriousness because that might say, "God, you know," but it is that much more pervasive of what somebody else said/of perfection, a perfect child. If it is a little off, it doesn't matter how off--

MS. HANRAHAN: Is that something you realistically think parents and doctors--is that an attitude that they can assume at the birth of a handicapped child? Is there really going to wind up being a different attitude toward a child that has maybe a deformed hand and one that comes out without arms?

MR. ZOLA: At this moment in time yes, there are attitudes. Those attitudes are created, socially constructed and socially reinforced, and it is our job at this time to work to their undoing. So yes, I would think that many parents would indeed have these feelings, but I want to create a society in which those differences don't matter.

MS. HANRAHAN: Can I ask you last, to comment on one of the themes in writings you submitted with your resume previously; one of the themes was the person's--disabled person's self-conception. Could you comment on how that is developed as a reflection of other people's, of society's attitudes and also the extent to which society's attitudes color parents' attitudes upon the birth of a handicapped child and what their views are at that point?

MR. ZOLA: Well, without trying to in any way denigrate all the medical efforts that were needed and were important in my medical rehabilitation, as one starts to get defined, you start with language, as a patient, and our literature perpetuates it. I'm a patient when I'm in the doctor's office. When I'm outside the doctor's office, I'm not a patient; yet, if he and my parents think of me as a patient, all the connotations come with that. "The patient" implies sick, implies dependent, unable to deal.

It starts very early. My parents, as it turned out, objected to this conception. But they felt so guilty about going against doctors' advice, which included my being institutionalized because we lived on a fourth floor walkup. One look at me they said, with that: "One leg brace, make arrangements for him to be institutionalized," and my parents and I said, "no."

We were embarrassed to tell anyone, so ironically enough, we contributed in certain ways to the lack of a movement because we--I was lucky, big extended Jewish family that was hell-bent on preventing little Irving from being sent off. So it starts very early. And I would imagine that anyone who has been mainstreamed, whatever that means, in the last 20 or 30 years, will tell a history of their having to fight the system, you know, in one way, and the success stories of when the system is bent, probably not when the system is made an outrage. It was what they let us do.

MS. HANRAHAN: Thank you, Professor.

Dr. Darling, would you like to present your opening statement?

MS. DARLING: This is really a summary of a lot of different points summarized very briefly, and with not very much to back them up, but I would be happy to answer questions. It is summarized from some of my research and writings that I have also submitted in support of this.

Decisions about the treatment of disabled newborns have been marked by lack of sufficient and/or appropriate information on the part of both physicians and parents. Educating decisionmakers provides only a partial solution, however, because quality of life is not highly predictable even with the best information about a child's current situation. Often, quality of life is better than what early prognoses would suggest.

Parents lack information because they generally have little direct experience with disability prior to their child's birth. Because of the prevalence of stigmatizing societal attitudes, their indirect experiences with disabilities have been largely negative. As one mother said, "I remember thinking before I got married, having a handicapped child would be the worst thing that could ever happen to me." Like patients, physicians lack information about the experience of living with disability. They too have been exposed to societal stigma towards the disabled, resulting in attitudes like these expressed by pediatricians I interviewed: "It is hard to find much happiness in this area. The subject of deformed children is depressing. Other problems I can be philosophic about; as far as having a mongoloid child, I can't come up with anything good it does. There's nothing fun or pleasant. It's somebody's tragedy. I can find good things in practically everything, even dying, but birth defects are roaring tragedies. Death doesn't bother me, but the living do."

In addition, medical education and practice have traditionally been based on a goal of curing. In the Baby Doe situation, treatment does not produce a cure in the traditional sense. The child will still have a disability in spite of treatment. Many physicians find no reward in such treatment. As one pediatrician said, "I don't enjoy it, I don't really enjoy a really handicapped child who comes in drooling, can't walk, and so forth. Medicine is here to perfect the human body. Something you can't do anything about challenges the doctor and reminds him of his own inabilities."

Not all physicians have such negative attitudes. Many devote their lives to treating children with disabilities. In my experience, some of the doctors with the most positive attitudes have been those with close family members who were disabled. In the decisionmaking situation, parents are likely to feel confused when confronted with a disability about which they know little. As a result, they rely heavily on the information and attitudes communicated to them by the physician. In most cases, the parents' decision reflects the physician's decision. The physician's decision, of course, is also based on limited information, particularly regarding some of the more favorable aspects of the quality of life of the disabled.

Even if we could legislate truly informed consent, however, we could never have certain knowledge about any child's future quality of life. Some of the parents who have the most negative attitudes in the immediate postpartum situation, learn to love their children dearly months, weeks, or even days later. Some children with the poorest medical prognosis shortly after birth develop into normal, healthy children. Very few cases are predictable with any degree of certainty. Treatment in most cases, therefore, seems appropriate.

MS. HANRAHAN: Thank you. Can I ask you briefly to state what the research was that went into your statement, what the background work was that you did?

MS. DARLING: What I didn't mention when I introduced myself is that I'm also a sociologist and I have done research studies with parents of disabled children and also with pediatricians who treat them.

MS. HANRAHAN: Can I ask you how widespread do you find a lot of the physicians' attitudes that you discussed here? There were some excepts in the writings you submitted. Is this across the board thing, as far as different kinds of physicians? Do you find it more prevalent in some cases than other cases?

MS. DARLING: I can't say I have done any statistically, nationally based study of any kind. I can't say with any certainty what percentage of physicians have these attitudes, but they seem to be quite widespread in my contact with people who work in programs like my own around the country. I did my original research in Connecticut. I'm now living and working in Pennsylvania and find almost the identical attitudes there that I found before. I was in a metropolitan area before; I'm in a more rural area now. The attitudes are still very similar, so I would suspect that they are quite widespread.

MS. HANRAHAN: Can you comment on the differences between the attitudes of physicians and parents? In one of the articles you submitted, you got into areas such as the physician having a more universalistic attitude and the parent more particularistic, and affective versus nonaffective. Could you explore that a bit?

MS. DARLING: The physician and parent are coming at this from very different places. They have different world views, so to speak. Most physicians have had virtually no personal experience with disability. In a small sample of pediatricians I looked at, only 7 percent had a close family member with a disability. So physicians' attitudes are shaped by other things than the experience of living with disability. They are shaped, as all our attitudes are shaped, by the general pervasive stigmatizing attitudes that society has, that everybody has mentioned already. Physicians are people like everyone else, and they have grown up with these kinds of attitudes and carry them with them in the treatment situation.

Secondly, the socialization that takes place in medical school tends to very heavily stress, as I alluded to just now, this concept of curing, of making perfect. Studies of physicians have shown that their greatest rewards usually come from successful cures. This is one reason why many people go into medicine, because this is what they want to do. They want to make people healthy, make people well again. This is the whole idea behind the science of medicine. A child with a permanently disabling condition doesn't fit that image. That child may be treated and may survive as a result of early surgery, but that child will survive with a disability and so in the doctor's eyes, that child is still not perfect.

And this bothers a lot of physicians, as some of the ones I quoted. They don't really find much reward in this area. They don't find much reward in performing surgery on a child who will still be deformed or mentally retarded or have other kinds of problems. As a result, a large majority of physicians try to avoid treating these kids if they can. Pediatricians in particular told me they became pediatricians because they enjoyed normal, healthy children. They enjoyed kids, working with kids, and seeing beautiful, perfect, little children, and these kids just don't fit that image for them. As a result, they tend to have a negative kind of bias in the treatment situation. It may not be an intentional kind of thing, but it comes to them as a result of what they have been exposed to.

Parents, on the other hand, start out with the same kind of background, that stigmatizing attitude physicians have. They also come to the situation with very little knowledge about disability. Most of us in society, unless we know someone personally with disabilities, don't know a lot about these things. Many parents have never heard of the particular disability their child has until the child is diagnosed. It is something we push aside and don't want to think about until it happens to us. When a baby is born with a problem, parents are suddenly faced sometimes with making a decision about something they know very little about. They know nothing about outcomes or what it is like to live with a child with this particular kind of disability. All they have to go on is the whole series of stigmatizing exposures that they have lived through as being members of society like everyone else.

They are also very vulnerable in the decisionmaking situation. They have just given birth to a baby. All hopes for a perfect child have been crushed by the fact that the child has a problem. They are upset emotionally. They are looking for someone to tell them what to do and often in that situation, the physician is the one they look to to provide them with answers. The physician is not the unbiased person we would like him to be, and yet the parents often don't have access to other kinds of people in that situation, possibly disabled adults or other parents of children with similar disabilities who could also describe some of the things that come later after the birth. Even though the initial experience tends to be negative, usually within a short period of time, attitudes turn around.

Parents realize that this child is just as lovable as anybody else's child, and they begin to see positive aspects of life with a child who is disabled. Many parents have said that it has become a maturing kind of process with them. Living with a problem that can't be solved is a very maturing kind of thing. Many become exposed to a whole world of people and activities that they never knew existed before. Once it happens, they learn to make the best of it, and even learn to find some positive aspects of it and those aspects are the very things parents don't hear right at the beginning in that decisionmaking situation, and physicians also don't necessarily hear, because of the kind of limited exposure they have had.

MS. HANRAHAN: You talked about the gearing of the medical profession toward cure and the type of training in medical school as far as preparing the physician to view more negatively, at the outset, than the parent, what the possibilities for the child are. Is it fair to say that the average physician, compared to the average Joe on the street, is more inclined to discriminate against a handicapped child because of those factors in his or her background? Are we dealing with a discrimination that exceeds what we all might feel in a situation, an average situation, with our own ignorance and prejudices that we don't admit to ourselves?

MS. DARLING: I'm not sure it exceeds what other people have as prejudices, but the physician is in a position to act on those prejudices, and the rest of us are not, and as a result, it is almost more important that they receive a broader base of information than the rest of us get, and that's where there is something lacking, I think.

MS. HANRAHAN: You talked about the bonding of the parent to the child after the birth and cases where the parent might also feel a lot of negative feeling toward the birth of a handicapped child, but those feelings change over time. Is that an experience that other nondisabled adults can replicate in their dealings with handicapped? Is that where a lot of changes come from? Is there a lack of experience, so there is a fear and prejudice that is not reality based, and if you were in the position of the parent, to have that kind of ongoing experience, do you think other people would react in a similar way?

MS. DARLING: Definitely. I think that's why you see the few pediatricians who are wholeheartedly in support of treatment for the disabilities that I have known have all, interestingly enough, had a sibling or other close family member who did have a disability. I think that the experience of getting to know a person with a disability is a significant experience in changing the way a person views that situation, and I think it is one that all of us could have. It is not difficult, certainly, for people to come into contact with disabled people. It is just that our upbringing, for the most part, has been just the opposite. Children are sometimes pulled by their parents to the other side of the street if a mentally retarded person is walking toward them. We have grown up to avoid those people, to shun them, to look the other way. Just the opposite, I think, from what is needed.

MS. HANRAHAN: I want to ask you about the bases for the attitudes and, if you are able to answer, with respect to nontreatment decisions affecting handicapped children, what are the factors that those decisions really are based on? Is it people not wanting to be burdened by a care that they can't figure out, that they don't know what the communities resources are, or that they have to make a decision and there's no time for input? Is it that parents really want a normal baby and don't want a baby with handicaps? Is it a fear of costs or disruption of the family? What are the things that enter into it, and how much is a real concern for the quality of life of the child and his happiness or her pain or--

MS. DARLING: I think all those things enter into the minds of the people making the decision at the beginning, and I think to some extent, it is true that because society is not particularly supportive of people with disabilities, it is difficult to raise a child with these kinds of problems. It is extremely expensive. We don't have nearly enough financial support for parents of children with disabilities. It is very difficult in other ways, depending on the disability. It may require more than the normal amount of effort to get the children into school and get them an appropriate education, even though the law says they are supposed to have that. My experience has been the law may say that, but you have to fight for it if you want it. Housing accommodations may have to be different from those that any other family might be able to have where a family lives. I have known families that have had to refuse job promotions because they needed to be near medical treatment facilities for their child. There are not enough respite care and support facilities for parents who have a child who is severely handicapped and will need continuing care and support well into adolescence.

These are not problems that are inherent in the disability. If we had sufficient support facilities in society, if there were enough resources out there, much of the burden would be removed from parents, and the quality of life of all concerned would be significantly increased, but that seems to me to be a matter of changing society and providing more. It is not necessarily a justification for not treating in the first place.

MS. HANRAHAN: I would like to refer to one of your articles that you submitted. Would you like a copy? It is called "Quality of Life and the Costs of Disability: What are Society's Obligations?" On page 2 of that article, there's a case number 2--I'm sorry, case number 4, page 3, about a child called Katie. In describing her, it says, "blind, severely physically handicapped, has a seizure disorder which has not responded to medical treatment, socially responsive." And at a later point in the article you are describing what the projected qualities of life of those children are. Hers you described as "questionable." My question with regard to quality of life is: Do we frequently, and perhaps physicians more so, make a judgment about quality of life that comes out of what our standard is, which may not in fact at all apply to a child? We may perceive some certain level of intellectual or cognitive or affective functioning that, say for a Down's child, who may not even be aware of the opportunity to have such kinds of experiences, like maybe going to law school, which is not so wonderful after all, but do we presume that that child needs the same things that we need to have a good quality of life and is that a valid understanding to make?

MS. DARLING: There have been studies that have shown that people, with respect to retarded children, in particular mentally retarded children, that there seem to be differences in reaction to them based on social class. Middle-class people have more difficulty accepting mental retardation than lower class people do. Physicians as a group tend to come from the middle classes. They tend to see things from a particular point of view and may have no conception of how a lower class parent, for example, may view that same child. I think every family that we see has its own value system, not based just on social class, but ethnicity and religion, and where they live and what kind of family support structure they have and other things that the professional knows little about, and I think it is presumptuous of the professional to try to impose his or her world view on the family.

Another case I had in that article is a better example of that, case number 3, Eddy. This is a child who is quite disabled. He had a birth history with an intraventricular hemorrhage and hydrocephalus, is moderately to severely retarded, has a number of medical problems still. Eddy's parents happen to be mentally retarded themselves. This is their second child. They have an older daughter also. They are just--Eddy's 4 now, I believe. His parents are just thrilled with him. He is 4. He still does not walk or talk and is just beginning to feed himself. He is quite delayed developmentally, but his parents couldn't be happier with him. He smiles and laughs and they absolutely enjoy taking care of him. Who is to say, you know, who has the right to say that those parents should not be entitled to the joy that they are getting by having this child in their home. I would think that most professionals would look at that child and say, "Boy, I'm glad he's not mine." But his parents would never say that, never even think that. I think every family situation is unique. We cannot impose our views on a family's views and make those kinds of decisions for them.

MS. HANRAHAN: Thank you, Dr. Darling. Mr. Chairman?

CHAIRMAN PENDLETON: I would ask one question and I'll yield to my colleague, Commissioner Destro, and maybe come back.

As I have been sitting here for this period of time, yesterday and today, a couple of things come to mind. It does seem to me over a certain period of time, an acceptable period of time, a body of data has developed about the potentials for a productive life, whatever that--however elastic that term might be for people who are either genetically or developmentally disabled, and I hear you talk about what the physician does not do, not you, but panelists.

Mr. Sherwood yesterday gave us some little tidbits of horror stories that tickled our memories a little bit. Is there some body of knowledge that physicians get in a continuing medical education way? Now we have the health channel television, and physicians can sign up and take a course off of television and fill out some papers and send something in. I'm not saying that's what happens in this case, but it does seem to me either in a continuing medical education way or--in some medical school way, that that information could somehow sensitize physicians as they begin to deal with parents.

