# Hearing
# Before the
# United States
# Commission on Civil Rights

## PROTECTION OF HANDICAPPED NEWBORNS

## HEARING HELD IN
# WASHINGTON, D.C.

JUNE 12-14, 1985

## 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 Congress.

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**Neonatal Practice**

**The Federal Role in Treatment Decisions**

Open Session

# Protection of Handicapped Newborns

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**Wednesday, June 12, 1985**

The U.S. Commission on Civil Rights convened at 1 p.m. in the auditorium of the Medical Society of the District of Columbia, Chairman Clarence M. Pendleton, Jr., presiding.

Present: Chairman Clarence M. Pendleton, Jr.; Vice Chairman Morris B. Abram; Commissioners Mary Frances Berry, Esther Gonzalez-Arroyo Buckley, John H. Bunzel, Robert A. Destro, and Francis S. Guess; Acting Staff Director Max Green; General Counsel James B. Mann; Deputy General Counsel Joel C. Mandelman; Assistant General Counsel Gail Gerebenics; and Staff Attorneys Christine Jones, Peggy Massey, Jill Robinson, and Robert Schultz.

## PROCEEDINGS

CHAIRMAN PENDLETON. Good afternoon. I want to call these proceedings to order.

Are there persons here who are hearing impaired? If so we have a translator available.

[No response.]

CHAIRMAN PENDLETON. There being none, then we can let you rest until such time as someone identifies himself as being hearing impaired.

My name is Clarence M. Pendleton, Jr. I am the Chairman of the Commission on Civil Rights. On behalf of my colleagues on my left and right—the only person who is not here right now is Commissioner Mary Frances Berry. Commissioner Ramirez will not be here. She has illness within her family. Therefore, there will be seven of us conducting these proceedings.

On behalf of my colleagues I would like to welcome you to the Commission's hearing on protection of handicapped newborns. The purpose of this hearing is to attempt to determine the nature and extent of the practice of withholding medical treatment or nourishment from handicapped infants and to examine the appropriate role for the Federal Government.

Section 504 of the Rehabilitation Act of 1973, as amended, prohibits discrimination against qualified handicapped individuals under any program or activity receiving Federal financial assistance. In the spring of 1982, reports of the death of a Bloomington, Indiana, infant with Down's syndrome, from whom available surgical treatment to correct a detached esophagus was withheld, prompted widespread attention on the medical treatment of handicapped newborns. Following the Indiana incident, the Department of Health and Human Services [HHS] issued a notice to recipient hospitals reminding them of the applicability of section 504 to the treatment of handicapped infants. HHS then issued interim and proposed rules governing nondiscrimination in the treatment of these newborns, both of which were challenged in courts and struck down.

Last fall Congress passed the Child Abuse Amendments of 1984, requiring States seeking child protection funds from the Federal Government to take certain steps to protect handicapped newborns. HHS has issued rules and model guidelines under that statute which have been made final and will become effective in October of this year.

The primary focus of this hearing is the role the Federal Government should play in ensuring section 504 rights of handicapped newborns.

I just want to repeat that the primary focus of this hearing is the role the Federal Government should play in ensuring section 504 rights of handicapped newborns.

Preliminary consideration will be given to whether section 504 affords coverage to newborn infants in hospitals, including whether Congress intended section 504 to apply to decisions made in hospitals about the treatment of newborns and whether considerations of family privacy or parental rights outweigh any section 504 interests of the newborn. Over the course of the next 2½ days, we will be hearing testimony from representatives of the medical and academic communities, ethicists, Federal officials, advocates for handicapped citizens, the parents of handicapped children, and the general public.

After the close of the scheduled testimony at 11:30 on Friday, there will be an open session in which members of the general public are invited to testify. The time available will be allocated on a first-come, first-served basis. If you wish to testify at this open session, please consult the Commission staff. There are three Commission requirements governing such testimony: Testimony must be limited to 5 minutes; it may not defame or degrade or incriminate any person; and it must be directed to addressing withholding medical treatment or nourishment from handicapped infants and the appropriate role of the Federal Government.

I would like to remind the audience that the Commission by statute is prohibited from addressing the issue of abortion. The witnesses for this hearing have been advised not to discuss abortion. Anyone signing up to testify in the open session is also bound by this prohibition.

Due to time constraints, we will be unable to entertain any questions from the audience.

And I might add, in addition to this, in the past we have left the record open for some time after the hearings to allow people to submit any information that they think is appropriate for the Commission to have, and if there is no objection from my colleagues, I would certainly request that the hearing record be kept open in case we have missed some testimony. Is there any objection on the part of the Commissioners?

COMMISSIONER DESTRO. Mr. Chairman, I know this is a bit out of the ordinary, but I have had some correspondence from individuals who would have liked to testify, but for one reason or another were not able to. A number of them have written statements that I know they'd like to put in, and I assume that this covers that.

But what I'd also like to ask is whether or not it would be possible, if any of the Commissioners have questions based on that testimony, for them to get answers to the questions based on things which come in after the hearing.

CHAIRMAN PENDLETON. I think so.

With that introduction, we will turn to our first panel, "Medical Overview": Dr. Koop, Dr. McLone, and Dr. Stahlman. I will not read their backgrounds, but I think what is important is that we are able to hear from you. And we ask that the General Counsel initiate the questioning, as has been customary in the past. The Commissioners will probably at some point have some questions to ask you. I will now turn it over to the General Counsel, Mr. Mann.

MR. MANN. I'd like to thank all of you for coming. To start with, beginning with Dr. Koop, will each of you in turn please state your name and position for the record.

CHAIRMAN PENDLETON. Excuse me. I have made a serious mistake. I have to swear in the clerk and the witnesses.

[The clerk and the witnesses were sworn.]

CHAIRMAN PENDLETON. Now you may proceed. It is now official.

## Medical Overview

### TESTIMONY OF C. EVERETT KOOP, M.D., SURGEON GENERAL, U.S. PUBLIC HEALTH SERVICE; DAVID McLONE, M.D., CHAIRMAN, DIVISION OF PEDIATRIC NEUROSURGERY, CHILDREN'S MEMORIAL HOSPITAL, CHICAGO, ILLINOIS; AND MILDRED T. STAHLMAN, M.D., DIRECTOR, DIVISION OF NEONATOLOGY, VANDERBILT UNIVERSITY

MR. MANN. We will start with the hard questions first. Please tell us your name and your position for the record.

DR. KOOP. I am C. Everett Koop, a medical doctor. Currently, I'm Deputy Assistant Secretary for Health for the Department of Health and

Human Services and the Surgeon General of the United States Public Health Service.

Before that I was in academic surgery and specifically, in pediatric surgery, since 1946.

DR. MCLONE. I'm David McLone. I'm a professor of surgery at Northwestern University and head of Pediatric Neurosurgery at Children's Memorial Hospital in Chicago.

DR. STAHLMAN. I'm Mildred Stahlman, a pediatrician. I'm head of the Division of Neonatology at Vanderbilt University School of Medicine. I have been involved with pediatrics for the last 38 years. I have been involved with neonatology since 1961.

MR. MANN. Thank you. To stay with you for a minute, Dr. Stahlman, can you please describe the medical conditions and the range of currently accepted medical treatment underlying most of the Baby Doe cases?

DR. STAHLMAN. As I explained to your counsel, with whom I talked on the phone, my field of expertise is not that of neurosurgery, nor is it of pediatric surgery. I'm a neonatologist, and my primary concern is with medical problems rather than those congenital anomalies that require surgical intervention.

The problems which face the neonatologist in the newborn intensive care unit, I think, ought to be divided perhaps into two groups. One is the dilemmas that face the obstetricians with or without neonatal consultation in the delivery room, which have to do largely with the extreme ends of birth weight and viability, and with the extraordinarily asphyxiated baby who shows no sign of life at birth.

Those again are not my primary concern. We receive the babies after they are resuscitated and brought to an intensive care unit, and the myriad of medical problems which these very low birth weight babies face would take several days to describe.

The primary problems which we face are the problems of those babies who are of extreme low birth weight, low gestational age, who have frequently had an extraordinarily poor intrauterine course, a difficult delivery, a difficult resuscitation, and are then placed on extraordinary means of support and are carried for many days, many weeks, many months, and on occasion many years, in an effort to keep these children alive.

Many of them, fortunately, turn out quite well. Many of them have self-limited problems with which modern technology can deal and can tide the baby's course over until it can assume medically, physiologically, biochemically those functions which extrauterinal life demands.

But many of those babies are of such degrees of immaturity in all of their organ systems, which includes brain, lung, gut, kidney, liver, etc., that the very treatment itself is of extraordinary danger to them. It requires decisionmaking continually, not one decision at one point in time, but it's an ongoing process of decisionmaking as to best judgment in, many times, extreme emergencies.

So the failure of multiple organ systems in these infants presents dilemmas to the physicians who are caring for them, to their parents who are attached to them and love them, and to society in general, I think, who must assume some responsibility for those decisions whichever way they are made.

So I would have to respond to each of your questions as far as organ systems are concerned—the easy ones are respirators, those babies who are placed on respirators who are never able to get off ventilators. There are other babies who are placed on parenteral alimentation, feeding all of their calories intravenously, are never able to take any food by mouth, and at some point in time would simply run out of available vessels into which the lines can be placed, and tough decisions have to be made in their interests.

As I say, the immaturity of each organ system is a whole set of medical problems and can't be dealt with as a package to be remedied by surgical procedure, and the outcome relatively easily known.

MR. MANN. Can you give us some idea of the number of children involved in these types of cases?

DR. STAHLMAN. I can only speak for my own region and extrapolate that perhaps to other regions.

We have a regionalized center involving around 25,000 deliveries a year. And from our experience over a 5-year period, we have looked at this kind of problem and have estimated that perhaps 1 in 1,000 live births will present some decisionmaking dilemma in the newborn intensive care unit. I am not talking about the delivery room, and I'm not talking about the surgical cases.

MR. MANN. I take it that, with respect to at least some of those children, at some point a decision is made not to treat the child further. How widespread do you think the decision not to treat is?

DR. STAHLMAN. I can't answer that except in my own experience.

MR. MANN. Please.

DR. STAHLMAN. As I say, the decisionmaking which has traditionally gone on, I believe, with neonatologists is that they are their patients' best advocates. And they are the ones who take their patients' best interests as their primary concern. They then, I believe, try to consider the interest of the parents and finally the interests of society, but the patient's interest is their main concern as a physician.

I think that there are, as I say, legitimate concerns as to what is in the baby's best interest fairly frequently. And those dilemmas are thoughtfully, conscientiously, and prayerfully, and with as much guidance and consultation from outside sources as one can muster—those decisions, I don't think, can be abrogated by the physician. I don't think a committee can make that decision. I don't think any committee has the responsibility to a patient, and most committees are not committees of experts in the medical field that the patient's problem lies.

MR. MANN. Thank you.

Dr. McLone, could you please answer the same set of questions?

DR. MCLONE. Well, the disease that I interact with most commonly which fits into the category which we are discussing today is myelomeningocele, which is most commonly known as spina bifida. Approximately 6,000 children—and it may be higher than that—are born each year in the United States with spina bifida. Spina bifida has been referred to as the most complex disease which is compatible with survival. The involvement at birth is most of the children have hydrocephalus or water on the brain. All of the children have an open spine with their nervous system exposed to the surface of their body into the outside world. Most of them have some degree of paralysis in their lower extremity, and most of them will be incontinent of bladder and bowel.

The problem arises that if they are not operated on within a few days of life, they will acquire a potentially lethal infection, and if they are left unoperated on, approximately half of the children, in most studies, will die. If their back is repaired and closed, then about 90 percent of the children will go on to develop rapidly progressive hydrocephalus and require a second operation to install a shunt, a small tube to drain the fluid from their brain into another body cavity.