Bear with me just a minute. There is something that we have not discussed here that comes out a little bit in your interview--the speed with which the decision has to be made. It is not something that can necessarily be delayed until next week, next month or some point later in the newborn's life; and parents, as you mention, are hit with a shock right away and are uninformed, perhaps unprepared. I guess what I'm getting at is: How are parents prepared for a potential, and what prepares the physician to prepare them for the potential, and is there some way, through this process that I'm talking about, we can inform the broader public? I think there are some assumptions in here that we have to go on. This does not have to be decided right away. We have time to do this. We heard in our first hearing--a lady came and they were told a day or so later, "Your baby is not in Tallahassee, your baby is on the way to Miami for some treatment." And these things do have great impact. And I wonder how you can respond to what I have asked, not as a question, but how we can bring things together here.

MS. DARLING: There are moves already in the right direction. I know of several courses instituted in medical schools around the country to attempt to acquaint physicians in training with developmental disabilities. This is a relatively new area, and it has just been happening in the last few years as far as I know. As far as where this will lead or what the outcome may be, it may be too soon to tell. I have done some continuing education thing in the community with physicians who are already practicing. I have done presentations at medical staff meetings and that sort of thing.

CHAIRMAN PENDLETON: Do you see some sort of result from that process? Is there something different about the way they would treat the patient?

MS. DARLING: I think there is in some cases. Some physicians are very open to that sort of thing and are willing to hear what you have to say, and to make an honest effort to change. On the other hand, there are some that won't even come because they already feel they don't need to hear what you have to say. They already think they know all there is to know about the issue, depending on things like when they got their training. It seems to me that those who were trained a long time ago seem less willing to change now than those who have been in medical school more recently, when they were exposed to things like medical ethics courses and a broader range in the medical curriculum. Some of the younger doctors do seem more receptive to these kinds of ideas.

MR. ZOLA: I think for me the answer would be what kind of time frame I have. If you were saying to me, you wanted to do something in the next 5 years, based on what my involvement in continuing education would be, I find that it is the ancillary health care workers that are much more interested in the kinds of issues we are dealing with than, ironically enough, the physicians. When I give rehab workshops, even sponsored by the rehab hospital, I'm much more likely to get the nurses, all the other ancillary staff, and one or two physicians, so there's a short run.

If you have a longer time span, in terms of what we're dealing with, the physicians are part of the rest of the society. The degree to which we can, earlier on, much more realistically deal with death, pain, and suffering, if you will, as part of the human existence, including differentness, meaning starting, you know, in the earliest stages of any kind of schooling in any child. I have a 3-1/2-year-old and a 20-year-old. It turns out that my 3-1/2-year-old has a disability consciousness which is quite extraordinary. One of the differences has to do with--I thought I was good 20 years ago. I bought the idea of when you should tell little kids heavy things, and I have learned. My 3-1/2-year-old knows more about braces, wheelchairs, etc., because I believe that you could tell them certain things when they were even nonverbal. What I'm saying is: You start educating kids like that, and the next generation of health care workers--should my daughter become one, she will be part of that group. I think we have to go both ways--the real long haul and the short term intervention.

CHAIRMAN PENDLETON: What I'm trying to get at is that the month of birth is a very critical period. It is a psychologically stressful period as we've heard in the testimony of parents. I am wondering how we get the best information to the parents through the physician who has to make that decision and what I'm hearing you say, Dr. Darling, is that all doctors are not bad people in this case. I think what we heard before is that there is some presumption here that most doctors or all doctors are bad people. That's kind of the universality. People we know about are bad people or leave that impression. There has been some progress made with respect to how you make those decisions, how the physician makes that decision at the very critical moment when there's a newborn. I'm concerned, maybe you can't tell me here, but how do we get that person to understand what you have to say to that parent, that there are options--there are choices other than saying, "We're not going to treat" or "We're going to treat; here's what we're going to do." Maybe there should be a checklist here, what I do here, what I say. Maybe that's wrong too, maybe that's right too. I haven't heard enough about what really happens and how we can make the changes. That's where the abuse occurs and we haven't gotten to that critical point.

MR. ZOLA: I honestly don't think at this moment in time, we've given sufficient attention to even how that information is transmitted. There's evidence piling up that the way that the traditional doctor-patient communication, goes on, is so rife with anxiety, that it's difficult for both parties to hear each other. Let me just throw out a question, probably a rhetorical one. We may have taken too much for granted as to how little time there really is available for parents to make those decisions. I want to open up that as a question. Let me just--if we were in this room in 1979, and this was a hearing which did take place, but not at the Civil Rights Commission, as to what role women should have in terms of radical mastectomy, and the medical argument was being made that, if indeed, you couldn't separate the biopsy, that is, when they came in they had to sign off that, indeed, cancer was found on a biopsy, then right afterwards, you would have to have the operation--

Major segments of the women's movement found that that was not a good way to deal with it. They believed at the time what some of the medical evidence was, namely, that if they didn't do it right then, they would have increased risk and maybe the nature of the biopsy itself might stimulate the growth of certain cancer cells. But a number of them started to say, "Maybe that's a risk we have to take. If indeed I can't make the decision a priori, in other words, sign off or it is not enough time for if I get woken up, what do you want to do? I have the right to take and maybe even expand certain of the aspects of risk, so I can make an intelligent decision." That's what happened in 1979; a National Institute of Cancer panel said, "we're going to separate finally the procedures." But it was the patient's groups that were pushing for that right. They wanted to live with the possibility of risk. Maybe we have taken too much for granted even on how speedy some of these decisions have to be made.

COMMISSIONER DESTRO: Professor Zola, let me turn your attention to one of the comments that was noted in your interview notes, and let's take it to a situation that's not exactly on the point of the hearing, but you did mention it. It is one in which there is a lot of time to make decisions, and that is, some of the issues we have heard of medical care discrimination later in life. There you are not dealing with questions of timing, that you have to make decisions immediately. You mentioned those attitudes of pity and fear even within the family. And one of the interesting factors in Justice Stevens' opinion in the Bowen case is the notion that the family can't really be guilty of discriminatory attitudes. You noted here the case of Elizabeth Bouvia and the film "Whose Life is it Anyway?" How did those cases relate to this issue?

MR. ZOLA: Well, particularly in the movie, what they've done is they stacked the deck, as occasionally does happen. I think Roz inadvertently alluded to this, that the patient in both those cases is presented as an isolated individual who has had no experience with other people with disability. Therefore, it becomes an argument between an able--like in "Whose Life is it Anyway?"--an able-bodied physician trying to convince somebody who has just become a quadraplegic that his life is indeed worth living, and it is argued on the basis as if he has a right to take his own life rather than what could the quality of life be for someone with quadraplegia. They set up the play in such a way that he is kept continually in isolation in an acute care setting. He literally never sees anyone with quadraplegia, so a false issue is played out in that way. In terms of the Bouvia case, the courts and media have played it as an issue of how tragic it is that she has the kind of medical problem that she has, and make it an issue that giving her life is so tragic--doesn't she have the right to take her own life and be assisted in it? Again, the issue with Bouvia, as with so many others, is what kind of resources society has given to her.

The issue of resources gets very important when you talk about physicians. Part of the reason that this thing comes up about the quality of life becomes a self-fulfilling prophecy--you ask if there is any national data.

I sat in on a study, that was reported at a convention about 6 weeks ago and I could get the reference in which a person did a national study on what board-rated ophthalmologists knew about the resources that existed in the community for low vision and all kinds of disability conditions only connected with the eye. Well, it turned out that it was abysmal. They knew lots of medical data, but given that they didn't know what kinds of resources existed in the community, one could understand how they could come to an idea that there was no--if they had no knowledge there were any resources out there, then that part of the thing that goes into the opinion when you say what the quality of life is and how they tell the family that they would be unable to cope, because they have no conception of what's out there that, indeed, the family could use. So there you get a self-fulfilling prophecy. If they don't know anything about what's out there, then by definition, the only thing they have is what they see in terms of some physical suffering, so that they then overinterpret. It has to be a burden for them, and what else can they do?

COMMISSIONER DESTRO: Would you support legislation that would impose on the hospital or on the social service staff or the physician himself or herself ultimately, as the director of the whole process, the duty to make sure that those kinds of information are transmitted?

MR. ZOLA: I probably would. I hadn't thought about it as explicitly, but in terms of a guarantee of certain kinds of information as a right, yes. I might be convinced that there are better ways to do it than just legislation, but I would not, prima facie, go against it.

COMMISSIONER DESTRO: Isn't the alternative a malpractice case, where they say that informed consent was not given in the first place?

MR. ZOLA: Well, I suppose if I were a physician sitting here I would say, "My God, I hadn't thought of that before. Let us try to educate ourselves."

COMMISSIONER DESTRO: I was intrigued, Ms. Darling, about the article that you wrote, and you said that the negative views are communicated to parents especially--this was your article on parents, physicians and spina bifida--that the views are communicated to the parents about what the best mode of treatment would be. Could you expand on that a bit? We talked about what physicians know, what they don't know, but what about--do you have any evidence in your research about the impact those recommendations might have on parents?

MS. DARLING: They have a very strong impact. Almost always, regardless of what the physician recommends, the parent goes along. It is very interesting. If you look at some studies published by John Lorber in Great Britain during the early seventies, when he was advocating his position of not treating most children born with spina bifida, he was recommending that most infants not be treated, and he reported that most parents agreed with him and thanked him later and said that was the appropriate decision.

Physicians in this country who recommend just the opposite and recommend that the parent opt for treatment also find that the parents always say that's the right decision: "I want to do what you tell me to do." I think regardless of what the physician recommends, the influence of the physician in that situation is so overwhelming and the parents have so little to go on other than that, that they are likely to agree. And the reason, 10 years down the road we believe we made the right decision, is we always do that. We always rationalize our decisions and say we did the right thing.

COMMISSIONER DESTRO: Would you say--is there other published literature that indicates that that seems to be the case? Because again, this is the--I'm using as the basis of some of my questions here Justice Stevens' plurality opinion in the <u>Bowen</u> case, where he says, "Well, there's really no evidence that doctors are really that influential in the decisionmaking process." Do we have American studies, for example, akin to the British study, that indicate that in Britain they followed the advice and in America they followed the advice, but the advice happens to be the opposite?

MS. DARLING: There's a wealth of literature in medical sociology on the concept of medical dominance, and not just in this situation but in virtually every situation involving patients and physicians. It is usually the physician's point of view that prevails. And often it is structured so that it will prevail. It depends on the situation, but typically, physicians don't provide the patient with all available information so that they can make an intelligent decision of their own, and there is a number of sources for that, too.

Part of it is kind of a paternalism that's been around for a long time and the idea that the patient can't be burdened with all the information, that somehow the patient is not capable of handling this kind of information. In some of my other publications, there are quite a few quotes from pediatricians who say that they usually don't inform parents about birth defects immediately after the baby is born because they believe that they are somehow protecting the parent, that the parent is in such an emotional state after having given birth that they can't handle this kind of news.

Interestingly, had you asked parents about it, almost all of them say, "I wanted to know right away," but doctors don't believe that's true. They are not doing it necessarily out of malice, but they really believe they have an obligation to protect patients, and part of that protection involves making the decision for them.

COMMISSIONER DESTRO: Dr. Zola, would you have access in any reasonably short period of time to a reading list that would give the Commission some background on this notion of professional dominance? And that's an important point. It may or may not prove anything, but it is an important point to plug a hole in the record.

MR. ZOLA: Absolutely. What we also do--I think what we're also trying to do--we wouldn't deny, I don't think either of us would deny, that if you went in with an anxiety measure at the time that a parent has to deal with this, their anxiety may be off the scale. What we fail to realize is how much of that anxiety is, for lack of a better term, structurally induced. It is not just that they are anxious about the nature of the birth and what happened. It is very often the nature of how that encounter takes place. Think about when you get a lot of information you get from physicians. You may be in a physical position that's not the nicest. You may already have been intimidated by a whole series of questions he asked that you don't have answers to, like I don't know what my grandfather died of and I don't remember what those little red pills were that gave me an upset stomach 15 years ago. One could go on and on about a structured situation in which--in fact, if it is really thought to be a learning experience, in other words, when teaching is going on--one of the things I have done with my classes--I have told students, "Go to a doctor's office the next time you go, with a pad of paper so you can take notes if you are given information, so that you can do it." Most of them get thrown out of the office. The situation is not structured ordinarily, though there's a lot of lip service to it like, "I'm trying to teach," etc., to play down the anxiety.

COMMISSIONER DESTRO: Let me ask in terms of the notion--I'll try to formulate the question--what I want to get at is the notion of something that was mentioned in Ms. Darling's article again that I mentioned before, that you were talking about: interaction of the medical personnel with the child. I want to take off on that and move it into a slightly different area, and Dr. Zola, you have certainly had some personal experience with this.

What would be the role of a separate advocate for the child in a situation like this, because from all of the materials I have read on this, there are so many mixed feelings, the doctor's feelings, the parents' feelings, but the child is not represented. And I know Mr. Roberts mentioned yesterday that sometimes even today, he will go to a restaurant, and his assistant is asked what does he want.

And what I'm concerned about is: we're talking about the individual who is otherwise qualified under section 504 and it seems to me that the Supreme Court decision basically says, "Somebody else who may have an interest can decide whether you are otherwise qualified without you ever having a voice in it." How do you react to that?

MS. DARLING: I think certainly that might be an important part of a decision. I think it is important that the child's interests be represented, but I'm not sure, you know, if I had to decide in the last, you know, in the end whose position had to prevail, I'm not absolutely sure in all cases that I would believe it would be the advocate's rather than the parents', since they are the ones who must spend at least the first 18 years with that child; it will radically alter their lives and life chances and possibilities and lifestyle. In my own mind, I'm still bothered about that. I think it is a good idea, and I think that we need as much representation as possible for the child's interests and the child's point of view, but in terms of weighing which is more important, I'm not really sure.

MR. ZOLA: I would like to expand just a little bit what the potential role of an advocate could be. You see, I think that a good deal--if you really--with the few studies that have come out, when we try to study what the doctor thinks he said and what the patient thinks he or she heard in the situation, the discrepancies are so enormous that one might go so far as to say that any doctor-patient encounter should have a mediator or somebody else there that could help both parties communicate with each other. I'm not being entirely facetious when I say that. The degree to which the communication is so loaded, one might indeed think about expanding the relevant number of people that are there, giving way to the parents' privacy, etc., when certain of this information is being given, etc.

I know that I now, as a matter of practice, when I think it is anything but the most minor of situations, when I go to a physician I do not go unattended. It has nothing to do with my capacity as a personal advocate. I feel that the nature of the information that I'm getting, the speed with which it is coming, my anxiety-prone position when I'm getting that information, is such that I'm not really always in the best position to hear and thereby make good judgments on it. If that's true with me, who I think of as a well-trained advocate, etc., I think the situation is much broader for others. I'm trying to--we really have to rethink many of the ways that we communicate the information, how it is done, even who does it.

CHAIRMAN PENDLETON: What do you think doctors should do in the decisionmaking process? I heard what he shouldn't do. What should the doctor do? The decision is going to be made by the physician ultimately because that's the way the situation runs, but I'm hearing now all kinds of little ways that we help the doctor to do something. What should that physician do?

MR. ZOLA: If it's at this moment, this time, 1986, and I'm being serious, and our judgment is that the doctor doesn't know what the alternative treatments and resources are in all of these situations, then the nature of the communication, whenever it is being communicated, should be supplemented by other sources of information and other people.

CHAIRMAN PENDLETON: Is there some liability for that as to the hospital or the doctor?

MR. ZOLA: I'll jump. Even if it is--because I have heard the liability issue brought up in lots of kinds of exchanges, then it becomes beholden on us, who have a stake in it, to push for a change in the way that liability goes, that it is not anymore someone else. In other words, the women's movement worked out some of the liability issues around that 1979 decision as to whether or not the doctor would be liable if they didn't have the radical mastectomy right away.

CHAIRMAN PENDLETON: I'm not hearing you say there needs to be a convening of nondoctors at some point that says to the physician: "Here's what you should do?" Are we going to--I'm trying to--

MS. DARLING: I think the doctor's role should be restricted to simply presenting the medical facts in the case. I don't think the doctor is any more an expert than anyone else in making an ethical decision, and I think that decision should be made by the parents with the help of as many other people who can provide the essential information as it takes to give that information. I think the doctor should be just the source of strictly medical information about what can be done surgically, what the results will be, what will happen if we don't do it.