The problem is that people have attempted, beginning in the 1970s, to predict the quality of these children who survived as adults, and have set up various criteria, and based on those criteria, have made judgments on who should and who should not be operated on at birth.

We have, since I have been at Children's Memorial Hospital, not used the criteria and have operated on all children and have not used any form of selection.

In looking at those first 100 children, who are now somewhere between the first and fourth grades, we find that 85 percent of them survived and 15 percent of the children have died from complications of the disease. Of the 85 survivors, 73 of them have normal intelligence. Approximately 85 percent of them have a shunt for their hydrocephalus.

Eighty-nine percent of the survivors are community ambulators. What I mean by a community ambulator is someone who can walk from the school bus to the classrooms, between classrooms, and can walk in their neighborhood. A significant number of those children who are community ambulators, however, are walking with braces and crutches. We have a very small number of children who are in wheelchairs. Ninety-five percent of them have no bladder and bowel control, but are rendered socially continent of bladder and bowel by training in the use of intermittent catheterization. We would, therefore, estimate, based on these numbers, that something like three-quarters of the children who survive will be competitive and independent as adults.

There will be another 10 percent, 10 to 15 children, who will require some kind of sheltered care, and about 10 percent of the survivors will be impaired to the point that they will require some kind of nursing care throughout their life.

We at Children's Memorial see about 40 newborns a year with this problem, and, as I say, we use no selection criteria. And then we acquire another 60 to 70 children from the community. We are at the present time following approximately 1,000 children with spina bifida and growing at the rate of about 100 new children each year.

The problem that I have noted and have been involved in with the decisionmaking process has been primarily ignorance on the part of the physician who is first confronted with the child, who then misinforms the family, and based on inappropriate information, the family usually makes, in my opinion, the right decision based on that information. However, the information they have been given is so inconsistent and out of line with what most major centers in the United States are experiencing at this time that the child is denied care based on misinformation.

MR. MANN. Thank you.

Dr. Koop, could you please give us an overview of what you think the issue is here?

DR. KOOP. Yes, sir. I'm assuming that you and I mean the same thing when we talk about a Baby Doe case. In my particular field of expertise, which would exclude the two that you have already heard, most of the case findings center around youngsters who are born with a surgical problem that is incompatible with life, but nevertheless amenable to surgical correction. So it would be something that would be perhaps a genetic defect, or it could even be what I would call an assembly line defect, that something just went awry in the development of that particular embryo and fetus.

Most of these youngsters have problems which can be diagnosed leisurely over a period of 24 to 36 hours, and the best success for surgery occurs in those youngsters who have their surgery within the first 72 hours.

However, there are occasional problems such as a child born with a diaphragmatic hernia where the abdominal organs are up in the chest, are compressing the lung on that side, pushing the heart so it compresses the lung on the other side, where one does not have the luxury of easy and leisurely diagnosis, but where decisions have to be made almost instantaneously and where surgery done in less than an hour might not be fruitful.

These children have various qualities of life in the days ahead following their surgery. Most of them do extremely well. My own lifetime has seen a complete reversal of success and failure. When I first began in the field of pediatric surgery in 1946, most of the things that now have a 95 percent survival had a 95 percent mortality, and indeed, some carried a 100 percent mortality.

The specific problem that gave rise to—the baby in Bloomington, Indiana, which was the first modern Baby Doe in the context of our discussion today, had, in addition, another problem, which was Down's syndrome. And many times, in addition to the things that I have described as congenital defects incompatible with life but amenable to surgical correction, there are associated problems, such as those that Dr. Stahlman referred to, because many of these babies are premature or low birth weight babies or have some other accident during delivery, might have had a ventricular bleed or some such thing, or they may be youngsters with some form of mental retardation that can be assessed in general at birth, but not specifically as to severity down the road. And some of the children have all of the things that I deal with all in one baby, so there can be multiple defects. And it is around the child who has a problem that will kill him without surgery associated with mental retardation that most of the problems come.

If you let me go back to the original Baby Doe, it had esophageal atresia, which is correctible by surgery, and it had Down's syndrome. If it had had either one of those problems alone, there would have been no controversy. The Down's syndrome would have been treated to the best of anyone's ability by support of the family and support by the community. And the esophageal atresia would have been corrected surgically and would have likely had about a 95 percent success rate. But when the two exist together, it provides an opportunity for one to influence the treatment of the other, and hence the initial concern that children who were so treated were, in a sense, having their civil rights abrogated.

I'd like to add just two other statements that I think are pertinent to any such discussion.

As I look back over almost 45 years' experience dealing with youngsters with congenital defects, I think there are two things which lead to the development of the Baby Doe situation. One is a snap judgment made by an inexperienced physician in the delivery room that he then finds for many reasons—some of them pride—difficult to withdraw from.

The other thing is that no pediatrician can be expected to know what all of the community supports are that might be available to a child with a given diagnosis. He might understand hemophilia perfectly well in the community, but not cystic fibrosis. Therefore, it has been my lifelong endeavor to prevent snap diagnoses, prognostications made without sufficient knowledge, on the one hand, and the development of data on community resources, on the other, to prevent the development of such situations referred to now as Baby Doe.

MR. MANN. Thank you.

Having now seen three different approaches to this complex issue, I think I am prepared to turn it over to the collective wisdom of the Commission.

CHAIRMAN PENDLETON. Do my colleagues have questions?

I have one question. I was asking my colleague, Mr. Abram here. "Myelomeningocele"—I understand the term, but I think absent some anatomical understanding. Where does it occur? In the end of the vertebral parameter that comes up the side or down the spinal column?

DR. MCLONE. The myelomeningocele or the spina bifida defect on the back—the central nervous system, brain and spinal cord, are formed from the skin of the embryo. They originate on the surface. In the infolding process which normally occurs, the neural tissue is rolled into a tube and it sinks into the embryo. A portion of that does not roll into a tube and remains as a flat plaque of embryonic-formed neural tissue on the surface of the child's back, and it varies in size from a small opening with the neural tube exposed to an extensive opening which might encompass the child's entire back.

There is a related neural tube defect which is called anencephaly in which the brain portion of the neural tube is left open and that is not compatible with survival.

CHAIRMAN PENDLETON. I understand something about the physiology of this, in terms of the anatomy, but what part of the spinal column itself?

DR. MCLONE. The spinal column is a block of bone with a hollow canal.

CHAIRMAN PENDLETON. That part I understand, and the spinal cord goes down.

DR. MCLONE. Right.

CHAIRMAN PENDLETON. Where you have myelomeningocele, where do you operate?

DR. MCLONE. Usually there is a bony roof over the canal. The spinal cord is contained within that canal. That bony roof is missing and is everted open, and the spinal cord is, therefore, on the surface of the child's back.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. I find that I need a little more information from the three of you, but I'd like it if you can answer a question for me.

What I heard from Dr. McLone and Dr. Koop—Dr. McLone said ignorance of the treating physician, and when Dr. Koop talked about a snap judgment, I hear in that—I hope I'm not wrong—some ignorance also of the procedures and things that are available to a physician to do.

My concern is: If we make a statement that there is some ignorance sometimes as far as the resources or the knowledge and techniques that are available to a pediatric surgeon, then how can we ease that dissemination of knowledge to other doctors that are out there treating the spina bifida case, the child with multiple defects? How can we do that to help prevent some of these errors?

In some of the cases we have read, they have been in small hospitals out in rural areas, not in large hospitals, and not in a community that has the facilities to do all these fantastic operations that can help a lot of these children. How do we deal with that ignorance or lack of knowledge or lack of facilities to help this problem and help those children?

DR. MCLONE. I can respond.

COMMISSIONER BUCKLEY. I'd like the three of you to answer. I have a concern as to perhaps some of the problems that happened in the diagnosis and treatment of these children.

You, Dr. McLone, talk about how successful you are with your spina bifida cases. You know how to do it. You do a good job and help these kids. You have a very high success rate with them. But there are a lot of doctors out there in some hospitals who possibly don't have the facilities to do this. How do you help equalize this treatment so we have accessibility to these techniques available there too?

DR. MCLONE. One of the problems, I think, with spina bifida is that a pediatrician in practice may see one or two of these in an entire lifetime of his practice. The American Academy of Pediatrics has been very concerned about that problem and from a variety of standpoints. The American Academy of Pediatrics has been very much involved in setting up programs for education of the pediatricians, and to set up means to get this kind of information to them.

I think that things 10 years ago were much worse than they are today. The dissemination of the information on the treatment and outcome of treatment of spina bifida has been greatly enhanced by, first, the involvement of the media in the cases that have occurred and, second, by the physicians' organizations themselves, especially organizations like the American Academy of Pediatrics, which has been instrumental in getting this kind of information to the pediatricians.

So I think things are better than they were. It's just that there still are occasions in which physicians are confronted with spina bifida who are not aware of the outcome or the changes that have occurred over the last 20 or 30 years and give information based on what the outcome was 30 or 40 years ago. It's just not appropriate.

CHAIRMAN PENDLETON. Do you have more questions?

COMMISSIONER BUCKLEY. I'd like to hear the other two witnesses answer.

DR. STAHLMAN. Perhaps I can address that from a different point of view. I think physician education is an important part of it, certainly as far as the two sets of problems which have been addressed by my colleagues.

The care of the high-risk newborn we assume is in the hands of highly trained specialists in most areas of this country. That is not true worldwide, but in this country neonatology is a subspecialty. The physicians who run those nurseries are presumably well-educated beyond their pediatric training in the special care of high-risk newborns. So their educational process should be commensurate with the need of their patients.

Their relationship to the physicians on the outside who refer their patients is another level of responsibility which is usually addressed by regionalization programs, and there are high-risk perinatal and neonatal regionalization programs in almost every State, for which education is a major thrust.

So I think that those are being addressed through existing mechanisms to a very large degree, as far as my own area is concerned.

But if I were to say what is needed as far as education is concerned, it is patient education; it's parental education; it is education and availability of high-risk obstetrical care; the education of mothers in proper management of a pregnancy; the availability of physicians in their regional communities, which is many times lacking; the problems of their own education; and the poverty and the social problems which are undoubtedly related to high-risk newborn delivery rates in this country, which are a disgrace.

In my opinion, the quickest way to solve these problems would be research and education of the public. And by that I really mean the recipients of medical care, and research towards the prevention of these problems that have to do with prematurity and high-risk delivery.

Outcome of high-risk delivery is a changing spectrum. It changes every week; it changes every month; it changes every year, and usually for the better. At some point in time, we run out of expertise, and our technology is better than our ability to keep a baby alive in the long term. At some point in intrauterine life, there's a cutoff point, and knowing where that is and when that is, I think, is a matter of extraordinary difficult judgment.

CHAIRMAN PENDLETON. Dr. Koop.

DR. KOOP. I think it's clear that the kinds of patients Dr. Stahlman is talking about are quite different from those that Dr. McLone and I are talking about.

I would like to try to expand on the things that I said. In general, the whole educational process by, let's say, a pediatric surgeon towards pediatric colleagues is quite good. And there is another maneuver that is helpful in some States. For example, in Pennsylvania where I practiced, for any hospital to have a license by the State to function as a hospital, it had to have a protocol for the referral of the kinds of patients I'm talking about to a tertiary care surgical center where these patients might be cared for.

Now, there is still the opportunity for the two things that I mentioned. The snap judgment by the physician in the delivery room can be based upon ignorance. It can also be based upon prejudice. And that prejudice might be of two kinds. One, having seen a similar patient in the past that he didn't think had the quality of life that he liked, he might advise that family that nothing should be done. Or his prejudice may be along the lines, which I think is more common, and that is a stranger looking at a defective newborn baby says, "Gee, if that were mine, I couldn't hack it." But it isn't his, and the parents feel quite differently about their child than a strange physician.