CHAIRMAN PENDLETON: I want to thank the panel very much. We'll take a short break.

[Recess.]

MEDICAL PANEL

Testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc., Bloomington, Indiana; and Patricia Ellison, M.D., Research Professor, Department of Physchology, University of Denver

CHAIRMAN PENDLETON: We will convene the next panel. May I swear you two persons in, Dr. Owens and Dr. Ellison?

[The witnesses were sworn.]

CHAIRMAN PENDLETON: Counsel, we can say that Mr. Destro is here and start the questioning.

MR. PASCALE: Could each of you please state your name and address and present occupation and position for the record?

DR. ELLISON: I'm Dr. Patricia Ellison. I'm a pediatric neurologist by training. I presently have a research post at the University of Denver in the department of psychology, and I also do private practice with a group of pediatric neurologists in the city of Denver.

MR. PASCALE: Thank you. Dr. Owens.

DR. OWENS: Dr. Walter Owens, Bloomington, Indiana. I'm in private practice in obstetrics and gynecology.

MR. PASCALE: I understand you have an opening statement, Dr. Owens?

DR. OWENS: Yes, verbal. I'm almost afraid to admit that I'm a physician after all the attacks on physicians here. Mr. Bopp, this morning, made a rather aggressive attack on medical decisionmaking, misused the term "medically indicated," I believe, and implied that he and the people that he works for, the Right to Life group, have the answer in these situations. They want the Federal Government to use its might to force this decision upon everyone faced with these tragic situations of defective children. I wish I were as certain about what needs to be done in all these situations. I'm going to speak not from the standpoint of some lofty Olympian height of idealistic concern, but from a practical standpoint, facing reality, facing what we have in the community and the families, and from a practical, commonsense standpoint as to what has to be done in these situations.

To begin with, I would like to give a little history of the Bloomington Baby Doe situation. I was the obstetrician for the mother in this delivery. She had an uneventful pregnancy and labor, and had a rapid delivery. Upon the birth of the child, two things were immediately apparent: one, the child was obviously a Down's syndrome baby; second, that it was severely depressed. In the course of resuscitating it in the next few minutes, it became evident that this child had an obstruction of its esophagus, which was later found to be what we suspected, a tracheo-esophageal fistula. The pediatrician thought at first that the child had a congenital heart condition but this was disproved. The parents were told of this approximately 1 hour after delivery. The mother was not sedated at all. The parents were unusually well educated, unusually knowledgeable people. The pediatrician and the family physician simply told them this baby has to go up to Riley Hospital at Indianapolis to have its esophagus repaired.

I felt this was excessively authoritarian. I said, "I think there are some things you must know here, that if the surgery is done and if the surgery is successful, this will not be a normal child. This will still be a Down's child with all that that implies." The parents, fortunately, knew what this involved, and we didn't get into extensive explanations as we might with some parents. The pediatrician, as I said, was not prepared to give the family any further information at all, but simply to tell them what had to be done. I said, "There is a choice of doing the surgery, in which case the child will be a Down's syndrome if it is effective, or of doing nothing, in which case the child will die within a short period of time."

The parents consulted with their best friends, who were with them at the time, and announced their decision about a half-hour later, I would say. They announced that they did not want to have the child treated. After that and only after that, I told them I thought they had made a very wise and courageous decision. I have asked the father about this repeatedly: "Did I give you any indication of my personal feelings? I tried to be as dispassionate as possible," and he said, "I had no idea how you felt about it at all." The child lived 6 days. During this time, I do not believe it suffered any pain. It didn't move around a great deal. On the few occasions when it exhibited some restlessness, it was given sedation. The child died 6 days later, not of starvation, as the newspapers indicated, but of pneumonia, a result of the abnormal communication between its stomach and its lungs.

Subsequent to that, 2 years later, after having genetic studies and so forth, the parents had another pregnancy. They now have a 2-year-old child who is totally normal, a very healthy child. I met the father in the supermarket or actually the shopping mall the other day, and he said, "We're going to have to take--back to the hospital." My face fell. I said, "Oh, my lord, what happened?" He said, "Somebody has to take some of the energy out of that kid." But this is now a family with three children, the youngest of whom I'm sure would never have been conceived and born if the other child had survived. I think the result--they have no regrets whatsoever in this, and I think the result, from the standpoint of observation of the family, of what this has done to the family, to say nothing of what it would have done to the community and everything else, has not been a bad outcome.

Now, these are very difficult decisions to make. Most of the time, babies are normal when they are born. Of the ones that are not normal, most fall into one of two categories: either easily remediable things or relatively easily remediable, at least with the hope the child will be normal or nearly normal when this is done or with the hope it can be a functioning member of society and, on the other hand, things that are hopelessly lethal and there's no point in doing anything. There's only a small number of situations such as this, where surgery can be done or other major treatment done, and the child will survive with great effort or has a fair chance of it at least, but will never be a normal individual. In such situations, someone has to make a decision. What should be done?

Now, that decision cannot be made in a vacuum. In an ideal society, one might say we should consider only the welfare of the child, but this is not an ideal world and we do not have unlimited resources.

To begin with, the financial costs, to say nothing of other things, are enormous. Insurance usually does not cover this and even when it does, it is spread over the community obviously. There usually is a major part not covered, and this has to be picked up either by the hospital, which again means it has to be spread over the public. The parents often are devastated from a financial standpoint by such things, and the costs to the community and to the country are not negligible. Our funds or resources are not limitless.

Money which is spent--and we're talking of many times $100,000 or even $500,000 or even $1 million spent on such children--that is money not available for the education of normal children. That is money that is not available for the rehabilitation of children who have hopes of being restored to a relatively normal circumstance. I might say that I received vocational education rehabilitation aid when I was a young man, too. I also have my own credentials. I have within my extended family a fairly severely retarded individual, and one of my own children suffered from a chronic disability that eventually resulted in his death. I think I know a little from a personal standpoint of what these things involve from many aspects. The cost to the family from an emotional standpoint is enormous, especially when there's little hope.

Unfortunately, some of the various agencies and advocates for the handicapped have, I think, given an excessively optimistic picture of what to expect. This is natural. They have to remain optimistic or they couldn't function, but they have given sometimes an optimistic picture of what could happen. All too often, the results are devastating to the family. It results in misery for the parents, especially the mother. She's usually the one who gets the care of this child. It results in financial hardship for everyone; it may impair the education and training that the remaining children in the family can receive.

Quite aside from the effect upon the family, in that respect, is the effect upon the country as a whole. As I say, these are funds that are not available for the rehabilitation of the teenager who gets in trouble with the law for the first time and needs counseling. These are funds that are not available for national defense; these are funds that are not available for all the multitude of things we have pressing upon us. Gramm-Rudman, whether or not it is upheld by the Supreme Court, should make it abundantly clear that funds are not limitless in this situation. Some decision has to be made. Who should make the decision and what should the decision be? I don't think the physician himself has a right to make the decision and impose it upon the parents.

Sometimes we're dealing with parents who simply are incapable of making a decision, either through irresponsibility--I understand Loma Linda Hospital may have had some questions about that in regard to the baby receiving a transplant recently. Sometimes parents cannot make a decision. Sometimes they are too ignorant, too irresponsible, and someone else has to do it. But when the parents are intelligent, responsible people, I think we have an obligation to tell them the circumstances, to explain to them what the situation is, what the alternative outcomes are, give them the opportunity to discuss this with whomever they wish, including their ministers and other people and so on. And then when they make a decision, unless it seems quite outrageous, I think we have an obligation to support that decision. I might add that if the Baby Doe parents had made the opposite decision, I would have supported them and done everything I could to have helped them in that situation.

The decision, I believe, should be made by the parents, not by self-appointed moralists, not by government people or anything of the kind, because the circumstances in the individual case vary so much, both from a medical standpoint as to the findings and the outlook, the facilities available from a medical standpoint, the family's own ability to handle the situation, and the resources available in the community. They vary so much that I don't think it is appropriate for anyone outside the family to specify to the family: "This is what has to be done."

Now there are circumstances in which families may make what seems to be an inappropriate decision. We have mechanisms, I believe, in every State in the country to review those, and that was done in the Baby Doe case. A rather lengthy hearing was held, for example, before the child protection committee of our local welfare society. Mr. Bopp glossed over this, but a lengthy hearing was held at which not only I, but one or two of my partners were present; two pediatricians were there; a nurse who is herself the mother of a Down's syndrome baby was there; and several other people who were prepared to give information about the community resources available. This was given before a six-member group of the local welfare board which itself, I think, was fairly knowledgeable concerning what was available. The local welfare board's child protection committee chose not to appeal the previous decision.

It is very easy to gaze from Olympian heights and say, "This should be done; doctors don't know what they are doing; they are being authoritarian; they are making decisions which they have no business making." We are not making decisions.

Occasionally you will see an authoritarian physician or a physician who is not knowledgeable. I think those are in the minority. There are arrangements for overriding improper advice in that respect and so on. I think the majority of physicians are trying honestly to give the best advice they can. And I think also that a little credit should be given to those physicians; although they may not have taken a recent course in medical ethics 101, these are men and women who have practiced over a period of years and have seen the outcomes of these things, not only upon the individual concerned, but upon the family and society.

An interesting pattern emerged in our own community. The pediatricians, who by definition are limited to the care of children, all felt that our Baby Doe should have had surgery. There was a virtually unanimous feeling among the other physicians in the community, most of whom had more to do with families and so on, that this child should not have been treated. Now I do not have the answer on these things. I don't think most thinking physicians have a categorical answer that we're prepared to impose upon people. I think each individual case has to be considered by the people who are most intimately associated with it, who have the most to lose and the most to gain from it, who presumably have the most love for this child. It has to be considered by them with all the help we can give them in every respect, and we should support their decisions in every way we can.

The resources are limited. As Ms. Asch said this morning, there are grossly inadequate funds for the care of the children that do survive, for the care of the handicapped people that are with us in our communities, trying to do the best they can. I think we need less emphasis upon mandating care of children where the outcome is dismal or the result would be misery for their families and a financial burden on them and the community, a little less emphasis upon mandating care for those people, and a little more emphasis upon providing adequate facilities for the handicapped people that are here and now, and that may come to be in the future, where there is some hope of helping those people.

MR. PASCALE: Thank you. Do you feel that there's a role for someone or some organization to serving as an advocate for parents and for society in general in these Baby Doe cases?

DR. OWENS: I believe we have such a thing. In our case, there was a guardian ad litem.

MR. PASCALE: I mean to help or represent the parents in this case.

DR. OWENS: They had their own attorney to represent them.

MR. PASCALE: Do you feel this debate is characterized by a lot of misinformation towards physicians or from physicians?

DR. OWENS: We get a little paranoid sometimes. I feel--well, to a certain extent I feel sort of like the situation with a previous minister in our church, who was a great authority on child raising, except he wasn't taken too seriously by the congregation because he had no children of his own. I would feel a little better if I had heard more from people who had been more deeply involved in this than some of the previous people who have spoken, and people who perhaps were a little more removed from it in that sense, too. I think we have to realize that the person who is involved in any particular aspect of care is enthusiastic about what he is doing. If he is not, he can't function, but he is not necessarily objective. I think that applied to the pediatricians and pediatric surgeons here. I'm told that Dr. DeVries, for example, is still very enthusiastic about permanent artificial hearts, but I don't think anybody else is. The one who is involved in such care has to be enthusiastic about it or he can't do it, but sometimes his enthusiasm is not tempered by sufficient realization of the broader aspects of what he is doing.

MR. PASCALE: Do you really think that parents make the decision or that the physician--there has been testimony about the physician really making the decision, and the parents just really ratify the decision that the physician has already made?

DR. OWENS: I think this depends greatly on the circumstances of the case, the physician, and the parents. I can assure you that in the case of our Baby Doe, the decision was made by the parents; that I'm quite sure of. It is possible that, as I mentioned, the pediatrician and the family physician were not prepared to do anything at all. They were saying this child must go up to Riley Hospital. They were making the decision there. I'm sure that there are authoritarian physicians or people who try to be authoritarian, who try to impose their will in either direction, but also the majority of physicians, as well as the majority of attorneys, as well as other people, are conscientious people trying to do the best they can under the circumstances.

MR. PASCALE: In a conversation before the hearing, you mentioned something called the utilitarian approach. Could you elaborate?

DR. OWENS: I think it is just that--considering the circumstances, not making decisions based upon abstract ideas, but considering the circumstances of the individual case and the effect that the decision has on this individual case, taking into account the milieu in which it is originating, the family, the community, the resources available, the effect upon everyone, the quality of life available to the child and some things of this sort. In connection with that business of the quality of life, I have placed on the record with counsel two letters that were among the many which we received after our Baby Doe was born, telling something about this business of quality of life. I will read them if you wish, or leave it at your discretion.

MR. PASCALE: If you would like to read them, please do. I have them here and I will include them in the record.

DR. OWENS: The first was addressed to the parents of Baby Doe. This was from a couple who--

"Dear parents, I have been thinking of you since the first news of your baby reached me. When I read about your suffering in today's newspaper, I had to write.

"Twelve years ago our baby boy was born with Down's syndrome and esophageal atresia. We were faced with the same decision presented to you. We elected to have the surgery and life for our infant son--or so we thought. My husband and I chose life and got a hellish existence instead.

"The first few years were marked by severe upper respiratory infections and frequent trips to the emergency room. Now Charles' health problems are more of a chronic nature: severe allergies accompanied by congestion, fatigue, irritability, sinus, and ear infections.

"The real trouble started for Charles when he became old enough to play outside. Although there were some instances of cruelty to our Down's child, the main expression to him by neighborhood children has been to ignore him. For seven years, Charles was a bystander who was permitted to sit on the side and watch their ball games. As a result of this experience, our son became a nonperson. His self-image plummeted, and one day he began to stutter. At first barely perceptible, the stuttering increased to a very severe level.

"This past fall we told our public school that although we appreciated their efforts on Charles' behalf, we felt his social, emotional, and health needs were so complex that he was not able to benefit from the six hour a day program offered. We asked the school system to fund Charles for private residential placement under the provisions of Federal and State laws. Our request was refused. We have just now completed an 11-hour due process hearing in an attempt to have our son's educational needs met. Charles does not live with us any longer. He is now with the nuns at--school for exceptional children in--on partial scholarship. We are presently able to manage the remainder of the tuition fee. Our son is now protected from the "kindness" of society. How long we'll be able to afford this protection, I don't know. But for today, Charles is safe.

"The future? Will there be a group home and some sort of semi-independent living arrangement for Charles or will our son be reduced to the subhuman institutional existence presently endured by the majority of retarded citizens?

"Summing up, the past 12 years have been marked by a degree and amount of anguish that cannot be expressed in words for my husband, for Charles' sister, for me and most importantly, for Charles. I hope this picture will help you gain the perspective that will allow you the peace that has eluded you so far. Society as it presently exists would not have permitted your innocent son to live any more than it has granted our son life. Our choice was made with some optimism and trust and in ignorance of what lay before us. Our rose-colored glasses were removed long ago and the stark reality has been horrible. We know we have to keep trying. We can't let ourselves give up. Somehow, we have to find the strength to endure.

"You have graciously spared your baby the devastation that he would otherwise have faced. Be happy. I hope you will accept the inner peace that you deserve for your act of love and kindness.

"In regard to those who have been casting stones at you, ask them what they have done to make it possible for parents like us to choose life. Their answer can only be silence. May God forgive your persecutors. They know not what they are doing. Truly until the responsibility for ensuring life instead of an excruciatingly painful existence to handicapped children is taken by society, forgiveness is all the present society in this United States can hope to get and that is far more than it deserves."

MR. PASCALE: I would like to turn the questioning to my colleague, Eileen Hanrahan.