When it comes to the other problem of the resources, that is just as likely to occur in a tertiary care center as it is in a community hospital. And as I said, it's very difficult for somebody to know, for example, as a pediatrician who sees only one or two of these in a lifetime, if that, just how other parents have done innovative and creative things, have rallied community support, have established organizations that are anatomically designed for that particular defect; and therefore, he tends to be a little less enthusiastic about what can be done than if he had all of this information at his hands.

I think, as Dr. Stahlman and Dr. McLone have stated, what has happened in just the past decade was a tremendous acceleration of what happened before that time. And we are not perfect, but so much better than we were 10 years ago that it is very significant.

COMMISSIONER BUCKLEY. Dr. McLone, is there ever any case—and you deal more with spina bifida—in the spina bifida children where you feel that you should not operate and you don't? Do you determine, for example, that if they are above T-10, you're not going to do the operation, or do you do it all the time? Do you decide at some point?

DR. MCLONE. I think one of the things you can say absolutely in medicine is that you can't say absolutely. Because there are children born who are agonal, who are in the process of dying, who have such bad deformities, so much of a spine open and occasionally both sides of the child, on the abdominal side, that it's a surgical impossibility. That probably occurs in less than 1 percent of the time. In those cases you can't operate, and in those cases we obviously don't attempt to. We know that this child is in the process of dying, and we can only operate on the child so as to possibly prolong it for a matter of hours or days.

But when you look at the criteria that have been used, such as a child who has a T-12 level shouldn't be operated on—Dr. John Warburg, a pediatrician from England, is the one who first advanced that criterion—when you look at the results that he published in 1981, in which he treated something like 30 percent of the entire population—if you look at those 30 percent survivors and compare them to our study in which we treated essentially all children, they are not significantly different. So the selection criteria that have been used to select these children that is supposed to be predictive of quality of life or outcome have been shown in almost every center in the United States to be invalid and not predictive and do not produce a population of children with spina bifida who are superior to the group where everyone is treated.

COMMISSIONER BUCKLEY. Let me go back to Dr. Stahlman.

I live 150 miles away from the nearest pediatric surgeon. And if I have a baby right now, I don't know that I can get him over there in an hour's time. How do we help that child? What can be done to improve the chances of that child surviving? Maybe there's a helicopter available, but that still may not be quick enough. How do we deal with it? How do we improve that situation for that baby?

DR. STAHLMAN. You're addressing a surgical problem of intermediate surgery or—

COMMISSIONER BUCKLEY. Even if the infant were to survive 24 hours, and he now needs immediate special intensive care. Parenteral feeding may not be possible. Something needs to be done now.

DR. STAHLMAN. The way we have addressed that problem—and I live in a rural State, and we have the responsibility for the 39 counties surrounding our own county in a radius of about 100 miles. And most States, as I have said, are now regionalized as far as perinatal care is concerned, high-risk perinatal care. As far as newborn care, this is largely done at a State level. It may be done at a regional level as a consortium of States to consolidate facilities and available resources across State lines.

It is perfectly clear that every local hospital can't have an expert on everything. So the regionalized concept of referral, I think, is the best way to utilize scarce resources. And even in an affluent country such as our own, resources are always limited, so one makes the best use of what one has.

What we try to do is to train local personnel in each one of those 39 counties, in each one of those 43 rural hospitals, to be able to: (1) recognize problems immediately; (2) stabilize that baby; and (3) refer when referral is needed. And we have a transport team which we hope will be able to arrive within a very short period of time at that referral hospital, stabilize the baby there, and transport the baby back in a stabilized state in a mobile newborn intensive care center on wheels, with a physician, a perinatal nurse, and a driver, and all the equipment around it that is in an intensive care unit, rather than taking the baby away from its life support systems and hoping it's going to survive until the next area.

I spent the last 10 years of my life trying to regionalize middle Tennessee, and education is the keystone to it—physician education, public education, nurse education, and, I must say, hospital administrator education—to be able to have that kind of network available.

COMMISSIONER BUCKLEY. Thank you.

CHAIRMAN PENDLETON. Maybe I missed something in your question. We talked about a time frame. She talked about an hour. You talked about a reasonable amount of time. What is a reasonable amount of time in the context that you are in in middle Tennessee?

DR. STAHLMAN. In most instances, we would say 1 or 2 hours. Now, if it's a matter of crisis in a delivery room, and it's unrecognized, things can go bad, and nobody can anticipate in certain circumstances that things are going to go bad.

But in most instances, we urge and we have, we hope, educated obstetricians to anticipate high-risk, difficult deliveries, and to refer the baby in utero to the regional center so that he can be delivered with resources commensurate with the need, immediately available, rather than having to transfer the baby ex utero in a critical state.

So that is where the perinatal part of it comes in, that the obstetricians have to be equally educated, the resources for high risk obstetric education and maternal care in the boonies have to be just as good as the neonatal educational process, and the referral process hopefully happens well ahead of the game. So that the woman with diabetes, the woman with hypertension, the woman with impending bleeding problems, and so on, or impending delivery of a baby at 15 weeks before normal term—those mothers will be transferred, rather than their babies dumped in a rural hospital with no facilities around to manage them and a crisis situation arise secondarily.

COMMISSIONER PENDLETON. Are you through, Commissioner Buckley?

COMMISSIONER BUCKLEY. Yes.

CHAIRMAN PENDLETON. Commissioner Abram.

VICE CHAIRMAN ABRAM. Dr. Koop, I know that you are one of the fathers of pediatric surgery in this country, and I would assume because of his age that Dr. McLone is also among that group to whom we owe so very much.

I want you to understand by the questions I am going to put to either or both of you that I am not indicating any disagreement with a point of view. I am trying to reduce the matter to its ultimate essentials.

Would one of you—I don't care which one—tell us what Lesch-Nyan syndrome or disease is?

DR. MCLONE. You can probably speak to it better than I, Dr. Stahlman, but it's a neurological involvement, not a surgical disease, but a disease that I almost never see. It's cared for mostly by pediatricians and by a neurologist. My expertise is relatively limited.

VICE CHAIRMAN ABRAM. Dr. Stahlman, what is the outcome? What happens?

DR. STAHLMAN. I must say I don't think I've ever seen one. I have dealt exclusively with newborns over the past 25 years, and if I've seen one, it's been unrecognized.

The outcome, I would guess, to those children is really very, very poor. It is what we call an inborn error of metabolism, which is a problem for which we have no solution at the present time. And there are many such.

VICE CHAIRMAN ABRAM. How long do they live?

DR. STAHLMAN. I can't answer that. I don't know.

VICE CHAIRMAN ABRAM. Do they tend to mutilate their parts?

DR. STAHLMAN. Yes.

VICE CHAIRMAN ABRAM. They eat themselves?

DR. STAHLMAN. They certainly chew on themselves.

VICE CHAIRMAN ABRAM. And it is without any known cure?

DR. STAHLMAN. True.

VICE CHAIRMAN ABRAM. Now, Dr. Koop, I was very taken by your analysis of the Bloomington baby situation. It was simple, but it was very piercing. You pointed out that if the child had not been born with Down's syndrome, certainly no question would have arisen as to what was done in this case—which I disagree with; I disagree with the court in this case; I disagree with the parents' decision. But if the child had not been born with Down's syndrome, the problem would not have arisen in this form. If it had been born with esophageal atresia, as you point out, and had been otherwise a perfectly normal baby, there would have been almost no question at all that it would have been surgically treated. And I think that's a very interesting analysis.

Let us suppose a child is born—and I do not know whether or not you could recognize it at birth—but it has Lesch-Nyan disease, and it also has duodenal atresia or esophageal atresia. Would either you or Dr. McLone feel that in that case the intestinal defect should be treated, if you're sure it has that disease? I don't know whether you can be, but let's assume that you can.

Dr. McLone.

DR. MCLONE. Sure. And this is the point of physician ignorance. Because of my lack of information on what the possible outcome and various functional levels of the child with that disease could be, I think one of the first things that should be done is someone who is an expert in the area should participate in that decisionmaking process.

However, if based on that decision, this is a child who, say, has a life expectancy of 10 to 15 years, and they know that he will be significantly retarded, and has a surgically correctible lesion. Then I think it's appropriate to surgically correct that lesion and try to have that child as comfortable as possible for whatever life expectancy he has.

VICE CHAIRMAN ABRAM. If it had Tay-Sachs?

DR. MCLONE. In Tay-Sachs disease—and, again, I am not an expert in this field—their life expectancy is relatively short, and they are, in fact, in the process of dying from central nervous system degeneration. I certainly think, again, that the child deserves to be made comfortable, and if it can be established so that the child can eat and receive water and so forth, I think it would be appropriate to do what is possible.

VICE CHAIRMAN ABRAM. To do the operation.

DR. MCLONE. Yes, I would think so.

VICE CHAIRMAN ABRAM. Dr. Koop.

DR. KOOP. I think I would agree with everything Dr. McLone has said. I think there are two additional things I'd like to state.

The child who has a surgically correctible lesion very frequently before that uncorrected defect will kill him will go through an extraordinary amount of discomfort, and I think that that kind of treatment is inhumane.

The other thing that a person of my experience can speak to that perhaps other people find odd is the satisfaction that parents get even from a relatively short association with a child. I have had no experience in treating or caring for Tay-Sachs children, but one of my colleagues had two such children, and I was present at the death of both of them. As a matter of fact, the second one died in my arms. And I could hardly believe that father when he stood with his arm around me and said, "You know, these children never gave us a moment's trouble." Well, you and I would think the trouble they gave was insurmountable, but they were their children and they didn't see it that way.

VICE CHAIRMAN ABRAM. Dr. Stahlman, do you agree with the two other physicians about the Tay-Sachs child, the operation for esophageal atresia, and also in the case of the Lesch-Nyan disease?

DR. STAHLMAN. I think I would agree that an easily surgical remedial condition ought to be performed if it offers a relatively pain-free existence beyond that. I believe that human beings ought to be allowed to die without pain and without fear, and that the physician's responsibility, when they are no longer able to help their patients medically and/or emotionally, is to relieve pain and to relieve fear.

VICE CHAIRMAN ABRAM. My final question, then, is as follows: What is the opinion of each of you as to whether or not the failure to treat a nondying patient, a nondying child, can be in the best interests of the child? Dr. Stahlman.

DR. STAHLMAN. I think the key to that is "dying." In the regulations which we discussed at some length with Dr. Koop, the word "imminent" was finally deleted. And what one defines as dying then becomes again a spectrum of: Are we talking about minutes? Hours? Days?

VICE CHAIRMAN ABRAM. If we are talking about years?

DR. STAHLMAN. If one talks about years, then I think one has to concern oneself with pain; whether or not we accept it or not, with resources—I am bitter about resources; whether or not the individual that is dying over some length of time has any humanness in the quality of their life—is it a human existence? Are they aware of anything?

VICE CHAIRMAN ABRAM. Dr. McLone, do you believe that the nontreatment of a child who has several years to live is ever in the best interests of the child, or whether that should be the governing principle or a governing principle?

DR. MCLONE. I think the governing principle—and I think Dr. Stahlman put it very nicely—is the question of dying and how long that process is going to be. And what we are really talking about—I think a child who is in the process of dying, to perform an operation which will increase the longevity of that child's life minimally is not in that child's best interest. To leave a child with an illness which is correctible and would make the child's quality of life better and more enjoyable and less painful—to deny that child that in the hope that they would acquire a fatal illness that would take their life sooner, I think is inappropriate.

**VICE CHAIRMAN ABRAM.** Dr. Koop.

**DR. KOOP.** I would have just one caveat for what has been said by Dr. McLone. There might be a circumstance where my patient was in the process of dying, even relatively soon, and had a surgical problem that might be producing excruciating pain, such as an imperfect anus. I think it would be inhumane not to do a colostomy on that child, even though his death were, quote, "imminent," unquote.

**VICE CHAIRMAN ABRAM.** Thank you.

**CHAIRMAN PENDLETON.** Commissioner Bunzel.

**COMMISSIONER BUNZEL.** I'd like to follow up on Mr. Abram's questions and go back to a comment that was made by the first witness in terms of the discussion about the 1 in 1,000 live births that are likely to present some dilemma of choice. Irrespective of whether those figures are scientifically accurate, they are usable, and I'm not too concerned with their accuracy.

In the last round of questions and answers, it occurred to me that the decision of whether or not to do X or Y, whether the nontreatment of the child was in the best interests of the child, even if it were not done—is that a decision that is left to the doctors to make? Or is it a decision that is left to the doctors to educate the mother and father about, in consultation therefor? If the doctors have one set of views—and let's say for the moment that both parents are in agreement, which is not always the case—do the doctors abide by the wishes of the parents? And is that a guiding principle?

**DR. STAHLMAN.** I can only speak for myself, perhaps not for anyone else, having dealt with this kind of problem over a long period of time.

Most of our decisions are not should one do something, but is it appropriate to continue to do something? Is it appropriate to continue to literally artificially keep a baby alive who will not eventually benefit from it? Withdrawal of a ventilator, withdrawal of a TPN line—primarily those are the things we face in an unconscious baby or a baby whose lungs are destroyed, or a baby whose bowel is destroyed, or some organ system has completely failed. Those are the dilemmas which we have, which aren't going to be remedied by an easy out of decisionmaking, "Yes, let's do X, Y, or Z in a surgical procedure."

It is my firm conviction that the physician's first responsibility is to the patient and secondly to the parents. Now, I have always felt that if the parents disagree with the physician's best judgment, with his colleagues conferring—if he needs a geneticist, if he needs a pediatric surgeon, whatever kind of consultation he happens to need, he ought to have those available to him. He then tries to educate the parents to the problems which their infant faces, and if the parents disagree as far as continuation of extraordinary means of keeping a baby alive, we have never gone against the parents.

On the other hand, in certain instances there are times when you know a baby can be salvaged, salvaged intact, where a parent because of religious beliefs or one reason or another wants to deny the baby treatment. The Jehovah's Witness problem is one we face not infrequently. And there are other religious sects that want to withdraw treatment. With those babies, we intervene and try to do what is in the baby's best interest when they are clearly salvageable.

I don't know whether I've answered your question or not, but I think the physician must assume great responsibility. He shouldn't be a physician if he is not prepared to do that. That's the essence of the ethical practice of medicine.

COMMISSIONER BUNZEL. If we have the time, what I'd like to do before I get to both Dr. McLone and Dr. Koop is discuss whether or not, in terms of the curriculum of the medical schools today, physicians are getting more than a week or two, as I learned in one school, of ethical questions. Because when we are talking about ethical questions and we are saying at the same time, if we are, that the major responsibility for the answer to these ethical questions lies in the hands of physicians—and there are those who believe that—that, in turn, raises some very difficult ethical questions.

DR. STAHLMAN. May I just respond to that? As far as the curriculum changes are concerned, those are coming. They are coming slowly, but most medical schools now have a medical ethicist, which 10 years ago there was no position for. So they are coming in formal curricula.

Most medical ethics is taught at the bedside. Most medical ethics has traditionally been taught by precept and by example, by physicians such as Dr. Koop and Dr. McLone, who have medical students and house officers and colleagues around them who listen to their judgment and take their medical-ethical principles and utilize them for the rest of their lives.

So I disagree that there isn't or hasn't been medical ethics taught in medical schools, because it's always traditionally been taught. It has not necessarily been formally taught, and I'm not sure it's better taught.

COMMISSIONER BUNZEL. I understand.

Dr. McLone, can you answer whether or not, in some of the difficult scenario cases that you have had to deal with, there has been a conflict between yourself and both parents?

DR. MCLONE. I'm going to speak mainly to spina bifida and the decision to treat or not to treat, and I can give you some numbers.

We were concerned about the very question you are asking, and there have been some articles published in *Pediatrics* in which they have discussed this issue.

We asked 300 parents a couple of questions, and the important ones for this discussion are: "Did you at the time of surgery give an informed consent, and do you feel you were, in fact, informed?"

Our problem with spina bifida is that we make this decision in 24 to 48 hours, sometimes as long as 5 days to a week, but usually within a very short period of time.

Three hundred families responded to the questionnaire and it was unrewarded and anonymous. Fifty-two percent felt that they did not give informed consent.

The other question we asked them relevant to this conversation was, "Do you regret your initial decision?" And of the 300, there were 13 families who regretted their initial decision. The interesting thing is that 9 of the 13 regretted their initial decision not to treat. There were only three families who regretted the initial decision to treat.

So the numbers of families in spina bifida that you are confronted with on the night of the decisionmaking process who are at variance with the physician is extremely rare in my experience. In fact, I have now treated about 300 newborns and had this midnight discussion with about 300 families, and I have not had one family, once fully informed of the availability and the likely outcome of treatment, who has refused to have the back repaired at the time of birth.

In my experience in the cases I am familiar with where the decision was made not to close the back, that decision, in essence, was made by the physician and by what he told the family, and the family went along with the decision of the physician not to close the back.

I agree totally with what Dr. Stahlman has said. We are physicians to the child primarily, family secondarily. We must act in the best interests of our patients. If the family has gone contrary to what we think is in the child's best interest, we have two options: withdraw from the situation and ask them to acquire a physician who agrees with them, or invoke legal means to make sure the child is appropriately treated. I prefer not withdrawing and staying involved with the child who is my patient.

COMMISSIONER BUNZEL. Dr. Koop, do you want to add to that?

DR. KOOP. I agree with almost everything that has been said. When you face the situation with our traditional value without parental authority and you come up with a difference of opinion, one is on the horns of a dilemma. I think that both of the previous speakers have indicated that the physician is largely responsible for the decision that parents make.

I don't know how many newborns I treated in my lifetime, but I had over 100,000 patients as a practicing surgeon. I never had a family that refused the advice that I gave them to the point where I felt it was necessary to go to court in order to reverse that decision. I think that only speaks of the fact that it was truly informed consent. They knew what the risks were, what the hazards were. And I, like Dr. McLone, did not sit in an ivory tower and go back and hope nobody would ask me questions of my parents. I went back and had the parents made available to others to see, in some of the difficult things I did with newborns, how they felt about it. And my statistics are about the same as his, that most people had very positive feelings to what you and I might consider a very hazardous and difficult life. But again, it's their family.

COMMISSIONER BUNZEL. Am I correct in inferring from what each of you is saying that when it comes to a difficult choice, when the options are not the easy and obvious ones and when there are decisions to make both of a medical and consultative nature with the parent, and when both the quality of life of the child is involved and whether there are ethical concerns, that in point of fact what you are really saying is that the doctors themselves on a committee or who are in attendance are in agreement. Or to put it another way, have you been in situations where in point of fact, as we have been reading recently, doctors are in disagreement on a given case? Then what happens? Does this make the role of the ethicist more or less pronounced? Does this present a different set of problems for the parents? Does their role become augmented or is it confusing? What happens in that kind of situation?

DR. KOOP. My answer to that is that I think there is a captain of the ship, and the physician who is responsible with the parents for that child, recognizing that the child is the patient—I think that individual's decisions are reinforced by his ability to consult with a committee. I think many times, no matter whether the decision is pro or con, he has it strengthened by the ability to work with his colleagues toward what might be a possible solution. And in those situations where parents are permitted to listen in on this discussion, I think they frequently come to a very much better informed consent than if they are talking to one person alone.

DR. MCLONE. I agree with what Dr. Koop said, that the physician who is the primary physician to the child is the one who ought to be responsible for making that decision. And there are occasions when there are other physicians who are in consultation who disagree. I think in both the Baby Doe situations that were in the press, the initial physician who advocated surgery, the parents had agreed with him, and then another physician who wasn't in the role of the surgeon, who wasn't going to perform the surgery, gave options. And in the case of the child with spina bifida, he gave grossly inappropriate and a great deal of misinformation to the family. And I think the family, based on the information they were given by that physician, made the right choice. It just happened to be that the information was incorrect.

CHAIRMAN PENDLETON. Are you finished, Mr. Bunzel?

COMMISSIONER BUNZEL. I guess so.

CHAIRMAN PENDLETON. Commissioner Guess.

COMMISSIONER GUESS. Thank you, Mr. Chairman.

I was struck by something Dr. Stahlman mentioned earlier in terms of her bitterness over the lack of resources, which undoubtedly contributes to making decisions in many instances. For those of us like Dr. Stahlman who live in middle Tennessee, it is often pointed out how Vanderbilt is conceived of as an institution of unlimited resources, and in many instances receives a bad rap—

DR. STAHLMAN. Thank you.

COMMISSIONER GUESS. —for its failure to treat patients in some cases because of the economic question.

What I'd like to address to Dr. Stahlman and the other members of the panel is: To what extent in making these decisions should the question of resources and who is ultimately liable for those resources—since we recognize the fact that medical treatment is not free—play a part in the decisionmaking process?

DR. STAHLMAN. I don't think it should play any. I have never been denied any admission to the newborn intensive care unit, nor has any child ever been denied admission to Vanderbilt University Hospital as long as I have been there, and that's been since 1943. So as far as children are concerned, I don't believe that that is a problem in that particular setting.

It becomes a problem, though, in many settings where one knows that a baby's hospital experience will cost $300,000, $400,000—and I'm talking about a primary medical experience and not the rest of his life or his continued operative problems that may happen later on or his readmissions and so on. It is estimated that the very-high-risk newborn baby probably costs a million dollars during his lifetime. In this country and in England, these estimates have been made, and I think they are probably reasonably accurate.

So somebody is paying that bill. The somebody is the taxpayer at the moment, because it can't be an individual parent. Insurance companies pay a certain portion of it. If the parent is insured—in many instances in our experience they are not insured—the local communities don't assume any responsibility for them once they are transferred. The tertiary care unit gets dumped on repeatedly. It accepts that responsibility. And we run huge deficits. My hospital administrators point that out to me every week. We lose more money than any other unit in the hospital and have for the past 30 years.

So I do feel that resources are not equitably allocated, first, to the prevention of perinatal problems. The priorities are not there. The national priorities are not there, not with our Federal Government, not with our State government, in the prevention of high-risk perinatal problems. The research money is not there, and that might obviate the necessity for all this medical care that we talked about today. And once the disaster has happened, it is the public's responsibility, because no single individual can manage those kinds of costs. So I am extremely disturbed by our priority system.

COMMISSIONER GUESS. Dr. McLone, should resources play a part in the decisionmaking, and who is liable?

DR. MCLONE. When you face the question of limited resources, you can look at it from two points of view. You can look at it, one, from the point of view we have limited resources, and then say we will decide which children will have the resources available. Or you can look at it from the point of view of, "How do we correct our resource problem?"

I think it is inappropriate to use the patient to solve the problem and to use a cost-benefit analysis of what these children are going to be like to solve your problem. The solution to the problem and the direction of attack should be—we have limited resources; we have to increase our resources. We have to reallocate our resources so we can solve these problems.

COMMISSIONER GUESS. Dr. Koop.