MS. HANRAHAN: Dr. Ellison, do you have opening remarks that you would like to make?

DR. ELLISON: I didn't prepare an opening statement, however--

CHAIRMAN PENDLETON: If you would like to at some point beyond today give us something for the record, we would be glad to have it and would include it. You don't have to, but if you want to, you may.

DR. ELLISON: I think so. Perhaps several points of clarification need to be made in regard to any position that I would take. My work has basically been in the neonatal intensive care unit. It has been in regard to children who are sick in the newborn period. In the newborn intensive care units with which I have been most closely associated, there would hardly ever be a Down's syndrome child. There would be very rarely a child with spina bifida. Most of them would have gone to another unit. In short, they would have been referred to the surgical unit for care of the children, and much of the thinking and writing that I have done has not been in relation to a decisionmaking process about children with these particular defects. I think that's extremely important for a number of reasons.

Much of our ability to gauge or judge brain function or dysfunction in the newborn relates to acute processes. These children are, in general, unless they are asphyxiated at birth, not subject to acute processes. They are subject to long-line processes in utero, and the judgments made about them and the information we have about them is about groups of them as they go through infancy and into early childhood and, as many of you know--and part of the argument that has been presented is that--the children have a reasonably wide range of function and this is very difficult for many of them. Indeed, this has been precisely where a lot of the problem has been, particularly for the spina bifida children, in selecting those children who would be at one extreme as opposed to those at the other extreme.

However, many of the other children or newborns in the neonatal intensive care unit do have acute processes, and I think one of the comments that should be made at this time is that the technology in terms of neurology could best be called "exploded" within the past 10 years. In particular, first the CAT scan, then the ultrasonography, now the magnetic resonance imaging, which are increasingly available across the country and give us more information than we ever had into the neonatal brain. Much of my thinking evolved from working with families with children with handicaps of various sorts, and I was well-exposed both to the community, to their homes on some occasions, to the school situation, and to the developmental disabilities for children in the State of New York, as a part of my training and as a part of my early professional experience.

The work that has come out of the neonatal and intensive care unit also has taken a stand that there should be some decisionmaking processes about some of these children, and I would emphasize again that these are not children with birth defects. There are two particular groups of children about whom we have some problems, or at least I would perceive that we have some problems. The first of these groups of children would be the very, very small premature babies. I'm not talking about 2,000 or 3,000 gram babies. I'm talking about babies that weigh 800 grams and less, some people draw a line at 750 grams and less, some at 700 grams and less. In the very low birth weight group, as well as with respect to some who have repetitive neurological insult, and I'm choosing those words deliberately--I do not think it was a single neurologic insult, but repetitive insult during the course of birthing and during the course of treatment in the neonatal intensive care unit.

The second group are severely asphyxiated newborns who had difficulties during intrapartum and birthing processes and who have problems in the neonatal unit as well, in terms of level of consciousness, repetitive seizure, etc., and I have simply said that to me, the present social policy in this country is untenable. It is untenable because we have taken a stand in many ways--and one could go at some length to enumerate this--that these children should be preserved and the utmost should be done, and measures that support their care should be carried out. And at the same time, we have not always looked as well as we should at the ways of judging the function of the newborn brain, and at the same time, we have not provided adequate services for the children ranging all the way from failure to provide, in my own State, physical therapy, use of the respirator--if you run out of a respirator at 6 to 7 months of the financial year, you don't get the respirator, or it is not paid for by the State if you do get the respirator. If it is at the 8th month you don't get the surgery or it is not paid for by the State. If you are in the 9th month of the funding for the year, your physical therapy is not given to you. In other words, it is not a matter of whether or not exotic resources should be provided. It is a matter of whether very basic resources are being provided.

Knowledgeable people in the State of Colorado have communicated to me that the situation with the mentally retarded is a time bomb, with an increasing problem in terms of the amount of facilities, the number of dollars available, and the number of people in need of the services. I think if we want a policy in which we want to preserve life at all costs, we must have a policy in which we provide appropriate services. Thus I would make the statement again that I personally find this an untenable policy in this country at this time.

MS. HANRAHAN: If I may ask you to clarify one point. When I had spoken with you earlier in our interview, we talked about technologies now available to treat handicapped children, and I understood at that time that you thought that there had not been a great growth recently in that kind of technology.

DR. ELLISON: I don't want there to be a confusion between technologies for brain imaging, technology in regard to wheelchair use and electronic and computer devices for children with certain kinds of handicaps. We have those. I specifically said while we, say, were making more advances in the actual care of the newborn, many of these are refined many times on procedures that are already in process, for example, our capacity to use the respirator well, which has probably been one of the major devices in terms of permitting us to keep alive very small and asphyxiated babies.

MS. HANRAHAN: So the difference then is in the technology to measure as opposed to the technology to treat?

DR. ELLISON: Yes.

MS. HANRAHAN: And secondly, with respect to the difference in the population that you serve who are the asphyxiated and the very premature infants, in what respects do those treatment decisions affecting those children differ from treatment decisions affecting children born with birth defects?

DR. ELLISON: In situations that I have understood have been brought up here today, there have been statements made such as "a decision to treat." Well, literally all of the babies that I'm speaking of are immediately put on the respirator. There's no decision to treat. Treatment is initiated. There are usually not immediate surgical procedures, although sometimes surgical procedures are required. For example, the Down's syndrome child that was cited had esophageal atresia, and had to have an operation immediately. They would have to have it on the basis of a patent ducus arteriosis, the heart area didn't close, or surgery on the stomach because the gut had an infarct and became gangrenous or because they had to have something like a shunt following an intraventricular hemorrhage. These are quite different decisions in many ways, although they are very complex and the whole issue of when to continue care and when to consider that really continuing care is not a wise idea are very complex decisions.

MS. HANRAHAN: So the decisions you would be most familiar with are whether to withhold, or rather, to withdraw treatment already initiated?

DR. ELLISON: And usually they are in regard to whether to continue use of the respirator. Those are the particular issues I have tried to address in my writings.

MS. HANRAHAN: With respect to decisionmaking in those kinds of cases, we talked a lot about the decisionmaking process through the course of this, and Dr. Owens addressed that somewhat, too. What do you see as the interplay between the parents and physician?

DR. ELLISON: In any neonatal intensive care unit in which I have ever been, there's more than one physician; there are nurses, there are social workers, or at least one social worker, and there are physicians of different categories. That would be the hospital staffing, so to speak. In addition, there is the family, the grandparents and the priest or chaplain or whoever else the family wished to consider, and I think these decisions should be made in that kind of context with the parents participating. I think the word "imposing" would be about as far removed as any word I could think of in terms of the kind of process that is going on, and I think it is a process that takes some time and some deliberation. None of us has the wisdom of Solomon.

We wish we did. There are difficult things, but I think that there should be a group of people from different kinds of backgrounds who are participating in some of those discussions. I think the parents are one of the key groups, key people.

MS. HANRAHAN: I guess I'm trying to understand how much of an input or of a final responsibility for the decision the parents have. I would like to refer to one of the articles you submitted entitled, "Decisions to Withdraw Life Support in the Neonatal Intensive Care Unit," in the November '83 issue of Clinical Pediatrics. In part of that article which is subtitled "Decision-making Process," there is some discussion about the conferences with parents and other members of the hospital staff. The end of that particular section--well, I'll start with the sentence preceeding the last, "The difficulty talking about these issues," and "the mixed emotions were aroused and that was also discussed, during which they were asked to give an indication whether or not they concurred that support be withdrawn." Does that suggest that there was a preexisting opinion that support be withdrawn and that the parents were then asked whether they concurred or disagreed, or am I misunderstanding that?

DR. ELLISON: I think that's a misrepresentation. I think there are several steps to the process. First of all, in the units in which I have worked, there's been a tremendous effort amongst the doctors and nurses to communicate with the parents at all times about studies being done on the children and the results of those studies, so information is being given to them hour by hour and day by day. But a lot of times, and I think that's well reflected in the work of medical sociologists and in any medical sociology work I have ever read, you don't come to grips with that, the parent doesn't, and the discussion is not back and forth, and there hasn't been time for deliberation and to really interpret the meaning of that. And the purpose of some of the conferences, the early conferences, was to go over carefully the testings that had been done to explain them again, to talk back and forth with the parents, ask questions about whether or not there's understanding, what their questions might be, in other words, to have the kinds of sessions in which information is exchanged.

Other people would often raise questions and points in the conference. The nurse might say--they usually know the parents well, by first name; "Didn't you have a question about that that you were going to ask at this point in time?" There was not a decision ever offered by the doctor that support be withdrawn. However, it should be clear that if the issue is being raised, this is a consideration in the doctor's mind as well. You are not going to hold conferences for those babies about whom this would not be an appropriate concern. It should be also well-stated that with parents who felt that this was really something that was not in keeping with their concerns, none of the support was ever withdrawn from such a child. We would never have considered such a thing.

MS. HANRAHAN: In another part of that article, on the preceding page, you talked about that first conference and mention that "more detailed information was often given about the meaning of severe neurologic sequelae--that the child can never care for himself, skills would be extremely limited, that special care and programs would be required and that the brain damage was more than that of needing special help in school." Are the people that are giving that information sufficiently qualified to represent what is in fact the true case? A lot of people that testified feel that insufficient or inaccurate information is given to parents at that point, and that perhaps other parents of disabled children or rehabilitative therapists should be included within the discussion to get a more accurate presentation for the parents. What are your thoughts on that?

DR. ELLISON: I would have to say that I'm writing out of my experience. I was the one who gave the information. I don't know what a medical sociologist would review or do with my thinking, but I'm steeped in care for handicapped children, and a very good knowledge about what level of child can do what, and what the child's potential for function is. This is the area of my expertise and training. We weren't asking a neonatologist to make that kind of statement. That's not their area of expertise and training. This was one of the reasons to have a neurologist attached to this unit.

MS. HANRAHAN: Is the neurologist able to identify and discuss competently the sociological aspects, as people have called them, of the child's future as well as the more medical aspects?

DR. ELLISON: I think that would depend on what you consider the sociological aspects. Some of us have been to the schools for the children, we've worked with the families, we have been in the homes, we have been in the community for early identification education of both nurses and physicians and parents. I don't know how we would imbibe more information. At least for myself, I don't know how I would imbibe more information.

MS. HANRAHAN: Do you have any experience with whether--basically, call them negative prognoses with respect to the very disabled? I realize you're not dealing with children with birth defects, but the population that you are dealing with--whether those negative prognoses are borne out in practice or in the future, or is there not a correlation? Do you find that many times a negative prognosis depends upon circumstances that cannot be measured at the time of birth, and therefore that it is unreliable?

DR. ELLISON: Well, I think that there are several answers to that. I tried in the beginning statement to say that a lot of the children with intrauterine processes such as Down's and spina bifida have a potential for a fairly wide range of function. And I think many of the measures that we're using, such as the imaging methods and some of the EEG measures, do not give us a good indication of the level of function of the child and I said, "Let's take those and put those over into another category." But I have said many of these measures are giving us excellent indications of acute insult to the brain and the degree of that.

If you acutely asphyxiate a baby and do a CT scan at 10 days of age, with contrast, you can see the infarcts in those particular babies who have this problem. In one baby, for instance, you can see that there are infarctions of the major portion of both frontal lobes and major portions of the occipital lobes. That's like having strokes in all those portions of the brain, and the damage is there, and it is clearly there, and it is not a question of whether or not one sees it or doesn't see it. It is there. So that in those kinds of instances, I think we have very good and very reliable techniques upon which to make some decisions.

There are other instances in which the decisions are not so clear-cut and I don't think any of us who are--certainly I would have to speak for myself, I don't want to make a decision on hazy or in between kinds of testings. I can't do that. I wouldn't dream of doing that. I think one can only talk about such things when you have good solid evidence in your testings of what has happened to the brain. So that I would say it depends on what you are using, it depends on how knowledgeable you are, it depends on how you combine methods, it depends on a number of things, and this is not to say there has not been a number of inaccurate comments about such things previously or that there will not on occasion continue to be such. I expect there shall.

MS. HANRAHAN: In making a treatment decision, does it come down basically to a balancing of the predicted quality of life for the child versus the burden to other segments, such as cost to society or involvement of the family or disruption of the family? Are we talking basically, in the final analysis, about a cost/benefit analysis?

DR. ELLISON: I think the cost/benefit analysis is a most cruel and inappropriate way that anyone should ever make a decision. I think the decision should be made on other grounds, but what is extremely bothersome to many of us in this area at this time is that we will be forced and are being forced to make some decisions on the cost/benefit basis.

MS. HANRAHAN: I don't mean cost only in terms of dollars, but do we look at things in terms of advantage and disadvantage; is that what it essentially comes down to? And is the question, then, what factors do we include or should we include?

DR. ELLISON: I do think that factors, such as if you have to take home a child who requires 24 hour nursing care, and we send such children home from the unit, and society provides no other person but the mother and the father, but mostly the mother to do that, that is to say, there's no respite care, there's no homemaker service, there's no one else who is going to care for that child, and in addition to that, the family has to pay for a good many of the medical expenses for that, I think the family ought to be permitted to participate in that discussion and in that decision.

MS. HANRAHAN: Thank you, Dr. Ellison. Mr. Chairman.

CHAIRMAN PENDLETON: Mr. Destro?

COMMISSIONER DESTRO: Let me ask a few questions of Dr. Owens and then I'll turn to some questions for Dr. Ellison, Mr. Chairman.

Dr. Owens, I understand your specialty and I have heard it on the record. Have you had any training in rehabilitation services and in the diagnosis of future disability?

DR. OWENS: I have had no formal training in such things, however, I have had considerable observation of what can be accomplished and what is available.

COMMISSIONER DESTRO: I have here the findings of fact that the judge made in the Infant Doe case, and it strikes me that between the time of the birth and the time of the initial hearing there was about a 24- to 36-hour period. What kind of diagnostic testing was done of the neurologic capabilities of Baby Doe during that time period?

DR. OWENS: There was no further neurologic testing done during this time.

COMMISSIONER DESTRO: When you say "further," was there any done?

DR. OWENS: I don't recall any neurologic testing because of several things. First, this child was obviously a Down's syndrome child. Secondly, it was asphyxiated at birth and quite depressed at birth. Its behavior was that of a child which, let's say, showed very little activity and so forth in the immediate neonatal period.

COMMISSIONER DESTRO: Okay, when I look in the findings of fact, it says here and, certainly, correct it if it is wrong, that Dr. Owens testified that even if surgery were successful, the possibility of a minimally adequate quality of life was nonexistent due to the child's severe and irreversible mental retardation.

DR. OWENS: I think that's a somewhat distorted view of things. My testimony was to the effect that I had personally had contact of one sort or another with a considerable number of Down's children over a period of years, that some of these children were mere "blobs." They were incapable of doing anything, and I used that word. That others were able to--were no more than moderately retarded, that this sounded benign enough until you realize what "moderate retardation" meant. It meant that these children, as they grew up, were unable to do the normal things that normal children can, that I made the statement in regard to this, that I had never known a Down's child who was gainfully employed outside a sheltered workshop. I have had to revise that since I heard of one Down's child, a young woman, who is washing dishes in a restaurant. That's the sole one I have been able to encounter. I have never known a Down's child able to live on its own. They require constant attention the rest of their lives. Even the best. They have to be supervised. Their attention span is short and they require constant attention for as long as they live. If they last until the parents are old, then the parents have to make arrangements for their care after the parents are dead. There are a number of other things in regard to this that I testified. I think that's somewhat of a misinterpretation there.

COMMISSIONER DESTRO: What do you mean you use the term "normal child"? What do you mean when you say "a normal child"?

DR. OWENS: I mean by that a child--and I think this has to be taken in context also--I think by the term "normal," statistical definition of normal mentality is above an 80 IQ, I believe. Some would lower that to 70, I think, but in any case, a child who has intelligence that would enable him to function as an independent individual in our society, and whose physical handicaps are not so great that he cannot at least have some function, let's say.

COMMISSIONER DESTRO: Now again referring back to the--

CHAIRMAN PENDLETON: Could we get a response from you about what normalcy is, so the record will have some kind of continuum to it, if you don't mind? How would you define "normal" in this case? We have one definition of an IQ of 80 or maybe 70. Am I correct, Dr. Owens?

DR. OWENS: Yes.

DR. ELLISON: I guess it depends on some other definitions that you are not considering and that is--it is true that typical definitions of a normal intelligence have been a point of around 70 for many studies. However, most children who function in the mildly mentally retarded range, and that is, the range in which most retarded children function; that's upon where the majority of retarded children are functioning; that's the mildly retarded, the range of about 50 to 70, depending upon where you want to draw the cut points, but those are good enough for the discussion. The study shows that those children by and large live independently, they hold jobs, they do not attain levels of education of many people present in this room, but they function in society. And I think that, certainly, in my way of thinking about it, if you are talking about decisionmaking processes, your first concern should be that the group whose functions are at the far end of the spectrum. They are not in the normal or mild or even in the moderate; they are in the severely retarded range, and let's even be more specific, profoundly to severely retarded range, and that's at the other end of the spectrum. I would tend to lump children, if we're going to lump, with mild mental retardation, closer to that of normal children.

CHAIRMAN PENDLETON: Another question, if I can on this point, at what point can you determine whether the IQ is 70 or 50 or whatever it is. What point in life?

DR. ELLISON: The actual very good testing, you probably first begin around--that's almost an hour's discussion in itself.

CHAIRMAN PENDLETON: I figured it was, but we're making a judgment about newborns, talking about IQs and normal functions. When do you make that determination?

DR. ELLISON: Let's come back to the comment that I tried to make because it is very apropos to the--I said that children who have conditions such as Down's syndrome or spina bifida which occurred in utero, and in these two particular conditions, in particular, often have quite a wide range of function, of cognitive function, which is what IQ is meant to assess. And I said that a lot of our measures in the newborn period do not give us good indicators of what that level of function is. I also said that children who have an acute insult to the brain, such as asphyxia, such as a major interventricular hemorrhage, such as an ongoing ischemic process where you can't ventilate that child appropriately, give that child enough oxygen or blood flow for any number of reasons, and add to that infection such as meningitis or add to that repetitive seizures--we have measures that give us better and better indicators of how extensive that brain damage is. I'm speaking of acute brain damage. If you destroy or damage three-quarters of the brain as a part of these processes, the chances are highly reliable that you are not going to think well and move well. I mean, you are going to think very poorly and move very poorly as an outcome, but I'm being very clear-cut in the distinctions I'm making.

CHAIRMAN PENDLETON: From what you talk about in terms of the ability to talk about insult to the brain and so forth, that that kind of measurement is a predictor--

DR. ELLISON: That's right, and "predictor"

means--

CHAIRMAN PENDLETON: Means you might not get to an IQ test.

DR. ELLISON: It means that the correlation is high. Identification of a group in the severely retarded range becomes increasingly reliable. Have I been clear?

CHAIRMAN PENDLETON: Yes, yes.

COMMISSIONER DESTRO: Very useful.

CHAIRMAN PENDLETON: Thank you.

COMMISSIONER DESTRO: Let me go back to Dr. Owens. In the findings, you indicated or it is indicated, I should say, that you related no treatment of children with coexistent maladies of Down's syndrome and tracheo-esophageal fistula. Basically, does that mean that there is no successful treatment of the two?

DR. OWENS: I'm sorry, I don't understand the question. I'm sorry, sir.

COMMISSIONER DESTRO: Let me read the particular point. I quote from the appendix, pages 9 and 10, of the Supreme Court certiorari petition in the case. "Dr. Lovelin testified that he concurred in the opinions of Dr. Schafer and Wenzler and differed with Dr. Owens' opinion in that he knew of at least three instances in his practice where a child suffering from Down's syndrome had a reasonable quality of life. However, he related"--I'm sorry, I'm reading the wrong doctor's opinion. Let me strike the question altogether.

Let me turn to another question because I don't want to put any words in your mouth. It says, "Dr. Owens testified that he presented Mr. and Mrs. Doe with the two recommended courses of treatment and requested that they come to a decision." How was the issue of recommending course of treatment posed to the parents?

DR. OWENS: I think that's a little distortion. They were not recommended courses of treatment but simply alternatives. As I indicated earlier, the pediatrician and Dr. Schafer and the family physician, Dr. Wenzler, were simply saying to them, "This child must go to Riley Hospital to be operated on tonight." I'm not sure they even mentioned the Down's syndrome or they certainly downplayed it and were giving the impression to the family that surgery would make this child okay. Those were their words: "The baby will be okay."

My words to the family were simply, as I said before, that "I think you must realize that if the child has the surgery, and if the surgery is successful, that this child will still be a Down's syndrome child with all that that implies," and as I indicated earlier, the parents were pretty well-acquainted and had a good knowledge of what this implied. I said to them, "There is the alternative of doing nothing, in which case the child will survive a few days and will die." These were not recommendations in that sense at all. These were alternatives presented to the family of what could be done. They chose not to treat the child.

COMMISSIONER DESTRO: Is it fair to say, then, that the decision not to treat was based on the fact that the child had Down's syndrome?

DR. OWENS: I think it was, and all that this implied. In other words, that the gain, if you want to say this--that to go through all of this, to treat such a child with everything that's involved in that, and then to do all that with such a dreary, hopeless outlook as to the future, the parents felt this was not indicated either for themselves or the child.

COMMISSIONER DESTRO: Would it be perhaps--it is in that case then, if you look at the traditional child care standard of best interests of the child as opposed to best interests of the parents, that the conclusion was that the child would be better off dead than having the surgery and growing up to be a Down's syndrome child?

DR. OWENS: I don't think you can take these things in a vacuum. That's what I was trying to say earlier. You have to consider both. You are being foolish if you do not consider the effect upon the family or, worse than foolish, you are being harsh and cruel, if you do not consider the effect upon the family and the effect upon society as well as the effect upon the child.

COMMISSIONER DESTRO: I'm not suggesting that that ought not to be considered. I'm trying to find out what was considered in the context of the case.

DR. OWENS: You don't isolate these as specific things.

COMMISSIONER DESTRO: I certainly understand that. I wanted to ask, then, this, in terms of--you were also involved, I take it, then, in the child in need of services hearing held by the county welfare board or--

DR. OWENS: On 5 minutes notice.

COMMISSIONER DESTRO: Right. And basically did the--tell me, maybe you could just say how did that develop? Were the recommendations presented or the alternatives presented and was the decision fairly clear in your mind or in the mind of the board that it was basically a judgment that was being made that the child would not receive the services because it was a Down's syndrome child?

DR. OWENS: First of all, I think we have to point out there were several hearings. The night after the baby was born, approximately 36 hours later, again, on 15 minutes notice, a hearing was held at the hospital. It was only after my protests that the parents' attorney was called and allowed to attend. There is a rather sad story in regard to this--that of two things. The hospital's attorney apparently was not very knowledgeable of the law for one thing, and the hospital administration was highly partisan for another thing. If the hospital administration had said, "Let's find out what the law is and follow it," I don't think there would have been much problem. They were not willing to accept this at all.

There was a somewhat unsavory relationship between the hospital and one of the pediatricians concerned. They were not willing to accept any decision and they kept appealing the decisions, and these appeals were carried out on short notice. I literally had to run out of my office one time down to the county courthouse. I think these were carried out in the spirit of due process with adequate testimony by everyone who had anything to say.

COMMISSIONER DESTRO: Was it clear in the final--what the judge, in my conversations with him, indicated the CHINS statute in Indiana. As I read the statute, it says that "the physical or mental condition of the child is seriously impaired or seriously endangered as a result of the inability, refusal or neglect of his parent to supply the child with," among other things, "necessary medical care." Why wasn't the surgery necessary for the child's welfare in this case?

DR. OWENS: I have enough trouble with the technical aspects of medicine and with the ethical problems of medicine. I do not pretend to be a scholar of the law as to the exact wording in this.

COMMISSIONER DESTRO: But my question is--the alternative is to treat or not to treat. The legal question and the question that we're wrestling with here in terms of a definition of discrimination is: "why you decide not to treat." So my question is, in the case of--I assume that there could be children who were born, who were normal except for some kind of malformation of the esophagus that would require treatment. Why wouldn't the two be identical but for the Down's syndrome?

DR. OWENS: They largely would. This is not a question of discrimination at all in that sense. I don't think the word "discrimination" should be used in regard to this. Instead, this is a matter of competing values and competing rights. I think perhaps it is a little more analogous to the situation that's presently confronting the Supreme Court in regard to whether the last-hired, first-fired rule should apply to people hired in affirmative action programs. Here, we're talking about competing rights of a child to existence, and the question of quality of life certainly comes into that, as to what kind of an existence, and the right of the family not to be forced to undergo expensive treatment, then to be presented with a child who will give them nothing but anguish in the future.

COMMISSIONER DESTRO: Let me turn to Dr. Ellison for a minute.

CHAIRMAN PENDLETON: Just one second. Dr. Owens, while you are warmed up here, counsel asked you earlier--did you think that you need to have parent advocates, and I'm not sure you answered the question. Should there be parent advocates like in this case or should there not be parent advocates? And I don't know what that is, but you might have heard about that before. Could you tell me whether there should or should not be parent advocates?

DR. OWENS: If I can give you a little history on this particular case: Within a matter of an hour of the parents' decision, the pediatrician was threatening criminal action against the parents, and they talked with their best friends again, and he advised them to obtain an attorney, which they did.

The hospital made every effort to bypass this attorney and so forth I would add, too. This was a very unsavory thing in many respects.

CHAIRMAN PENDLETON: Are you saying here that the friends were parent advocates?

DR. OWENS: And the parents had an attorney representing them, too.

CHAIRMAN PENDLETON: Is the attorney an advocate in this case, then?

DR. OWENS: I don't know. Define "advocate" for me. I understand "attorney" is synonymous with "advocate" in many circumstances.

CHAIRMAN PENDLETON: Do you think that society--either you or Dr. Ellison--do you think society has enough information about this variety of conditions to decide about the enormous public expenditure required to maintain disabled persons in what someone calls a functional quality of life state, as compared to what I think you mentioned earlier--if I'm not putting words in your mouth--as compared to the well newborn? You talk about competing values and competing rights. How do you resolve that? Does society know what the difference is, or should society know what it is, and should society pay that public cost?

DR. OWENS: I think this has to be resolved with great difficulty on an individual basis. I don't think we can issue blanket rules. I think it would be the cruelest possible thing if the Federal Government mandated that every such child be kept alive regardless, and even crueler if the Federal Government, having mandated such a thing, then failed to provide the funds to carry that care out.

CHAIRMAN PENDLETON: Do you have some idea what the cost was in Infant Doe's case?

DR. OWENS: Relatively small in this case.

CHAIRMAN PENDLETON: What is relatively small?

DR. OWENS: A few thousand dollars in this case, because the child, not operated on, was not kept alive for months, and did not receive multiple operations as they usually have to, and so forth. I would add that the parents lost their home shortly after that; they had to sell their home partly to pay their legal fees and so forth. They have since recouped on that, and have a new home.

CHAIRMAN PENDLETON: What would be the cost of a child with Down's syndrome in neonatal ICU?

DR. OWENS: If this child had been operated upon?

DR. ELLISON: In general, Mr. Chairman, they are not in the neonatal intensive care unit.

CHAIRMAN PENDLETON: I'm sorry, you are right. What would be the cost over a lifetime of a Down's syndrome child?

DR. OWENS: Such a child as this, for a ballpark figure, a minimum of half a million dollars and more like $1 million over its lifespan for its care.

CHAIRMAN PENDLETON: What would that lifespan be, if you have some idea?

DR. OWENS: It would vary tremendously. For example, these children are more prone to develop leukemia, which is usually fatal. You cannot say whether this child would develop many infections, whether this would shorten their lives. The great majority of Down's syndrome children, if they survive to adulthood, develop premature Alzheimer's disease, and the last part of their lives is spent in almost total dependency.

CHAIRMAN PENDLETON: Are you talking about the total cost for Down's syndrome or the total cost?

DR. OWENS: I'm saying the lifetime cost would almost surely be close to $1 million. The immediate cost would be perhaps $100,000 in the first few months of life.

CHAIRMAN PENDLETON: I'll come back.

COMMISSIONER DESTRO: Dr. Ellison, I'm going to refer to your article that was in Clinical Pediatrics and ask you a couple of questions. There's one case in here that seems to be somewhat at odds with what you have said with respect to myelomeningocele, and I wanted to--I was curious as to why this particular case was noted in your clinical finding. There was one noted lumbar myelomeningocele, flaccid lower extremities, and leaking cerebrospinal fluid, and showed Apgar scores at 1 and 5 minutes of two and six, respectively.

DR. ELLISON: The concern there has been in the infection from the open, leaking lesion, and in this instance--and I don't know how clearly the details are given, I have to review that--but this was a child with fever and infection, and I have said that the distinctions in meningoceles are often very difficult to make on the basis of doing the imaging testings that we do in regard to brain functions. However, overwhelming infection of the cerebral spinal fluid puts that child into the category of meningitis, and this moves you into another predictive kind of category. That's the only reason this kind of child is included in this particular discussion.

COMMISSIONER DESTRO: That's the reason I asked, because it was indicated in the chart, and I'm looking at table 1 in the chart, case 14, where there was no interventricular hemorrhage or respiratory distress syndrome.

DR. ELLISON: You wouldn't expect to find that in a myelomeningocele child. That is not the problem that they have. The risk there is in the major infection in terms of further--in terms of causing acute injury to the brain.

COMMISSIONER DESTRO: When you talk about withdrawal of treatment in a case like that, what do you mean? It is easy in a respirator case to see what withdrawal of treatment is. What's withdrawal of treatment in that kind of case?

DR. ELLISON: I'm not certain whether or not that child was on the respirator. I would have to check the details. But usually, most of the instances that we've talked about have been withdrawal of respirator support and a lot of the children who have infection will also have some pneumonia as well. In other words, you don't just infect the CSF, you infect the blood, lungs, and other areas, and it is highly likely that this child had similar such problems, but I would have to review that.

COMMISSIONER DESTRO: I don't mean to get you into the details, I was just curious, in light of your other testimony. You indicated in a couple of the paragraphs--and I read several of your articles and found them very interesting--in one paragraph you say that while parents of children with lesser handicaps generally rally to the care of the infants and accept a slower timetable for development, parents of severely handicapped children often express frustration from the constant care and giving, with at most simplest return from the infant. I assume that--do you, or is there some procedure whereby the parents are told in situations like this about the kind of supporting mechanisms in the community for them, as a part of the whole diagnostic and judgmental process that goes on?

DR. ELLISON: In my professional experience, I have worked in the State of New York, the State of Wisconsin, and the State of Colorado. At the time that I worked in the State of New York, we had the best. This was at the time when the mentally retarded were being moved out of the institutions into the community, and very few newborns or infants were institutionalized. There was respite care; there was homemaker care; there were support groups; there were extensive services for the families at that time. Still, some of those families with the most severely handicapped child, at least to a neurologist, would be a child with severe cerebral palsy and severe mental retardation and usually a seizure disorder as well.

In other words, it is a multiply handicapped child. In addition to that, the child may have visual and hearing deficits as well. In other words, when I said "severely handicapped," I had in mind what I meant by that.

As I moved to Wisconsin and times changed, the services began to drop away. As we come to the State of Colorado, the services are further decreased and the times have changed again. We try, and we have tried, and continue to try, as best we can to put parents in touch with supportive services, but the supportive services are markedly less than they were earlier in my career.