DR. KOOP. I couldn't express it better than Dr. McLone, and that's in spite of the fact that I worked in the oldest children's hospital in the country that accumulated tremendous debts in just these kinds of problems over the years, and I was partly responsible for trying to raise the funds to meet those deficits. Yet, I never let resources be part of the manner in which I practiced medicine.

I remember the day the administrator took me into the intermediate intensive care unit and pointed out several patients and told me that they were mine, and their accumulated bill was $1.2 million in the hospital at the moment.

It was a shocking thing. But all those children are now fine contributing citizens. And I think we never should sacrifice the patient for the resources, but we should do something to fix the resources that enable that patient to benefit from them.

COMMISSIONER GUESS. Do you also agree with Dr. Stahlman that we need to reorder our priorities?

DR. KOOP. I think the things she said are absolutely true. Some of them are very difficult. I have been mounting a program in the government called "Healthy Mothers, Healthy Babies" for the past 4 years. I have come to the conclusion that education, no matter how well it is done, is not going to get the kind of target young lady that we are interested in to get to a prenatal clinic, and I think we ought to get a prenatal clinic to her. That's reordering priorities.

COMMISSIONER GUESS. In the interest of time, Mr. Chairman, I yield.

CHAIRMAN PENDLETON. Commissioner Destro.

COMMISSIONER DESTRO. I have a number of questions for the panelists.

Because the topic here is handicapped newborns and 504, I would appreciate it if the panelists would address a distinction that I heard that may not be correct—and I'd like you to correct me if I am incorrect. Is there a distinction that you draw between what might be considered a newborn with a malformation or some kind of a congenital defect which you might call a handicapped newborn and the newborn who is either of low birth weight and simply underdeveloped? Is that a reasonable distinction to make?

DR. STAHLMAN. No. I think the newborn I'm talking about is the unsalvageable newborn who has multiple organ failure.

COMMISSIONER DESTRO. Is that the patient that you talked about as being in the process of dying, then?

DR. STAHLMAN. Right. But I can't say when.

COMMISSIONER DESTRO. That's another question. What I want to do is just clarify the categories a little bit that we are dealing with.

Maybe the other panelists would like to address that. The distinction that I have drawn—does that make any sense?

DR. MCLONE. I'm not sure I understand what the distinction is.

COMMISSIONER DESTRO. I guess the question I am getting at is: Dr. Stahlman talked about the problem not so much being refusal to treat—in her situation—as being when to stop, if I understood her correctly. In the Baby Doe cases, Baby Jane Doe and Baby Doe in Bloomington, the decision appeared to be whether or not to render care to correct a correctible defect.

I have talked to a number of representatives of disability groups, and they have always tried to impress the distinction upon me that there is a distinction between rendering medical treatment and the disabilities that they have. What I am trying to do is see if we can't get on the record where the lines are between when the government is intervening in medical decisions, which are uniquely medical, and where we might be dealing with a discrimination problem.

DR. MCLONE. My understanding is that the problem that we are speaking to here today is not the problem of when to withdraw treatment from a dying patient but rather the patient who is born with a lifelong handicap and who could become a dying patient because of the withholding of treatment.

That is my primary interest with the children with spina bifida who would fall into that category. We have children who have been involved in trauma or who have been asphyxiated who are in the process of dying, and the decision has to be made at some point when to withdraw further treatment. That, I think, is a different problem than what we are concerned with here.

COMMISSIONER DESTRO. So the problem we are dealing with here is not the same kind of a problem that is probably better directed to Dr. Stahlman than the problem that the Frustaci septuplets have been having. They were just born too soon and too small, and that's not really the situation we're talking about here.

DR. STAHLMAN. I think that is perhaps an example of the type of patient we deal with all the time.

The decisions are the baby who has been on the ventilator for 8 months, and his blood oxygen can't be raised, his blood carbon dioxide can't be gotten rid of. He now has a tracheostomy in his neck and is totally dependent on a ventilator, which is now slowly but inexorably becoming inadequate to do anything. His cardiac size is massive. He's in chronic cardiac failure. His renal problems are secondary to all this other that's gone on. His bones have become leached out of their calcium, and he now has rickets and he's breaking bones right and left. He has brain hemorrhage, and he is developing hydrocephalus so he has a shunt. He has many times no cognizance of his surroundings. He may be totally blind because of retrolental fibroplasia. And you can go on and on with the multiple organ failures, but he is now 8 months old, and what are you going to do? How long until this baby is going to be allowed to die?

COMMISSIONER DESTRO. In other words, what you are describing is a baby who is in the process of dying.

DR. STAHLMAN. Not this day.

COMMISSIONER DESTRO. No, I understand that. What I'm just trying to do—

DR. STAHLMAN. So I think it's a major decisionmaking process, and the law certainly addresses that kind of baby.

COMMISSIONER DESTRO. When you say "the law," what do you mean?

DR. STAHLMAN. The Baby Doe law.

COMMISSIONER DESTRO. Would you expand on that a little bit?

DR. STAHLMAN. Well, it is my understanding that when one made a decision to withdraw management from that baby, in my own opinion, you either do everything you can do to keep a baby alive or you withdraw every resource from him, that there is no point in having partial management of a situation of that sort. So, as I said before, I think everybody deserves to die with dignity, without fear, and without pain. That's where I think we get into the dilemma with the law.

COMMISSIONER DESTRO. Okay, that would be in your particular specialty. But would you see there being a difference between the cases that Dr. Koop and Dr. McLone have described and the situation you described?

DR. STAHLMAN. I think with neonatologists, with reasonably well-educated pediatricians, at the present time Down's syndrome with duodenal obstruction, anal atresia, tracheal esophageal fistula is not a dilemma. That might have been a dilemma 15 years ago, I think, through ignorance. I think that's not a dilemma at the present time with neonatology.

The spinal bifida problem—we take our neurosurgical colleagues' judgments on those decisions. I can't ever remember a baby in whom our neurosurgeons didn't make the decision in behalf of the baby to be operated.

So I don't think that's where most of the problem lies in my own experience.

COMMISSIONER DESTRO. What I'd like to focus on for a few minutes, then, is the number of cases—and I'd like to address this to Dr. Koop—in his experience that are reported to the Department where the medical judgment to treat the medical condition rests on a consideration of the child's other handicap or other condition, for example, refusal to treat the atresia if the child has Down's syndrome or Tay-Sachs or whatever.

DR. KOOP. You're asking me to assess the number of cases?

COMMISSIONER DESTRO. Right.

DR. KOOP. I'd have to answer it in several ways. Those that were reported to the government were very few, certainly less than you could count on your two hands. It has always been very difficult to assess on a national basis how many children were so treated because it obviously is something that would not be highly advertised by those performing that type of care. Many estimates that were made—most of them came between 1,250 to 1,500 such patients around the country.

But I would hasten to say, from the point of view of a historian, if I might call myself that, of pediatric surgery, that even before we had the application of 504 to Baby Does, the practice of treating babies the way you have just described, not treating one handicap because of the other, was beginning to already peak out and change. I think that one of the advantages of the publicity about the various Babies Doe was that many people began to rethink their ethics and that area of gray, which people sometimes thought was broad, got much more narrow when they came to grips with it.

I would like to expand my comment, in answer to your first question, by saying that I would think, as you have heard the three of us discuss things, that there is a line between Dr. Stahlman's kinds of problems and ours. Now, it's not a wall, and sometimes our problems go over to hers and hers come over to ours. But she made the essential statement early on, not only does each of her patients have an evolution in itself, but the whole science of the care of those babies is evolving.

And if you want to be predictable about what's happening in science today, as lighter and lighter babies and earlier and earlier prematures are being saved, and as we know more about in vitro fertilization, theoretically, the day could come when those things meet, and the dilemmas will be much greater than they are now.

But I think Dr. Stahlman's dilemmas are quite different than ours, and I've always had that point of view.

COMMISSIONER DESTRO. I'd like to ask another question that also relates to a point that Dr. Stahlman raised that certainly came up in the Baby Doe Bloomington case. Would the three panelists comment on the question of whether or not the provision of food and water is medical treatment? That is a question I have been wrestling with for a while, and it seems to be a blurry distinction.

DR. STAHLMAN. If you want my opinion, food and water to a conscious patient is a medical management. I don't think there's any question about that. Food and water to a dying patient or to a patient to whom food would be a disaster, because they have an intestinal obstruction, could be mismanagement.

I go back to the distinction which I tried to make just previous to this, and that is, once the decision is made not to proceed with all force on behalf of your patient, in my opinion, everything should be withheld that would prolong life unnecessarily, and that the patient should be made as comfortable as possible, and allow the full and natural processes of dying, which we all face, to be done with some degree of dignity, not as a servant of a machine.

COMMISSIONER DESTRO. Would that include, for example, a liquid IV so the child doesn't die of dehydration?

DR. STAHLMAN. I think it's immaterial whether a child dies of dehydration or suffocation. I think how conscious a child is matters. If he dies without pain, I can feel my role has been completed.

COMMISSIONER DESTRO. Would the other panelists like to comment on that?

DR. MCLONE. Well, I'm not sure that I differ with Dr. Stahlman's assessment of the situation. However, I think if a child can take nutrition and is dying from some other process, to allow the child to become dehydrated, I think, in my practice and the way I approach a child, would be inappropriate.

Now, would I go to massive lengths to make sure that the electrolytes are well balanced and to do all kinds of chemistries? No. But if it can be done—a lot of children can't take nutrition because of bowel obstruction and so forth. But for the child born with a severe anomaly and is in the process of dying, which is going to take several days, and the child can take nutrition, then I'd give the child food and water.

COMMISSIONER DESTRO. Does that include IV food and water? Assuming the child has an atresia, would you give it an IV? Am I making a distinction here that I shouldn't be making?

DR. MCLONE. I think it depends on how long it is going to take that child to die. If the child has an atresia and is crying out for nutrition, crying because of thirst and so forth, I would try to solve the problem of thirst while the child dies. If the child had no brain, wasn't crying out for nutrition, was in the process of dying within a few hours to days, then I think it might be appropriate to withhold an IV. I think comfort and the relief of pain are important. I think that is what Dr. Stahlman was saying.

COMMISSIONER DESTRO. Dr. Koop.

DR. KOOP. Again, I think they both said the same thing, that once you have made the decision, that you still love the child, you still care for this child, you still comfort that child, if that means giving it some fluids by mouth in order to prevent its mouth from being dry and so forth, and that prolongs life a few hours, I think that that is reasonable and legitimate care, and it alleviates the suffering that we are there to do as well as to save life.

COMMISSIONER DESTRO. One last question. All of you have recognized that the dying process in the cases of patients who are dying is continual. What would be your cutoff, or how would you arrive at, which would probably be a more appropriate question—how would you decide what in your own judgment the cutoff is—in your own experience in your own case? You seem to have recommended, Dr. Stahlman, that the word "imminent" in the regulations bothered you. How would you make the decision in your own practice?

DR. STAHLMAN. I think it has to be highly individualized, and that's what I think the law fails to take into consideration. The law is concerned with processes and with protecting the rights of the population as a whole and not focused toward an individual set of problems. Every set of problems that we deal with has a whole myriad of different processes going on at one time, and I don't think they can be lumped into a category and say, "This baby is now in the process of dying within X period of time."

What we try to decide is: Is a baby salvageable? That may be a vague concept to a nonmedical person, but I think it is a very real concept to a physician or nurse who is at the bedside.

CHAIRMAN PENDLETON. Just before we go to Mr. Green—

COMMISSIONER BERRY. I have a question, but I'll wait for you.

CHAIRMAN PENDLETON. Dr. McLone, you do not believe that the regulations are going to work; is that correct, the ones that are on the books right now? Am I correct?

DR. McLONE. I don't think I've ever said that.