COMMISSIONER DESTRO: In one part of the article, the part that Ms. Hanrahan referred to a little earlier, in the decisionmaking process discussed on pages 731 and 732 of the article--apparently there's a process here where you said that some parents seem unable to absorb the meaning of the information. What kind of an observation or decisionmaking process do the physicians go through in, if you will, evaluating the parents' ability to absorb the information and then decide what kind of a role they ought to be playing in the process?

DR. ELLISON: Well, sometimes when you present information to parents, in fact, often when you present information to parents, that's very bad news. You don't have much interchange. You try to ask a question: "Did you understand what I said? Maybe we could discuss a little bit how one might feel about that" or other things in which you try to get some assessment about whether what you said was registering, so to speak. Many of us who have to do this on a fairly regular basis--I don't know that we're accurate, and I said before that we don't have the wisdom of Solomon. But we do try, many of us, to do a lot of assessment as to whether or not what we said was understood, and whether it was registering and whether the full impact of that was registering. In other words, if I tell you something very bad, such as, "Your baby has severe brain damage," and the parent smiles and says, "I have a new outfit of clothing at home, isn't that nice," you have not had full communication, and so you know that sometimes that takes time, meaning you meet again and again, and you begin to try to see that a response is coming from that parent, that there was an understanding, a registration of what it is you are trying to say. I don't know that we're accurate, but we do the best we know how.

COMMISSIONER DESTRO: I'm just trying to find out, again, the process. We've heard a lot of testimony about the process, and I'm not being accusatory in my questions, I'm just trying to find out how it works.

DR. ELLISON: The process is a difficult one, to give bad news consistently. That's one of the things that a pediatric neurologist is called upon to do. It takes a lot of insight and patience and wisdom and compassion, and some days we may have a little more than others, and some days probably a little less.

COMMISSIONER DESTRO: I'm sure. And then finally, in these decisions to withdraw the support, are the decisions--or who usually, in your experience, your own experience, has brought up the question of whether or not you want to continue with the ventilation or the treatment? Has it been the parents generally or has it been a member of the medical staff or the social workers or who? Who usually initiates that discussion?

DR. ELLISON: In the nursery in which we were working at the time, there was a lot of give and take amongst the social worker, nurses, neonatologists, neonatal people, and parents; a lot of times parents were there, and they would tell something to the nurse they wouldn't tell someone else.

In terms of when it seemed the right time to hold a conference, it might be initiated in any of several ways, such as the child having certain tests done that would indicate neurologic function and knowing the results of those, and which, by and large, as a neonatal neurologist, I would be called upon to comment that we were showing evidence that there had been significant brain damage. Other times, the parent would raise to the nurse, for example, "Are we doing the right thing; doesn't seem to me as though my baby is doing as well as we thought that the baby might be going to do." Sometimes, there would be a comment from the parent to the social worker. We try to respond to the questions and needs of the parents, but would never have held a conference where this issue of support would be set up in the sense of a decisionmaking process, unless we as physicians felt that this was an appropriate case to do that. We might meet with the parents and answer questions and say, "We understand your worries, but look, at this time, things seem to be doing this way and this is not a time for such a conference."

COMMISSIONER DESTRO: Thank you.

CHAIRMAN PENDLETON: Dr. Ellison and Dr. Owens, should we leave here with the impression that the Child Abuse Amendments and the 504 regs have forced doctors to do what they would not, had there not been these regulations? Would they have treated people anyway because of these conditions? What have we really done with the amendment and the regulations?

DR. ELLISON: Well, I would like to respond to that in a couple of ways. By and large, it has been my experience in all honesty, that most children, most infants, most newborns with what are labeled birth defects receive treatment. They had, in my experience, for years in the hospital settings. It is true that in my article there are at least two children who would be labeled as having birth defects: one, the infected myelomeningocele; and the other one is not a Down's that doesn't survive well. It is a different category of child. But in general, the children who needed certain kinds of surgeries got those surgeries, irrespective of whether they had some other birth defect.

In other words, the surgery was simply done. In my opinion as well, there are other serious questions in this country at this time in regard to treatment in the neonatal intensive care unit, that is quite aside from these issues, and discussions were taking place amongst nurses, doctors, social workers. I don't know that we had evolved greater wisdom, but discussions were taking place about what kinds of decisions should be made along these lines. And when the rulings came down and the notices were posted in the nurseries, I think it would be safe to say, all discussions promptly ceased. A lot of the issues that were very important and are important, I thought, were cut off at that time because of the rulings, because physicians are conservative people, and if there's a climate of fear, there's no question about what they do. They treat, and they continue to treat. I think there is also, as you well know, a lot of resentment in the physician community about the way in which all that was handled at that time, and certainly legal suits do go along with that.

In terms of the workings of the Child Abuse Amendments, many of us have long worked with people in child abuse. We're used to that system and we would be surprised if it were an overwhelmingly interfering system. That is to say, they have their hands full with child abuse in the community as it is, and one doesn't expect that they will be doing a lot of newborn investigation by and large.

DR. OWENS: I would endorse Dr. Ellison's statement completely. We have unfortunately made progress much faster--fortunately or unfortunately, I don't know which--made progress much faster from a technological standpoint than in facing up to the societal and ethical problems associated with it. We need to keep talking about this, and the last thing on earth we need is a bunch of rigid rules that tell us exactly what we have to do. It would be great from the physicians' standpoint to have such rules, because we would never have to make decisions. We could say to the parents: "This is what we have to do and if you don't like it, call your Congressman." But from the standpoint of being humanitarians, of trying to do what is right for our infant patients, for their families and for the country, this is a matter which needs further discussion to the utmost and, I think, needs individualization of approach.

CHAIRMAN PENDLETON: Thank you. Mr. Latham?

MR. LATHAM: Dr. Owens, recognizing that you have testified that the approach has to be individualized, how would you articulate a standard, our own personal standard if you like, of when the degree of handicap is severe enough to justify nontreatment?

DR. OWENS: Let me say I think we have certain obligations, and they enter a hierarchy. I think we have a basic and almost absolute obligation to relieve pain and suffering in our fellow humans. Fortunately, that's something that can usually be done at relatively low expense and everything of the kind.

Secondly, we have an obligation to take care of our normal children, in preference to everybody else, because our children are the future. Every good parent will do this. He will sacrifice to provide for his children's education. We put education in general and other care of children as one of our highest priorities, with the possible exception of national security. Beyond that, the next priority, I think, has to be restoration of children who have defects, children or others, who have defects, to a normal productive status, and that obviously covers a wide range, but the work that is being done has been done for 50 years under the vocational rehabilitation care, things of this sort, crippled children's services, things of this kind. I think we would all agree that that needs to continue if at all possible, and only if our country truly gets into terrible financial straits, should we fail to take care of the child with the cleft palate or anything of this kind.

Now, beyond that, we get into the murkier areas where I don't think you can make rules, because it depends so much on the facilities available. Dr. Ellison has referred to the deterioration in community facilities as she has moved from one place to another and with the passage of time.

My son, who is also a physician, is on the board of our local center for retarded children, and he expresses constant frustration at lack of funds and lack of facilities and the demands which cannot be met with the children they already have. I cannot give a categorical answer on these things and I don't think anyone else can. I think we have to consider them on an individual basis with provision for review by the "children in need of services" programs or the child abuse services, this kind of thing. We've always had the courts to appeal to if the physicians or other people concerned felt that the process was being abused.

MR. LATHAM: Well, again let me press the point just a little further, if I may. I recognize that the application of a standard to any particular set of facts will yield different results, depending on the set of facts to which the standard is applied. But I'm trying to get some sense of how a standard could be articulated that would say: if the facts fit this pattern, nontreatment is indicated. In other words, I assume, Dr. Owens, that you would agree that a child born without a toe should be treated even though it is a less than perfect baby.

DR. OWENS: If he's born without a toe, I don't know what you can do about it.

MR. LATHAM: That the child should not be denied sustenance because it is less than a perfect baby.

DR. OWENS: Of course.

MR. LATHAM: Then we have on the other end the Down's syndrome baby you testified about. My question is: Recognizing that the facts vary from case to case, how would you articulate a standard of looking at any given infant and saying, treat or do not treat?

DR. OWENS: This is the essence of what I'm saying. You cannot come up with a standard. There are certain children where treatment is totally futile, such as a child whose brain is destroyed by an intraventricular hemorrhage, who is 3 months old and in the neonatal care intensive care nursery and is obviously going downhill and so forth. The child who is born without a brain--anencephaly or equivalent things--these children obviously should not be treated. Treatment is totally futile and unproductive in those cases. There are other cases that should be treated: the child who has a correctable deformity or problem, which when corrected gives hope of a reasonable life. And there's a big gray area in between, where I think you simply cannot make standards, and my appeal to this group and to the Federal Government would be: for heaven's sake, don't try to make a rigid standard here.

MR. LATHAM: That leads to my next question. Should, in each instance where nontreatment is the option chosen, should, in each instance, that decision be reviewed by someone other than the physician and parents?

DR. OWENS: Again, I think that has to be taken in context. The decision not to treat an anencephalic, backing up a little bit--when these regulations first came out and all the notices were posted in the nursery, shortly after that a baby was born in our hospital with a perfectly normal appearing head that was actually empty. This child had its medulla. It could breathe and had nothing above the medulla. The pediatrician said, "There's no point doing anything for this child." Whereupon somebody called up the hot line number and--

CHAIRMAN PENDLETON: Called the squads.

DR. OWENS: Yes. I don't think the squad came out, but it was a damn nuisance to everybody concerned to explain something that was obvious. But that kind of case should not have to be reviewed. But I certainly have no objections to review of any such decision at all. Our case, for instance, was abundantly reviewed. My only objection was the confrontational nature in which the review took place.

MR. LATHAM: Should there be a review where, unlike your case, there is no difference of opinion among doctors or between doctors and the parents?

DR. OWENS: Who is going to review it?

MR. LATHAM: The question goes to: Should there be some sort of system where there is a child advocate or child review or somebody to look at it from, theoretically, the viewpoint of the child?

DR. OWENS: Frankly, I think that any money appropriated for that purpose would be much better spent in caring for the kids we are going to treat. We're not perfect. There's never going to be anything that's absolutely perfect or anything of the kind, but we have heard insinuations of widespread conspiracies to do terrible things and of stupid physicians making improper recommendations, things of this sort. I don't think these are true. There are unquestionably isolated instances where, when you and I would look at things, we would say, "That wasn't right." That's true in every profession in every field. We're dealing as a general rule with conscientious people doing the best they can under the circumstances concerned, and I believe, making what I think are appropriate decisions in most of the circumstances.

MR. LATHAM: Do you believe that nontreatment decisions are frequent or rare, or how would you describe the frequency with which these nontreatment Baby Doe-type issues in fact arise?

DR. OWENS: That has to be taken in context again. That depends on who you are talking about. The number of Baby Doe type cases is very small. However, the neonatologists and pediatric neurologists, such as Dr. Ellison, are constantly faced with this. They have 100 or maybe 1,000 such cases in their field for every one we have to face.

MR. LATHAM: Is it fair to say this is an area where you just feel that--I'm not trying to put words in your mouth, I'm trying to understand whether in your view this is an area that is gray, and that in this gray area law really cannot help to regularize the process and do justice?

DR. OWENS: I think that's exactly right, sir.

MR. LATHAM: Thank you, Dr. Owens.

CHAIRMAN PENDLETON: Thank you very much. We appreciate your time. It was lengthy. I think we've established a good record here, and we appreciate your bearing with us as we go through this. We will stand up and convene with our first public witness, Mr. Nurney. If there are persons who wish to speak other than the ones on the list, we ask you to sign up with the clerk, please. Thank you very much.

[Recess.]

OPEN SESSION

CHAIRMAN PENDLETON: As we convene, General Counsel would like to or is compelled by the process to make a statement.

MR. HOWARD: Since many of the people in the audience who may be testifying may not have been here yesterday, I have to caution people to avoid any testimony that may defame or degrade or incriminate anyone. If you could avoid that we would appreciate it. I think that should cover it.

Also if anyone has not signed up yet for testimony in the public session, please do so. Either come see me or Eileen Hanrahan to my right. Thank you.

CHAIRMAN PENDLETON: I would like to say that by previous arrangement we have agreed that Mr. Nurney will be able to respond to some questions if so asked. Other witnesses will not be allowed that privilege. The way we've had to design this hearing, we've come to this agreement, Mr. Destro and I, ahead of time. In the public witness session we've had people give us testimony, but there are no questions. That is the purpose of the public testimony and if there's anything you wish to leave us for the record, you may do so. Mr. Destro?

COMMISSIONER DESTRO: I would like to indicate that to the public witnesses that they do operate under a limitation that if you would, please address some of your comments to the testimony you heard. If you have been here before and listened to the testimony, if you have any reflections on that we would certainly like to hear what you have to say.

CHAIRMAN PENDLETON: Thank you. With that we will proceed to Mr. Nurney. I want to thank you for helping us, if I may make that statement, helping us put this process together. I think that it shows that we put a few pieces together and we thank you for being here.

MR. NURNEY: I also would like to thank you, Commissioner Destro and the staff, for doing what I think is a remarkably good job.

CHAIRMAN PENDLETON: Go ahead, sir. I didn't swear you in yet, sir.

[The witness was sworn.]

CHAIRMAN PENDLETON: Proceed.

Testimony of Thomas Nurney

MR. NURNEY: Essentially what I want to do, since the time is so limited, is to indicate some testimony that will be coming to you from some people who were not able to be here, and I understand the record is open for 30 days. I would like to do that and I have been asked by several organizations to present written testimony that I will leave with you.

CHAIRMAN PENDLETON: The record is open for 30 days beyond today's period.

MR. NURNEY: Three people who could not be here, Dr. Hank Bersoni, who is head of the research and training center at the University of Syracuse, on community integration, will be giving you information basically on severe disability, and how folks with very severe disabilities can be integrated into the community frequently at less cost than the traditional ways we have worked with those people. Dr. Ron Connelly has a number of papers that we would like to offer for the record. He's an economist who works for the Department of Health and Human Services and essentially is a public policy analyst of what's wrong with Federal legislation and programs, especially in terms of the disincentives in the present system to help families and to encourage and help people to become more independent. You may recall that the question of cost frequently raises its ugly head at discussions like this.

There are many of us who believe that we may in fact have enough money in the system presently, but it is used so unwisely and so irrationally that it does not achieve any of the objectives of that legislation. And one example I want to leave with you is the tremendous use of medicaid dollars to institutionalize severely disabled people. The medicaid budget today, almost 50 percent of it, although this is not the reason for the enactment of legislation, almost 50 percent is used to institutionalize elderly and mentally disabled people.

Tom Gilhooly in Philadelphia was going to be here. Unfortunately, he had a heart attack this week. He's been doing an analysis of State statutes with regard to people with mental retardation. It may explain if we can get that finished in the next 30 days some of the attitudes that you have heard, especially the kinds of attitudes we think are prejudicial as a history that sprang out of the eugenics movement in this country, and I think it is worth considering.

CHAIRMAN PENDLETON: If that is not finished in 30 days' time, we will hold the record.

MR. NURNEY: Thank you. One group that wanted to be heard today is the Nursing Home Action Group in Minnesota. They have given me a number of documents that indicate what they consider, and I too, ongoing medical discrimination against elderly people. I would like to leave that documentation with you. The second group that had asked me to present testimony and could not be here is the American Civil Liberties Union. Chris Hanson, who is an attorney in the national headquarters of New York, did an analysis of a case that you have heard spoken of quite a bit here. I think that's the Oklahoma case. The American Civil Liberties Union is a plaintiff in that case.

I know there's been some discussion of what it is this Commission could do, and aside from obviously fixing the Bowen decision and addressing 504 in some adequate way, I would like to suggest one other thing. This will be my last point.