CHAIRMAN PENDLETON. "Dr. McLone does not think that current Baby Doe legislation will be effective." Is that correct?

DR. McLONE. No, I don't think I ever made that judgment, sir. I don't really know how effective they are going to be. I think it's going to vary quite significantly from State to State, depending on how the child abuse laws are used in various States.

CHAIRMAN PENDLETON. Let me ask this question: What should be the Federal role with respect to Baby Doe? You talked about the treatments themselves, but where should the government be in these cases? Anybody can answer.

DR. MCLONE. Well, I can start it off. I hope that the direction we are taking isn't that the government is going to intervene in every single medical decision made with a newborn that has a handicap. As I pointed out, from our data, from our hospital, the problem cases are few and far between. And I think that's true throughout the State of Illinois. These are rare cases.

Just like the child who is denied medical care—the Jehovah Witness child who is denied blood transfusions, the child who is abused by the family—there are cases in which the problem has to be dealt with. There has to be a court of higher appeal. There has to be a court of appeals that will act in the child's best interest.

Those rare cases I think the government can serve, and these regulations can serve in those cases. They are not, in my opinion, going to be a great number of cases.

CHAIRMAN PENDLETON. Dr. Stahlman.

DR. STAHLMAN. I guess I really don't see a Federal role in this set of problems. I think it's now been relegated to the States to uphold the child abuse laws. And as Dr. McLone has said, in those rare instances where child abuse can be documented, under the law perhaps that may be one way in which it ought to be approached. I would hope that it was totally unnecessary.

CHAIRMAN PENDLETON. Dr. Koop, do you have a comment?

DR. KOOP. I feel that every individual who is a citizen of this country is entitled to the full protection of the law. And the fact that he might be too young or too weak or too poor to demand that for himself does not alter the situation. And the fact that he might be handicapped in some way certainly does not alter that situation.

You don't have to be a citizen for a week or month or 5 years in order to run for President. You just have to be born in America.

I think that is where we have the right to intrude, as people call it, into the care of patients if their rights are in any way being denied.

I would hope, as Dr. McLone said, that the regulatory process would very, very seldom come to a place where it required enforcement. I think one of the best things to look forward to is that the patient care review committees will tend to smooth a lot of these things out, and if there are inequities because of the different types of patients that Dr. McLone sees as compared to those Dr. Stahlman sees, I would hope that future regulations would alleviate those injustices.

DR. STAHLMAN. Mr. Chairman, may I make just one more comment?

I think you can have another kind of discrimination. And that is discrimination which is, because of the law, that a child who really ought to be allowed the dignity to die in peace might be inadvertently kept alive because of fear of the physician, of retaliation under the law. This is a real possibility.

CHAIRMAN PENDLETON. Just one other question. What is the impact of the Federal presence? What does that do to malpractice insurance?

DR. STAHLMAN. Guess.

[Laughter.]

CHAIRMAN PENDLETON. Do you have any idea?

DR. MCLONE. I'm not sure what the impact is on malpractice. Malpractice insurance in this country, especially for us neurosurgeons, is unbelievable. People on Long Island have premiums of $110,000 a year now. I don't know what role this plays in that, but the situation is totally out of hand.

CHAIRMAN PENDLETON. I would yield just for the sake of time. I got part of the answer I was looking for.

Commissioner Berry has a question.

COMMISSIONER BERRY. A fast question. Before I listened to your testimony, I had assumed these were straightforward decisions made by knowledgeable physicians who had at their fingertips all the latest information, and wherever you were in the country, it was simply a matter of that physician bringing their latest information and making a judgment. I found out it's much more complicated than that.

So I'd like to ask: Do you believe that most doctors that most parents of newborn infants encounter—especially those who have what you described as multiple defects—know enough to recognize these defects, or know enough to refer them to someone else who does, or know enough to make a decision about whether the child is so defective as to be dying, or whether the child ought to have surgery or not, or can at least make those judgments in a way that one could rely on them?

I know it's hard to ask physicians about other physicians, but do you believe that that kind of knowledge is widespread enough so that even if in Ms. Buckley's case—she's down in a little town in Texas in a rural hospital—that it is likely to encounter a doctor who knows all these distinctions, who knows when to refer and what these defects are and can tell whether or not there is a dying taking place, etc.?

DR. KOOP. I think that the doctor anyplace knows when he doesn't know any more. And that's all he has to know because then he moves it on up to the next echelon who does know more than he does. He certainly knows in most instances the difference between a patient's act of dying or entitlement to more life. But I don't think that it's as grim a picture as you sort of are implying. I think there is a better fail-safe mechanism.

DR. MCLONE. I think the situation has dramatically changed within the last 10 years. In 1975, 15 percent of the patients with spina bifida were held at the outside facility in the hopes that the child would die before they were then finally transferred to our facility for closure of their back. Today that is unheard of.

So I think in the treatment of spina bifida, the dissemination both by the lay press, by the Federal Government, by the American Academy of Pediatrics, and so forth has gotten down. And I think there are still rare cases in which a physician will wander in and out of ignorance assist the family in making its decision. But it's relatively uncommon.

COMMISSIONER BERRY. Do you agree with that generally, Dr. Stahlman?

DR. STAHLMAN. I agree with that in general. I think 10 years ago the survival of a baby under 1,000 grams on a respirator was really quite unusual. The survival now of babies under 1,000 grams in most tertiary level hospitals is over 50 percent, and most of those are without severe defects.

COMMISSIONER BERRY. The second question is: If the parents of a multiple-handicapped newborn infant ask for nontreatment, and the doctor agrees that the infant is dying—and I'm using the language the way you did, Dr. Stahlman—in a matter of days, hours, whatever; I don't mean dying right at this moment—and than the government intervenes and says that the child should be treated and should be maintained for as long as possible, then who do you believe should be responsible for the maintenance, medical treatment, and whatever else is needed for the development of this child, and who will finance it and who will pay?

I ask that because all three of you have talked blithely, in my opinion, about something costing a million dollars, and "Well, we ought to have the resources. Let's not worry about the decisions." From my own personal knowledge, I am aware of situations where the resources weren't there and where hospitals have refused to treat patients on occasion who didn't have money. So I'm asking: Who is going to pay for all this? How is it done, and where are you going to get this million dollars?

DR. KOOP. Well, the patient you pose doesn't exist. If you have a patient such as you describe, the government is never going to interfere in that because it already complies even with the law that Dr. Stahlman doesn't like. It lets you out of that situation.

There is no ready answer to the other situation. I think what Dr. Stahlman described, the change in mortality of children on respirators of the type she treats—the first few years of that obviously is going to be very high. And I think that in a situation where we are evolving kinds of management, things get cheaper and easier to do as time goes on. And any time you get into one of these questions about resources, I don't think you can limit them to just children alone. You have to look at them in reference to the other people for whom we provide resources. And without stating an opinion, I think you have to say: Is it better to provide X number of dollars to give a child a start for 70 years or provide an artificial heart for somebody who has already had those years?

COMMISSIONER BERRY. What's the answer?

DR. KOOP. I don't think there is an answer.

COMMISSIONER BERRY. How do we go about finding out the answer?

CHAIRMAN PENDLETON. Until the money runs out.

COMMISSIONER BERRY. I agree with you, but I'm not going to quarrel with the idea of supporting. I just want to know, with some specificity, what are we suggesting about where these resources are going to come from?

DR. KOOP. I have already gone on record in saying that I think for the kind of patients that we three are talking about here, catastrophic insurance is one way they can be handled.

COMMISSIONER BERRY. Do you agree with that?

DR. MCLONE. I agree. I think there is obviously not a family who can take care of the illnesses we're talking about today. And I think the decisions are difficult. We are faced with a decision: Do we cancel one Trident submarine and use those funds to fund all the neonatology units in the United States? We have to face those kinds of decisions. For me, the choice is obvious. It's the human being that is important in this situation.

But they are difficult decisions, and I don't have all of the information available to know how important that Trident submarine is to our country and so forth. But I think that we have to align our priorities based on what we think is important for humans.

COMMISSIONER BERRY. I'm not sure I want you to answer the question, Dr. Stahlman, since I'm from Nashville, too. I think I know what your answer is.

CHAIRMAN PENDLETON. Both sides of the table are from Tennessee.

COMMISSIONER BERRY. If you want to, you can answer it.

DR. STAHLMAN. Okay. You know, my approach is very direct. I would have the parents sue the President of the United States for the hospital bill.

[Laughter.]

DR. STAHLMAN. More realistically, catastrophic insurance is the realistic answer to this kind of problem—universally available catastrophic insurance. I have a colleague in Knoxville who always said it is the same cost for a boxcar load of dead babies as one foot of interstate.

COMMISSIONER BERRY. The last question I have is: Do you believe that using ethicists to make the decisions in cases where there are controversies over whether treatment should be withheld or not from a newborn—where there is a dispute, do you think this would be a substitute for the doctors making the decision?

DR. KOOP. Inasmuch as I don't know what an ethicist is, I would say no.

COMMISSIONER BERRY. My colleague, Mr. Bunzel, knows what an ethicist is. That's where I got the idea.

COMMISSIONER BUNZEL. They're home grown in California.

[Laughter.]

COMMISSIONER BERRY. One whose specialty is ethical questions and helping people to resolve them. Do you think that would help more than having physicians decide where there's a dispute? Do you think it would be a good idea for us to make that as a recommendation?

DR. KOOP. As I look at people who call themselves ethicists, they vary in stripe tremendously from way over to the right of those that are coming around from the other side. I rather think that ethics, based upon the kind of experience and wisdom that Dr. Stahlman spoke about earlier, is a preferable way of teaching one coming up in this profession.

DR. MCLONE. I think it's important that ethicists be heard and that they participate in the discussion. The decision is where it belongs, and that is between the physician, his patient, with the family participating. The physician can't advocate that position. He has to remain in that position.

CHAIRMAN PENDLETON. I just want to ask one question.

Dr. Stahlman, one question comes up: Black teenage pregnancies in this country is around 60 percent, and that in itself, becoming pregnant, is a waste of human resources. Irrespective of the dependency that could create a welfare system, do you have any idea, or maybe others of you do, what percentage of these babies are underweight babies, and what percent of them require the kind of attention and decisionmaking that you talked about today?

I must say to you, though, for the record, I found out at Dr. Bunzel's institute a young man doing research on black teenage pregnancies. In 1920 it was 10 percent of the population. Now, with all the Federal interventions and all kinds of programs, it gets to be about 52 to 60 percent.

I wonder how many of these babies are underweight and what is the prospect for the kinds of treatment you talk about. You had a scenario about one condition and another condition and another condition. You also talked about the educational processes involved. How does what you talk about and the situation I present here crank into the educational counseling process?

DR. STAHLMAN. That's a tough question to answer in 5 seconds. I don't think there is any question but what the teenage pregnancy is a major medical crisis in this country, that the outcome of those pregnancies tends to be much more at risk than other populations. Whether it's a black teenager or whatever, teenage pregnancy per se is a very high-risk factor in the outcome of newborns. They tend to be premature. They tend to be of low birth weight for the gestational age which they reach. They have multiple metabolic problems. These pregnant girls tend to have multiple problems with the pregnancy itself, particularly hypertension and all of its consequences to the pregnancy.

All of that impacts on the outcome of the pregnancy and the outcome of the baby, but it also impacts on the outcome of the child as it grows up in a social situation where the mother is really still a child herself and not able to take on the responsibilities of raising a family, and frequently as a single parent.

So it becomes a very big ball of wax as a social problem, not just a medical problem. I don't think there are easy answers to this.

I go to Scandinavia and I see prematurity rates which are extraordinarily low, and problems of teenage pregnancy almost completely nonexistent. The outcome of their pregnancies almost always go to term, and their infant mortality rate and neonatality rates are extraordinarily better than ours, I think because of the whole medical milieu in which those people have been accustomed throughout their lives.