The one story not told about the Oklahoma case is something this Commission ought to investigate. We have talked about 24 children with spina bifida who died because they were not treated. In fact, the house that they were sent to, the one that I think Carlton Sherwood called the charnel house, was exactly that. There were in that three-bedroom home at any one point over a period of years, up to 65 children and sometimes more, kids with all kinds of disabilities. Mental retardation, I believe, was probably the most prevalent condition. None of those children were treated and the irony is that the Justice Department intervened and helped the State of Oklahoma close down that shelter, but they did it not because they killed so many children, they did it because it was medicaid fraud. And I think if this Commission wants to investigate a situation where I think the facts would be clear that we're talking about massive discrimination and what many of us would consider killing, then I think that's the place to look. Thank you.

CHAIRMAN PENDLETON: Thank you very much. You had a question?

COMMISSIONER DESTRO: Yes, I do. One thing that we have not heard a lot about, and you raise it in your last point, is the attitude of the Department of Health and Human Services and the Justice Department. In watching Mr. Sherwood's news accounts or his documentaries, it didn't seem like the Department of Health and Human Services was overly interested in any of this except insofar as it might have been a medicaid fraud case, and in that case we may have more Justice Department involvement than Health and Human Services involvement. Why do you think--or in your experience, does there seem to be a lack of interest on the part of civil rights authorities in cases such as this that, at least on the surface, seem rather obvious?

MR. NURNEY: Since I'm under oath, I have to tell the truth, what I think about the Department of Health and Human Services and the Department of Justice. There's clear evidence here that not only are they not interested basically or have not been traditionally, with the exception of some individuals in both departments. When the article was published in Oklahoma and first came out in 1983, a group of us got together and wrote a seven-page letter of complaint, sent it to the Justice Department and to the Department of Health and Human Services. It was signed by major disability rights groups in this country, and one of the signatories was Nat Hentoff, a columnist for the Village Voice.

The letter was never answered and has never been to date. But as a result of tremendous inaction on the part of both the Justice Department and certainly the Department of Health and Human Services, I went to Carlton Sherwood. The only way we knew we would uncover what was going on out there was to get a good investigative reporter. We were reduced to doing that because neither department would enforce existing laws, and why they won't--I think there is within this administration a debate on this issue. I don't think there is a consensus. There is in the disability rights community a consensus, and it is an issue we thought we had in common with this administration, and a lot of us are not so sure we do anymore.

COMMISSIONER DESTRO: What are the debating sides? You say there's a consensus in the disability community, but there's a division or you perceive a division within the administration. What are the sides?

MR. NURNEY: First the Department of Health and Human Services probably has a lot of doctors working for it and I think there are some arguments about the primacy of the medical profession that carry a lot of weight with this administration and with others for that matter. I don't think we can necessarily single out the Reagan administration. I think that may have something to do with it. I think a lot of people are very uncomfortable because of the philosophy of this administration of not interfering with families, giving people, you know, the kinds of leeway to make choices and removing whatever the language of the rhetoric that you want to use, removing the government from the backs of people of this country. So for some of us it seems like a contradictory position to take a very good position on supporting the value and the lives of disabled infants and at the same time to have a philosophy that says get the government out of enforcement essentially.

COMMISSIONER DESTRO: The last question is: Oklahoma is one of the more obvious cases. Are there any other cases that are currently being investigated that have not reached our attention and ought to at this juncture so they can be in this record? I know we have seen the Yale-New Haven cases. We have seen the cases in other medical centers, the Duff and Campbell kinds of--I believe that was Yale-New Haven.

MR. NURNEY: That was.

COMMISSIONER DESTRO: I have heard tell of cases up in Detroit.

MR. NURNEY: That's correct, and Iowa.

COMMISSIONER DESTRO: Could you expand on that list and get those in the record for us?

MR. NURNEY: Believe it or not, there's an opinion in this country, Dr. Will Fenseberger at the University of Syracuse has massive archives, and it will take weeks to go through them, but he gave me permission and he has documentation that nobody else has seen, and the other kind of documentation you really have to pay attention to, I know the hearing these 2 days is on the application of 504 to disabled newborns. One of the things when we get this information together and get on the record, you will see is life-long pervasive medical discrimination against people with disabilities that is not limited to infants, and I have asked the protection and advocacy systems, that's one in each State, to begin collecting current cases and I will give you one example in the State of Iowa. A woman who was diagnosed as having breast cancer, is 50 years old, a current case. The doctor and her 90-year-old mother decided they would not treat the cancer. The reason, the woman is mentally retarded. It is much more common than most of the witnesses I think, you know, have testified previously.

COMMISSIONER DESTRO: Thank you.

CHAIRMAN PENDLETON: Thank you, Mr. Nurney.

We will now convene a panel of public witnesses: Patricia McGill Smith, Margaret Burley, Commander Patrick Sabadie, Dr. Bud Fredericks, and Betsy Trombino.

Are you all here? Who is here?

MS. SMITH: Patricia Smith.

MS. BURLEY: Margaret Burley.

MR. SABADIE: Commander Patrick Sabadie.

MS. TROMBINO: Betsy Trombino.

CHAIRMAN PENDLETON: Only one missing is Dr. Fredericks; is that correct?

MS. SMITH: He had to catch a flight.

CHAIRMAN PENDLETON: Would you please raise your hands and take this oath?

[The witnesses were sworn.]

Testimony of Patricia McGill Smith

CHAIRMAN PENDLETON: Thank you very much. Counsel, you will give us some instruction about how you identify yourselves and your organization, if you would?

MR. PASCALE: Yes, go ahead.

MS. SMITH: I'm Patricia McGill Smith. I reside at 2822 Hogan Court, Falls Church, Virginia. I'm the parent.

CHAIRMAN PENDLETON: We have your testimony for the record and you can tell us more about that or just comment on this.

MS. SMITH: I'm deputy director of the National Information Center for Handicapped Children and Youth, and I have a lot of experience working with parents of handicapped children around the country. I formerly lived in Omaha, Nebraska, and for 12 years have coordinated parent services and parent-to-parent programs, and I worked at one period with the University of Nebraska Medical Center and had a great deal of activity in my career of working with families right in the medical center.

I cited in my paper three different events, over and above the things I learned from my own child, of things that I think are pertinent to this hearing. I regret that I was not able to hear a great deal of the testimony. I just heard the end of the last panel. I would like to share with you what a couple of those events were that led me to come give testimony today.

First of all is in the actual diagnosis of my own child, who is now 16 years of age, but at that time, after a long period of time to try to get a diagnosis, I finally found a new physician who did indeed diagnose a case of mild mental retardation. I needed desperately to have help with these problems, and the doctor's advice to me was to take her home and keep her comfortable, and it is a very desperate thing for a parent to be given that kind of directive from the physician, because that was not the help I needed. Fortunately, I did not listen to that part of his information and sought help and ultimately was able to receive help for my own child.

At a later point, and the most important piece of work that I became involved in, was the family of a child born in Omaha about 10 years ago, a child with myelomeningocele and predictable mental retardation. They said she had a condition in the formation of her brain that would give them a prediction of mental retardation.

As the leader of the group that was providing parent-to-parent support, the parent advocacy that I heard someone ask about in the last panel, I was called to support this family. When I realized and learned from what they told me that there had been a recommendation of no treatment based on the fact that the child had spina bifida and predictable mental retardation, I was extremely distressed and made a referral to the local protection advocacy agency and also the local association for retarded citizens. This began an interaction between family advocates and legal people and doctors that went on for about 2 months debating whether this child should live. It was an extremely excruciating situation for everyone involved.

The young daughter lived through this. Her parents were loving, good people, but they were operating on the directive of the doctor who said, why sustain the life of someone who will have two kinds of disabilities.

We worked a long time with those parents and with the medical people and said, if you don't want to raise the child yourself, let her go into the system. The systems in Omaha were extremely strong, let someone else raise the child. Why does the child have to die?

Eventually the parents listened. I don't know how they made their decision, but they finally came to the decision to treat. The child received surgery at about 4 months of age, which is very late in time for a child with spina bifida. I have tracked the progress of that child and that family ever since. The young lady had no mental retardation whatsoever. She does have the spina bifida. She is perfectly fine.

The point that I would like to bring to this Commission--that's enough to think about, what I just told you--but the point that I was the most concerned about was the point that I was called in for, and that was supportive services to the parents. Those parents were given inaccurate information, and the people that supported all that decisionmaking were giving inaccurate information. They were giving projections and they were biased in their interpretation of what was going to happen with that child. I think it was wrong then and I think it is wrong now and I don't think that people have the right to make those kinds of value judgments on the child's life.

In this case, the child did not have severe mental retardation and yet there are people that do not understand that development can occur even when people do have more severe mental retardation or whatever the case might be. In the case of my own daughter, she is a person who, in the beginning, we had no idea to what degree she would develop, yet she has developed into a beautiful productive person who--from my perspective she will work, she will be a taxpayer. I hope she will live in a supported environment, but she has the right, just like anyone else, to her own life, and I was appalled at some of the things I heard just in the last hour as to who has the right to live and who shall survive. You have a weighty decision to make on your part to listen to this testimony and understand. I have supported hundreds of parents over the 12 years that I have worked, and when parents are supported in the help to their children, and when the medical support is given, even for severely handicapped children, I have not met a parent yet that does not want to do it if they can. And I think it is our job to make sure that they have those supportive services.

You asked before we began to respond to any parts of the testimony. I only heard a little bit. I must disagree with a couple of things I heard. From my perspective, and I'm in an international leadership role, there are better and more available parent-to-parent advocate support services today than there were 10 years ago. That doesn't mean that there are all the supports needed to sustain the help that families need, but as far as parent-to-parent supportive services, at the time when a child is born, there are people who are trained and who are willing to go in and help those families, and I would say I could find someone for every major medical center in this country that could do that. When you ask the question about parent advocacy, it is available and there are people who, if they have to make long distance calls or make a trip, will go and help parents when they find out they have this need. And indeed there are many systems in place to help the medical community, the legal community, the nursing staffs, to know how to get that help in. That comes through associations for retarded citizens and Down's syndrome groups and the National

Information Center and some of my colleagues that are present here.

I guess my last thing I would like to say is about the ongoing support. There has been, from my perspective at least, in many parts of the country, cutbacks in the ability to support families' needs, and in my paper I wrote about some of that. That is the only thing we need besides giving people the right to live and support that life and that is to support them over time.

CHAIRMAN PENDLETON: Thank you. Is this Mrs. Burley?

Testimony of Margaret Burley

MS. BURLEY: Yes, my name is Margaret Burley. I reside at 3505 Labor Prospect Road in Prospect, Ohio. I'm the director of the Ohio Coalition for the Education of Handicapped Children. I'm also the parent of a young man now 24 years old. He would have been described by some as very severely retarded and, in fact, I was advised by medical people when he was very small that it was likely that the rest of our family--I have four children altogether, three other children and this young son--and at that time medical people were telling me that my other children might be adversely affected by having this very severely handicapped young man in the family, and when that time occurred, as they assured me it really would, I should put him away. And when I asked where I should put him away, well, there are places for people like that, you know, so my experiences with the medical profession over time have not changed a whole lot.

I give you an instance of the last few months. He's now 24 years old. He was on medication. He was having some severe problems where he was losing weight. He was having tremors; he was beginning to be semiconscious; he was beginning to drool, and we were trying to get the doctor to look at perhaps side effects or something from the medication to tell us more about what might be going on. He said it really wasn't important because he was mentally retarded, and I had to go to a friend of mine who happened to have a Physicians' Desk Reference to look up the drug that I knew my son was on and find out the side effect myself.

This was today, not 24 years ago. This is today. This was 2 months ago today in Ohio, 1986, and I submit to you that is precisely the kind of treatment many in the medical profession give and their sense about the rights of people, particularly with severe mental retardation, that it is not worth them living. But I can tell you that it has been very worth my son living.

I have three other children who have all grown up to be productive citizens as well as my son who is handicapped. He works 5 days a week in a sheltered workshop in Ohio. A few nights ago he went out with some young friends and went to a rock and roll concert. He went to a nightclub. He drank a little bit, but he's 24; I figure that's okay.

CHAIRMAN PENDLETON: 24?

MS. BURLEY: Yes. I'm saying he has a very high quality of life. He was diagnosed at various times in his life as having an IQ of somewhere between 5 and 42 and that people were judging on some test. He is totally blind, somewhat hearing impaired. He's mentally retarded. It has been said he is emotionally disturbed. He has had every label you would want to put on him, but he can enjoy life. He works. He is just like anybody else, and I will tell you my other children have turned out to be better citizens, and I think our whole family has been improved. I just am very upset about the fact that we cannot get appropriate treatment for children.

I have, in my role as director of a parent center, been on panels where we have debated these issues. I believe it was in 1984 in Colorado, I was on the panel, and we questioned pediatric neurologists, and when I would ask questions, "Tell me the conditions under which you would perform surgery for any child, any child," they would say, "But it is different when the child is mentally retarded," and my question to you is: Why is it different? It is not different. It is the same. They are human beings, they have life, and they can be very productive.

I can tell you one other thing your Commission ought to look into, and that is the treatment of mentally retarded people in the State institutions of the State of Ohio as well as many other States. We've had the same experience in Ohio today, going on right now, that happened back in Oklahoma, that has happened in other places.

We have a report from a committee that investigated the Cleveland Developmental Center, the Warrensville Center, the three institutions in the Cleveland area, and they have been likened to Willowbrook and Penhurst, and I will submit to you there has been every kind of criminal act going on there, including beatings and abuse and rape and everything else. And the staff in those institutions are perpetrators of those acts and they are not prosecuted because, why? Because they don't have the right to justice because these people are mentally retarded, and I submit to you that that is not what we should allow to happen in the United States of America today.

CHAIRMAN PENDLETON: Thank you very much. Commander?

Testimony of Patrick Sabadie

MR. SABADIE: 12805 Willow Glenn Court, Herndon, Virginia. I'm the parent of a 12-year-old son with spina bifida, also on the national board of directors and the treasurer of the Spina Bifida Association of

America. It was not my intention to testify, but in reviewing last summer's testimony and also in hearing some of the questions that were not answered by panelists yesterday afternoon and this afternoon I thought I would just like to highlight a few things for you, sir.

CHAIRMAN PENDLETON: Thank you.

MR. SABADIE: It is my opinion that if the legal profession maintains that section 504 does not address the issue of infants then it should, and this Commission should modify or take whatever measures are appropriate to insure the treatment of infants is in fact covered by modifications to 504, amendments to 504 or whatever.

The question about continuing education. The Spina Bifida Association has identified what we call 11 specific markets for continuing education and public awareness. They range from the medical professionals to the medical support personnel, to the parents, to the individuals with spina bifida, to clergy, to teachers, to administrators, to government personnel. In other words, there's a different approach and there's a definite need for continuing education targeted to those specific markets.

Thirdly, I went home last night and got out 12 years' worth of tax returns to see what I was able to write off related to medical expenses or whatever terminology you care to use on Schedule A, and with a son with 20 surgeries, costs to me--and I have all the data at home that I could produce, what my insurance has paid--cost to me has been $20,910. That will include some dental on my wife and other son, but that's what I was able to document in tax returns. Not necessarily that I was able to write off due to the 3 percent and 5 percent limitations, and also the Spina Bifida Association is in the process of conducting a cost survey. We had the preliminary report at our last conference 2 weeks ago--1,200 families responded to the survey, and we anticipate having the final results by November at our mid-year meeting and would be glad to make those available to you when in fact they are here, and I personally could go home and dig out of my medical returns--what it is that it has cost to raise Mark or to treat Mark to this point.

Fourthly, I don't believe quality of life enters into this at all or should enter into it. That's period. It is a part of the formula in Oklahoma and I believe that's in error.

Fifthly, language, and it has been used here in my opinion erroneously, and erroneously by the professionals, and it was even in Dr. McClone's testimony from last summer. Spina bifida is not a disease. A disease carries the connotation of something that you catch. It is a mechanical problem. And you repair the mechanical problem and then go on and live with it. But in the use of language we foster attitudes and thoughts and prejudices.

Sixthly, it is not a "Down's" or a "spina bifida," it is "a child with," it is "an adult with" the particular condition or situation, disease or whatever you want to call it that they have. And I find that even in the supportive professionals that we deal with, they are categories of folks, and we've got to remember they are folks with problems.

If we get into a situation where the Federal Government, the State government, somebody legislates minimum standards or something, then there has to be definite attention paid to the support system for the duration of life. I'm in the Navy. I travel all over the country. I have been to clinics all over the country to have Mark treated, government, private, nonprofit, and the variety of treatment levels and support systems available across the country are amazing and the standards that one has to meet in various States to qualify or not qualify for various help runs a very wide continuum of standards and I believe that the role of the Federal Government would be in setting a floor, and I believe that if in fact we are going to treat these kids--and I believe that 99.9 percent of them should be treated--there is a gray area. I won't argue with Dr. Owens that there's a gray area, but the majority should be treated--that we have to look at the long range and at the continuum of care.

I think that in the support system, and finishing this up, that again we suffer as human beings from saying little Janie Smith cost $500,000 and needs A, B, C. When you do that, then we try to multiply that by X number of births per year or X number of cases per year and come up with a dollar figure and we're all staggered by it.

I believe a human being is a tremendously flexible individual, and there's more than one way to skin a cat. A lot of the supportive services come from strange and wonderful places and don't cost Uncle Sam directly, or the State, or me a lot of money. It may cost society something, but if the Kiwanis want to buy my son a wheelchair, that's the Kiwanis' business. Thank you.

CHAIRMAN PENDLETON: Thank you, Commander.

Ms. Trombino?

Testimony of Betsy Trombino

MS. TROMBINO: I'm Betsy Trombino, 121 East Voltaire, Phoenix, Arizona. It looks like I have come the furthest today. My son is also Mark. He is 16 years old and is orthopedically handicapped. Like Patty, I work in the field of parent support and I have done so for about 6 years. So most of what I say to you is based on my own experiences and that of talking with other families over 6 years of time.

One of the things I would encourage you to do as a commission in the next 30 days is perhaps to seek some more input from parents. You have four of us here. There obviously are lots of other parents out there, and speaking for myself, I think we are the real experts. You can listen to doctors and lawyers and all kinds of people, but it is the parents who are living day to day with the children and, I think, probably could give you some real interesting information.

I would also encourage you to check on one of the statements made by Dr. Owens, relative to the cost of supporting a child with Down's syndrome. I found that--and I don't know; I certainly am not a statistician, but he was talking about it costing $2,000 for him to live his very short life, the little baby in Indiana, and yet it would cost a million dollars to support him over his lifetime. That seemed a little extreme to me, and I'm not sure that that's a reality. At least for a child with Down's syndrome, once that repair had been done.

I have two major concerns. One is the impact on families at the time of the initial diagnosis. Unless any of you have ever been through that, I would doubt that you have any idea what that's like. Maybe you have. I don't know any of you. But I don't think you know what that does to a family, and my biggest concern is that we are so vulnerable at that point and the only information we have comes from medical people who are making judgments about our children and what the quality of their lives are going to be long term. To talk about quality of life, and they do that. I was frightened, I was afraid, and I didn't know what in the world was happening with my child; and yet I had to take all the information from medical sources.

I'm not sure that parents can really make good, informed decisions with only that one side of the picture coming to them and that is really my biggest concern. We're asked to make decisions as to whether our children live or die, and, yet, all the information is coming from people saying, he'll never do this, he'll never do that, he's not ever going to go to school or walk or talk or even roll over, so why would you want him to live? I think that's real unfair to families to then ask them to make an informed decision. I'm not sure how well informed we are at that point.

A couple of things seem to happen to parents. There's a very extreme lack of information. We don't get a whole lot one way or the other or we get this extreme, one-sided viewpoint, and it tends to be all very negative, or we get 16 different opinions and yet we're still supposed to make rational decisions.

I have a lot of difficulty with what is expected of parents at that point. I could probably count lots and lots of families who have said to me over 6 years that I have been working in this field, I wish that Dr. Owens could see him now. Those people who made those statements at birth, he will never, he will never, he will never. I wish I could take him back now so they could see what he's doing.

We also have our own little Baby Doe in Arizona and her name is Jessie, and Jessie was supposed to die the first night that she was born. She also had spina bifida, hydrocephalus, lots of severe brain damage, and all of those things that were not compatible with life, so no treatment was done for Baby Jessie. Days and days and days went on and Baby Jessie fooled everybody and did not die.

Finally about the 21st day, right at the time the signs were hanging up in the nurseries, somebody got real nervous and said, maybe she's not going to die, maybe we better do surgery. So by this time, unfortunately it was really too late to do much repair on her back, but they did put a shunt in and that little girl now talks in sentences and goes to regular preschool.

Her family really believed what the doctors said: She will die. So they just waited for her to die. And so for me as a parent I have a real difficult time with someone making that kind of a prognosis for a child and not doing any treatment. Because I have seen too many kids who defy all the prognoses made for them.

My other major point that I wanted to talk about, and I'll pick on my little friend Jessie again, what then unfortunately happens to families is that the babies are often saved, and in her case, she was, but the support services were not there for her family and the only way that they could manage was for her to go into foster care because financially they could not care for her. She lived in foster care for 2 years until her medical condition stabilized enough for her to come home.

So, on one hand, I believe, as I hope is obvious to you, that yes, we need to save 99 and whatever percent of these children and I think there are very few in the gray area, but we cannot then abandon those children and say to the parents, okay, we saved them, now it is your problem. Take them home. Doesn't matter if it costs you $300,000 a year, that's your problem because we saved them for you. I think the commitment to ongoing support from government, from society is still not really there to the extent that it should be. Thank you.

CHAIRMAN PENDLETON: Thank you very much for coming and spending time with us. I think the testimony is enlightening. If you have other things to send us, please feel free to do so. This is a good culminating activity.

COMMISSIONER DESTRO: I want to add my thanks to the witnesses, especially those who came from a long way, and you encouraged us to get in contact with other parents. The record is going to be open for 30 days, so if you would like to have the parents you know contact us, please feel free to do that.

MS. TROMBINO: Can we find out from you how to do that?

CHAIRMAN PENDLETON: Just send it to us. Our last witness I think is Mr. Robert Williams.

[The witness was sworn.]

Testimony of Robert R. Williams

MR. WILLIAMS: I have written testimony, but before it is given, I would like to just say that following the last panel will be a very hard act to follow. I would also like to respond to something which Tom Nurney said. You will be getting testimony from Hank Bersoni. I would encourage you to give it the utmost attention because I know that it will refute much of what you have heard about the so-called diminished potential of people with severe and profound disabilities to enjoy life.

Now for my written testimony.

Good afternoon. My name is Robert R. Williams, and I am a project analyst with the D.C. Association for Retarded Citizens. I'm also a member of the Association for Persons with Severe Handicaps. I'm here today, though, not as a representative of either of these two groups, but rather to express my own deep concern over the way infants with severe disabilities and their parents continue to be meted out inadequate medical care and advice in this country.

Over the past day or so the Commission has no doubt received volumes of oral and written testimony concerning the recent U.S. Supreme Court decision and the highly publicized Baby Jane Doe case. In a minute or two I promise you that I will have a thing or two to say about this ruling as well. But first, I would like to draw the Commission's attention to a second, lesser known decision that was handed down late last year. I do this not because of any precedent-setting quality that this decision may have, but rather because it illustrates the type of extreme stress and pressure that parents of newborns with severe disabilities labor under.

Like the Baby Jane Doe case, the second court case also involved a couple from Long Island, New York. In 1983, the couple, Chris and Warren Kosher, had a baby girl with Down's syndrome. Immediately after the little girl's birth the Koshers decided to place her up for adoption and she was adopted by the Stamatis family. The Koshers began to regret their decision soon thereafter when Mrs. Kosher visited some early intervention programs in the area. So impressed were they with what they saw at these programs that they filed suit to regain custody of the little girl.

Initially, they won their case in New York's family services court. Last November, however, the New York State Court of Appeals overturned this earlier ruling and awarded permanent custody of the toddler to the Stamatises. The court of appeals judge recognized the extreme emotional duress which the Koshers were operating under when they decided to relinquish custody of their little girl. But she ruled that: "Neither emotional duress nor mistake is a ground for vitiating consent. Release or surrender of a child for adoption is a traumatic event heightened here by Sarah's condition. But no consent, and surely no consent to the adoption of a handicapped child, could ever be relied upon if it were revocable on such a basis."

While it is difficult to argue with the legal reasoning of such a ruling, one wonders why parents with newborns with severe disabilities are even put in a position of having to make such decisions when they are clearly operating under so much stress. Physicians often serve to exacerbate an already highly charged and tense situation by presenting the parents of an infant with severe disabilities with life and death choices that they would never, ever consider presenting to parents of a nondisabled child.

This was certainly the case with respect to Baby Doe. Besides being born with Down's syndrome, the Bloomington infant was born with a esophageal blockage. Usually when this occurs, relatively minor surgery is performed to correct the condition, but because Baby Doe had Down's syndrome, his physician advised his parents not to go through with the procedure. Clearly, notwithstanding the four justices who signed on to the June 9 ruling of the high court, most fair-minded Americans have come to regard such practices as being highly improper and discriminatory. And so long as doctors insist on providing such disparate medical advice to parents with newborns with severe disabilities, they must be held responsible for their actions. For this reason the Commission, the Reagan administration, and Congress should work together to improve civil rights legislation designed to insure that newborns and others with severe disabilities are not denied adequate and appropriate medical care on the basis of their disability.

Last summer I was asked to prepare a refutation of Jeff Lyon's Playing God in the Nursery, a book that turns a blind side to all hopeful movements on behalf of newborns with severe disabilities and their families. To conclude my presentation, I would like to share this brief essay that appeared in numerous publications across the country. I hope you find the observations and insights to be useful to you in your deliberations regarding this vital issue.

"The birth of a child is always a trying time for parents. It is a time when parents are called upon to make massive adjustments in their lifestyles. This is true with respect to the birth of any newborn; these anxious feelings about the need to make significant shifts in one's lifestyle are, of course, felt even more keenly with the parents of a baby found to have one or more severe physical or mental disabilities.

"This was certainly true in my case. My parents were told from the start just how severe my disability was. In fact, they were advised on numerous occasions to put me away in the Mansfield State Training School, an institution 4 miles away from our home in eastern Connecticut. However, family circumstances allowed me to stay at home with four older brothers and sisters and grandparents, aunts, uncles and a slew of cousins, all within hollering distance of where we lived, I had a readymade therapeutic support system at my disposal. There was no need to institutionalize me. My parents recognized Mansfield for what it was, a human warehouse. They realized the care they could provide for me at home with the help of the rest of the family was the best any child could hope for.

"Unfortunately, not all infants with severe disabilities are born into families with the same kind of natural support system my parents and I had to fall back on. Often when a child is born his parents are torn away from grandparents, aunts, uncles and even other children. The physician takes the parents into his office, informs them that they have a child with a severe disability, then asks these people to make a life or death decision about a baby they might not have a chance to see or to hold.

"What kind of informed decision can come from such a process? Little or no attempt may be made by the doctor to inform parents of the progress their child may attain if he or she receives appropriate support services from the start. Many physicians still insist on offering parents of newborns with severe disabilities only one alternative to withholding early care: institutionalization of this child for life.

"Institutionalizing infants with severe disabilities is no longer the only option available to parents. This may have been true in the fifties and sixties when I was growing up, but certainly is not the case today. Physicians have a professional responsibility to know of available services for early intervention programs and in-home family support.

"It is an injustice to the Baby Does and Baby Janes of the world when their parents are told only that their child's capabilities are limited. Instead, parents need to know what their child might be able to do with love, care and the right package of necessary support services.

"This society needs to become more tolerant and more appreciative of individual difference. Having a disability does not mean lacking the abilities to perform certain tasks so much as it is about leading a different lifestyle.

"I come from solid blue-collar stock. My Dad and two brothers own and operate a small construction company and they work from 7:00 a.m. to 6:00 p.m. laying foundations and sewer pipe. It was clear from the start that I would not be cut out for such a life. My parents decided if I was to make it, I would have to do it by a different way and they provided me with ample support on my journey. As it turned out, I'm the first in my family to graduate from college, the first to have taken an active interest in politics, the arts, and literature.

"Now, I have a lifestyle vastly different from other members of my family. Part of the reason is that I have a severe disability. Without a doubt my disability has influenced my life; it has played a part in how I think and act, what I care about and what I hope for. However, being different and leading a different lifestyle has never served to estrange me from my family. If anything, it has brought us closer together.

"For example, it took me eight years to learn how to walk, which was quite different from my brothers' and sisters' life experiences. We've never talked about it, but I'm sure they saw it as different. When I finally did take my first few steps, no one was more overjoyed than they were. It was as if I had just made a game winning touchdown after I had always fallen flat on my face. That was how great their enthusiasm was for me.

"Brothers and sisters have to support each other. Siblings of an individual with severe disabilities are no exception to this. The brothers and sisters of a person with severe retardation can play an incredibly important role in that person's development. We are just learning how important the love and support of the brothers and sisters really is.

"Twenty years after my parents refused to put me in Mansfield, I visited there of my own volition. As I stepped inside the door of the back ward, something deep inside of me wanted to go from whence I came; something deeper still drew me inside. It was their eyes, the eyes of the residents, most of whom were on mats on the floor, looking straight up at me, noting every move as I walked across the floor. In my entire life I have never seen people with such severe physical and mental disabilities.

"Over the years, first as a volunteer with the Association for Retarded Citizens and now as a court monitor, I have come to see even more. What saddens me most is not that their bodies are so badly mangled, but that so much of it is completely unnecessary. Over 90 percent of the people who are multiply handicapped with whom I work, most of the current difficulties are due to long years of benign and sometimes not so benign neglect in institutions.

"The hopeful news, and the thing which has me committed to this field, is that these people can benefit most in small, family-like settings in the communities. Problems like scoliosis, due to years of lying in one place 24 hours per day, become less and less pronounced with passage of time.

"People with Down's syndrome and other severe developmental disabilities have the capacity to live life to the fullest if afforded an opportunity to do so. Contrary to Mr. Lyon's gloom and doom assessment of our lives, I'm here to say there's a great deal to be hopeful about.

"The lives of people with severe disabilities no longer have to be filled with the dreariness of an instutionalized life. People with severe disabilities are benefiting from living in the community in greater numbers than ever before. The way to secure commitments from the three levels the government is not, as Mr. Lyon seems to be doing, suggest that care be withheld from newborn infants with severe disabilities until an adequate funding is provided to help them obtain their maximum developmental potential. What benefit can result from this strategy? At best it can be seen as an extreme example of circular reasoning. At worst it can lead to the most vicious of circles. Appropriate support services necessary to assist the families of newborns with severe disabilities to love and care for their child in their own home will not be available as long as we devalue the life of a child so much that it becomes acceptable to withhold the most ordinary care.

"Society places too much emphasis on the perception of quality of life, perceived value, intelligence and physical agility. Traditionally, persons with severe disabilities have not been consulted on those issues which have affected them most. I think my life has been worth living; I'm confident my family and those I care for feel the same way. My life has been worth living not because of my academic achievements or the jobs I have held, but because I have had the good fortune of connecting with others and allowing them to connect with me.

Isn't that what this life is all about? The ability to reach out and touch."

I have been asked on occasions why I work with the vegetables. I have never been able to answer that question, but perhaps it is because with the folks I work with, I not only see growth in them, but I receive nourishment and emotional sustenance from them.

Thank you.

COMMISSIONER DESTRO: Thank you.

CHAIRMAN PENDLETON: Mr. Williams, you have made the point. Thank you. We want to thank the witnesses, the staff, certainly the General Counsel. I want to thank you and your staff for helping us today, and these hearings are recessed for 30 days to receive any papers.

It's formally closed, but the record will be held open 30 days.

[The hearing was recessed.]

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WASHINGTON, D.C. 20425