COMMISSIONER BERRY. Mr. Chairman, may I follow your point about black teenage pregnancies in 1920 being 10 percent, and then, if I understood you correctly, now being higher after a Federal role.

Could Dr. Stahlman or anyone else on the panel who is familiar with it tell me what the Federal role in medical care has been since 1920 that has stimulated teenage pregnancies? I'd be very curious. Because I'm only familiar with the Shepard-Towner Child, Maternity, Family Health Protection Act in the 1920s, which was to protect mothers who were pregnant to try to have healthy kids, and then the Aid to Families for Dependent Children, the New Deal program, which was simply to take care of kids whose father was either dead, lost, stolen, or strayed, so that they could be healthy. The idea was to keep the mothers home with them. Is there some medical legislation I don't know about?

CHAIRMAN PENDLETON. It's not medical, that's for sure.

COMMISSIONER BERRY. Or is there some other legislation that you who deal with these matters—I've heard about permissiveness and all that, but I didn't know there was a Federal program that promoted pregnancies.

CHAIRMAN PENDLETON. That's not what I said at all.

COMMISSIONER BERRY. Then I misunderstood you.

CHAIRMAN PENDLETON. That's not what I said.

COMMISSIONER BERRY. Well, I misunderstood you; sorry.

Does anybody on the panel have a comment?

[No response.]

COMMISSIONER BERRY. You don't have anything.

MR. GREEN. I have one question for anyone on the panel.

As far as procedure is concerned, what reason, if any, is there for dealing with a decision to perform or not to perform surgery on a newborn with handicaps—dealing with that decision any differently than dealing with a decision to perform surgery on an adult?

DR. STAHLMAN. I don't think there is any difference.

MR. GREEN. I wondered: Is there any reason for having special laws, regulations, and procedures for children when we don't have them for adults who, for example, may have suffered a very serious accident which may result in the very same kinds of consequences as spina bifida?

DR. MCLONE. I agree that there shouldn't be a difference, but Dr. Bartholomew, who is one of the people involved in this problem for a long time, gave a very good speech at Fordham in which he said we have as a society treated the infant or the child quite differently as far as our approach to care than we have the adult. And I think that's the genesis of these rules and regulations. There shouldn't be a difference, but in fact there is a difference in the way we approach the child.

MR. GREEN. Dr. Koop.

DR. KOOP. I think that you see these decisions coming before the public's attention at the two ends of life, and I have always thought that it was because these were people who were not adequately represented. I think if Baby Does were 35 years old, they'd have a very strong congressional lobby working for them and a large national organization. But they are too young, too weak, and too frail.

CHAIRMAN PENDLETON. We are about out of time. It is now 2:55.

COMMISSIONER DESTRO. But my question is more relevant than Federal roles in teenage pregnancies.

CHAIRMAN PENDLETON. For that putdown, Mr. Destro, why don't you ask the question.

COMMISSIONER DESTRO. I'm sorry if it's a putdown, but I think we get off the subject—

CHAIRMAN PENDLETON. I'm sure you'll put us back on it.

COMMISSIONER DESTRO. Let me just ask, in terms of the ethical question that came up, the distinction that seemed to be made was one based on salvageability of a child. Because I'm going to ask some witnesses later about this, I'd like to ask here: Where does the formula that was alleged to be used in the Oklahoma cases, $QL = NE \times H + S$, fit into all of this? Is that a decision that is being made after salvageability is determined, or is that one that is made to determine salvageability? Or doesn't it apply at all?

Dr. Stahlman, you're shaking your head.

DR. STAHLMAN. As far as I know, it doesn't apply.

DR. MCLONE. The data from the Oklahoma study that was used and placed into that formula has, I think, in almost every center in the United States been proven to be absolutely wrong and not predictable, and I think it has no place at all in this decision process.

DR. KOOP. I don't want to muddy the waters, but I think we ought to be sure that we know what we mean when we say "salvageable." I think the term as used by Dr. Stahlman would not be the same kind of term that would be used by either Dr. McLone or me. And I think it's important that the Commission understand that.

One of the things that the Baby Doe amendments to the child abuse law this year were criticized for was the implication that if a child was salvageable, it should be treated. And that was not the implication at all. And I think it's important that you understand that.

Chairman Pendleton. Thank you very much.

We'll adjourn for about 10 minutes.

[Recess.]

Chairman Pendleton. Our next panel is "Scope of the Problem; An Organizational Perspective." We have a rather distinguished panel. I must say that Dr. Strain has to leave early. We want him to feel comfortable, and if he has to leave, please do not feel as though you are deserting us at all.

[The witnesses were sworn.]

## Scope of the Problem: An Organizational Perspective

### TESTIMONY OF MARY AHERN, ATTORNEY, AMERICAN HOSPITAL ASSOCIATION, ACCOMPANIED BY STUART M. GERSON, COUNSEL, AMERICAN HOSPITAL ASSOCIATION; JOSEPH F. BOYLE, M.D., PRESIDENT, AMERICAN MEDICAL ASSOCIATION, ACCOMPANIED BY ROSS N. RUBIN, J.D., DIRECTOR, DEPARTMENT OF FEDERAL LEGISLATION, AMERICAN MEDICAL ASSOCIATION; THOMAS P. NICKELS, LEGISLATIVE DIRECTOR AND COUNSEL, THE AMERICAN NURSES ASSOCIATION; AND JAMES STRAIN, M.D., AND GEORGE LITTLE, M.D., AMERICAN ACADEMY OF PEDIATRICS, ACCOMPANIED BY STEVE WATTON, GENERAL COUNSEL, AMERICAN ACADEMY OF PEDIATRICS

Chairman Pendleton. Mr. Mann.

Mr. Mann. It is good to see all of you brought your lawyers.

Will each of you please state your name and organizational affiliation for the record? You can also mention your lawyers as well.

Dr. Boyle. I am Dr. Joseph Boyle. I practice internal medicine in Los Angeles. I'm president of the American Medical Association. With me is Mr. Ross Rubin, who is with our Department of Federal Legislation in the American Medical Association.

Dr. Strain. My name is James Strain. I'm the past president of the American Academy of Pediatrics, was president during the time of the initial proposal of the regulations and the final rule. I am a practicing pediatrician in Denver. I head the Genetic Unit at Children's Hospital, and by virtue of my general practice in pediatrics, I've had an opportunity through the years, 35 years, to see the graduates. I'd like to emphasize I am not a neonatologist; I'm not an ethicist. I'm a geneticist in internal practice.

Dr. Little. I'm George Little. I am a pediatrician and neonatologist and work at the Dartmouth-Hitchcock Medical Center in Hanover, New Hampshire. I presently chair the committee on the fetus and newborn at the American Academy of Pediatrics, which is a technical advisor/committee and have been heavily involved with the entire issue of neonatology for some time, and involved with the academy on the issue we are discussing today.

DR. STRAIN. I guess I should introduce Steve Watton who works with the Academy of Pediatrics.

CHAIRMAN PENDLETON. We couldn't quite hear you.

DR. STRAIN. This is Steve Watton who is the general counsel for the Academy of Pediatrics.

MR. NICKELS. My name is Thomas Nickels. I am the legislative director and legal counsel for the American Nurses Association.

MS. AHERN. My name is Mary Ahern, and I'm an attorney with the American Hospital Association.

MR. GERSON. I'm Stuart Gerson and I represent the American Hospital Association. Most pertinently, I am the lead counsel in one of the two cases before the Supreme Court on the Baby Doe issue and have represented the American Hospital Association in all the reported Baby Doe cases.

CHAIRMAN PENDLETON. Thank you very much.

MR. MANN. Starting with Dr. Boyle, could you please answer the question: Do you think there is an appropriate Federal role with respect to the medical treatment of handicapped newborns?

DR. BOYLE. We believe that the Federal role has been defined by the Congress. The Congress, in adopting the statute that it passed last year, did define the Federal role as one to see to it that the States did have the appropriate procedures and resources within their own State statutes applying to child abuse and making certain that there is dissemination of adequate information so that the opportunity for a better informed and a better defined process of decisionmaking will be available, that the resources will be available to both the physicians, parents, and hospitals, and that there will be adequate information available as to what resources may be available to individuals needing assistance in trying to make decisions and in trying to live with the decisions that they have made.

DR. STRAIN. The Federal Government is defining the role by establishing guidelines for functioning at the State level. In the academy, we believe that that is the most important place for the oversight responsibility, the State level. Those guidelines have been defined in the new legislation. Certainly, I think funds made available not only for child abuse agencies, but for physicians taking care of children, and the interrelationship between those two groups is important for the funding of that kind of thing that will certainly be necessary in years to come.

DR. LITTLE. I certainly believe that there is a role for the Federal Government with respect to all of its citizens. I think that's a basic principle that all of us have agreed on as we heard earlier today. Certainly, with respect to this issue, I think it's vital that the government at all levels be in the situation of being an advocate to educate and assist, stimulate, and move issues along.

I think where we've gotten into problems in the past is with some differences of opinion with respect to whether it's the role of the Federal Government to intervene, especially intervene in the practice of medicine at an individual level. I think the process we've followed in the last few years and recent months has been a healthy one in which we seem, I think, to be moving to get things into perspective, preserving what's good about the individual needs and local needs and so forth. We were on a different tack for a while, but we seem to now have an awareness of where the Federal Government fits into this thing.

Mr. Nickels. I'd like to give two sections of my answer to that. The first is basically to agree with what Dr. Boyle said. I think the Child Abuse Amendments of 1984 adequately address what the Federal role should be, and that is to encourage States to have reporting requirements for instances of the inappropriate withholding of medically indicated treatment and, second, to facilitate infant care review committees in hospitals. I think that we have supported some kind of a reporting department like that. The ANA has always promoted institutional care review committees. We think that that fairly well carved out the Federal role.

I think that there is a second element here that seems to be missing sometimes from the debate, but it was mentioned a little earlier by some of the Commissioners, which is we have accomplished what I consider to be some miracles in the neonatal intensive care units in the past 10 or 20 years. We have been able to accomplish things that were unheard of just decades ago. The problem is that once we've gotten the babies taken care of, they do not live lives that don't have some complications to them. They are oftentimes physically impaired, mentally impaired, have a lot of problems that have to be dealt with.

We, the ANA, see the Federal Government's role as helping these babies as they become children, young adults, and adults in the community by supporting financially social services, transportation, day care, education, rehabilitation, vocational education—all these kinds of things that will make them productive members of our society. That is what the Federal role should be, to give that level of financial assistance.

One section of the law which I'd like to mention is section 125 of the Child Abuse Amendments, which required HHS to conduct a study to figure out what the best Federal role should be in providing financial encouragement and what the proper Federal role financially should be. That report is due next month. We look forward to that. We think that the Federal Government has that role to help with these children once they are out of the hospital to become productive members of our society.

MS. AHERN. I have very little to add to what they have said. I believe that Congress last year defined what the Federal role will be, and that is through the Child Abuse Amendments of '84. The focus of the Federal Government that is in that law concerning the coordination of resources, of information, of education are terribly important, and we do look forward to the study next month.

MR. GERSON. Just as a point of clarification, most certainly there is presently a Federal role as to the issues and processes that have been described. It is significant to note, however, that at present that Federal role is not based on section 504 because the 504 regulations have been declared invalid by the courts that have dealt with the issue, albeit there is a petition of *certiorari* pending before the Supreme Court now, and that state of affairs could change at a future time.

However, at present there is no regulation in effect that is based on 504. Indeed, there is an injunction issued in the Southern District of New York that has been affirmed by the United States Court of Appeals for the Second Circuit that prevents the Federal Government from undertaking the kind of intervention in medical care that the Baby Doe regulation was premised on, or any such activity under 504.

So that the status quo is one in which there is a pronounced Federal role, and it's under the Child Abuse Amendments, passed by a Congress that was aware of the ineffectiveness of the Baby Doe regulation and the issuance of the injunction, a Congress which chose instead to pass and see promulgated the Child Abuse regulations upon a society and medical community where the body of knowledge is expanding rapidly, as you have just heard.

And what AHA and the American Medical Association have suggested to the Supreme Court, and what AHA suggests here, is, because we are not writing on something that is immutable, because the state of knowledge has expanded, and because a new regulatory mode has been adopted, it is significant to let it work, and that studying it is extremely important, but that amending 504 or using 504 as the point of attack, and sometimes a confusing one, is not the appropriate remedy.

MR. MANN. I take it, then, that all of you think that the Federal Government went too far in pressing its role in 504 in the Baby Doe cases; is that right?

Dr. Boyle, please.

DR. BOYLE. The issue of 504 regulations, as indicated right now, is before the United States Supreme Court as to whether or not they will hear it. The American Medical Association did believe that, in attempting to pursue regulations written with respect to 504, there was serious intervention, serious interference, in the decisionmaking process affecting parents and children. There have been cases that have been reported in which this intervention did create a very substantial hardship and uncertainty for the parents of children and unnecessarily so.

MR. MANN. Do you agree, Dr. Strain?

DR. STRAIN. Yes, I would agree, and also I believe the courts have agreed with this in terms of, certainly, what was said just a minute ago. In addition, I think Congress agreed that HHS went too far. They could have considered amendments to the 504 legislation and did not and elected to go in the direction of strengthening the activities of the child abuse agencies within the State.

We had some very bad experiences as pediatricians during the time the interim final rule was in effect. And I'm sure most of you are very familiar with the situation that existed at Vanderbilt in which there was recorded 14 cases of neglect. These were investigated and none were found to be valid.

There was another incident in Rochester where Siamese twins were being cared for. It was reported to HHS by someone who had read about the case in the newspaper and was not immediately involved in the care or certainly was not a member of the family. As a result of that, there was disruption in the nursery. The neonatologist who was a part of the Baby Doe squad that went to Rochester wasn't able to examine the baby because of lack of consent of the parents. It was a baby who was taken out of the nursery by the parents because of the sign that had been posted regarding discriminations.

So it was a very disruptive visit by the Baby Doe squads of HHS at both Vanderbilt and Rochester. So we have had that experience, and we think that Federal intervention of that kind is going to be destructive to newborn care.

MR. MANN. Could the rest of you respond as well?

DR. LITTLE. I agree with what people have said. I tend to look at it perhaps a little bit differently. I might interpret your questions just a little bit differently.

I wouldn't say the Federal Government went too far in its advocacy, but I think that the methodology and what was utilized—if you want to apply a label that it went too far, sure. I think we heard it went too far medically. It was disruptive. It was a process which was not a healthy one. Apparently, the courts and so forth had figured or at least to date have said that it was not legally appropriate.

But I'd like to make that distinction, because I think since then things have gotten somewhat better. So I interpret your question in that fashion.

MR. NICKELS. I really don't have much to add. I agree with Dr. Strain in that the organizations represented here think that legally the Federal Government went too far under section 504. Certainly, every court that's heard any case involving that has felt that way, and Congress very clearly felt that way. I think that issue is fairly well resolved.

Ms. Ahern. We started this, and I think our suit as far as the legal basis is concerned, we do feel that way, which is why, of course, we filed the suit.

Mr. Mann. Well, the question of the particular sets of regulations that were in issue notwithstanding, do you think section 504 even extends to the handicapped newborns?

Mr. Gerson. Let me take that, if I might, because the position that has been adopted by the courts—that is a relevant issue, and all the courts who have decided the question have decided that the answer is no, that you are not dealing here, although on the surface one might pose questions that look like they raise questions of discrimination, with something here that Congress described in 504. And to make 504 apply to such a situation would take a change in 504; that the infants of whom you are speaking are not otherwise qualified within the terms of 504, nor are the programs or activities that you are describing. The kinds of activities that Congress envisioned when it considered and passed 504 were programs of independent living, vocational education, things along those lines.

Let me suggest to you, based on what we have heard today and what one hears from the physicians, that the universe of concern that is before you on this issue is not one that involves discrimination. It is one that is entirely inhabited in this case by impaired children, and that resolution of problems within that issue, as the medical experts have described it to you today and I think will continue to describe it to you, have to do with two things: the availability of knowledge and the deployment of financial and medical resources. Those aren't discrimination issues. They can be dealt with in a number of ways. They ought to be dealt with in a number of ways.

What you have heard suggested here is that Congress has made an election in setting in place the Child Abuse Amendments, and they ought to be allowed to work.

Mr. Mann. Would any of the other lawyers care to add their views?

Mr. Watton. Lawyers love to add their views.

Mr. Mann. That's why I asked.

Mr. Watton. I would simply say that we would be very pleased, Mr. Mann, if you don't have them readily available, to submit to you our briefs in both the Baby Doe case here and our *amicus* briefs elsewhere. It is certainly our position—

Mr. Mann. We would be glad to receive those.

Mr. Watton. Thank you.

Chairman Pendleton. And the AHA.

Ms. Ahern. Yes.

Mr. Watton. Certainly, it is our point that Congress had no idea when it wrote section 504 that it would be applied in the way that it was attempted about 2 years ago.

DR. BOYLE. We will be happy to provide you with the AMA briefs on this also.

MR. MANN. Okay. More briefs than I can ever read.

I believe that's all the questions I have.

CHAIRMAN PENDLETON. Mr. Guess.

COMMISSIONER GUESS. I pass, Mr. Chairman.

CHAIRMAN PENDLETON. Mr. Destro.

COMMISSIONER DESTRO. Just a couple of questions. I understand that there is now a lawsuit challenging the child abuse rules. Am I wrong on that?

MR. WATTON. I'm not familiar with it.

DR. LITTLE. I'm not familiar with such a lawsuit.

COMMISSIONER DESTRO. Let me ask, then, with respect to 504: Assuming that Congress were to take up the question of whether 504 should apply to handicapped newborns, what would the position of your organization be with respect to that? Because that's the policy question that I think we are dealing with here. The Supreme Court has yet to rule on whether or not the Second Circuit was right or wrong, and if they don't take the case, I suppose we'll never know what their opinion is. But what would your position be with respect to section 504 if Congress were to take it up?

DR. BOYLE. As far as we are concerned, the Congress has dealt with the issue. We believe that this is the kind of thing which ought to be allowed to proceed and see if it will work.

I think it's important that people have some concept of what it is we are talking about, from the standpoint of the American Medical Association in this whole issue, whether it has to do with 504 or the Child Abuse Act or State actions or State doctrines or any of these things. The policy of the American Medical Association is that the individual patient is what counts. Nothing else counts. So far as the management of the children with severe defects, the same is true. The child is the patient.

Our ethic is that we should try to help the ill and do no harm. And in the same way, this applies here. The opinion of our judicial council, which is our Council on Ethics and Judicial Affairs, says very clearly that what we are concerned about is what is best for the individual and not the avoidance of burden to the family or society or any other consideration. Our ethic is a very clear statement that says that in every circumstance what is the interest of the patient will be our first consideration, and neither race, religion, nor politics nor economics nor anything else will ever take precedence.

That's where we are. We believe that the best interests of infants with severe handicaps can be served by informed physicians providing adequate information to parents to make certain that they come to the best possible judgment in making decisions that they must make, that they have the lawful obligation to make—not just the right to make, but the lawful obligation to make—on behalf of their newborn children.

In the instance in which the parent attempts to make a decision which is clearly not in the best interests of the infant, the physician is the advocate for the patient. The patient is the infant. And the physician's obligation under those circumstances would be to take whatever action is needed to see to it that the appropriate decision is made or that the jurisdiction or the right to make those decisions is removed from the parents and put into some other body—a guardian or other.

We think that the resources that will have been made available under the Child Abuse Act can be of substantial assistance in that there will be an opportunity to see to it that there are other resources to help physicians and parents in coming to an appropriate decision, that there are the resources of infant care review committees in hospitals that will be able to assist in the ethical considerations and the other things that may cause parents some pain in making some decision.

So all of those things can be helpful. But believe me, so far as we are concerned right now, the Congress has addressed the issue. We are doing our best as an association to support the implementation of that law.

COMMISSIONER GUESS. Mr. Chairman.

CHAIRMAN PENDLETON. Yes.

COMMISSIONER GUESS. Mr. Chairman, my point of inquiry would have been—since Dr. Boyle has brought it up, I will raise it—as to whether or not I am understanding you in saying that in your opinion—and I thought I heard this from the outside counsel of the American Hospital Association—that in your perspective, this is not a civil rights issue and as such should not fall within the purview of this Commission.

MR. GERSON. I think that might be somewhat of a misinterpretation. I am not about to suggest to the Civil Rights Commission that the infants with whom you are concerned today do not have rights that can or should be addressed. What I am suggesting to you is that the antidiscrimination provisions of section 504 were not intended to address those particular interests and, indeed, would be inappropriate for them. Because the issue that has been described to you today in guaranteeing that whatever rights infants with birth defects have are maintained is to assure that those who are treating them and the parents of such infants who participate and control to some degree the decisionmaking process have: (1) adequate knowledge of what the increasing state of the medical art is, and (2) can get deployed to them ample medical and other resources to see that that knowledge is effectuated.

I hope that if that was a misconception that clarifies it.

DR. BOYLE. I hope that I did not mislead you, either.

COMMISSIONER DESTRO. Let me just follow up on that statement. What about the case of the Bloomington Baby Doe, where it seemed, at least the way it's been described to us in some of the background materials we've seen and the press reports, that what we are dealing with is not a situation where the advances in medical technology would have made a whole lot of difference. What we are talking about here is fixing an atresia situation and refusal to fix it because the baby had Down's syndrome. And that is probably the pristine handicapped case that is not muddied up with the other kinds of issues, where if it were an otherwise doable operation, it is rejected on the grounds that the child is mentally retarded or has some other handicapping condition. What about the application of 504 in a situation like that?

MR. GERSON. Again, as I said a little earlier, there's a certain surface appeal in saying that there is discrimination here, but if you listened to the testimony of the first panel, as I know you did, and other physicians, you hear from all of them, even physicians who are supposedly poles apart in their views as to treatment, that there exists a continuum of decisionmaking as to impaired children, which even includes, under what everyone described to you, some decisions not to feed under certain circumstances.

What I am saying to you is that it is not a discrimination issue, that you are looking at a universe that is entirely inhabited by impaired children, and that every decision that is made in their regard has to do with that impairment. The whole level of decisionmaking doesn't even come into play unless you're dealing with the issue of impairment. It's not discrimination as to some other group, a nonimpaired group. You're only dealing with impaired children, and the question is how best one ought to deal with them.

CHAIRMAN PENDLETON. Do you have any more questions, Mr. Destro.

COMMISSIONER DESTRO. I'm sure I do, but I'll defer to everyone else. I want to think about that.

CHAIRMAN PENDLETON. Do you have a comment?

DR. LITTLE. I just wanted to comment that it is inappropriate to try to look at an individual case when you don't know all the details, and obviously, what we know about that case is largely through the media and so forth. But I think the issue that you are bringing up is one of access versus practice. And as a nonattorney, a nonfederal bureaucrat, the thing that I have had to think about a great deal recently on the issue of 504 and so forth and all the discussions of the last few years is the access versus practice issue.

It seems to me that what we have worked out, recent legislation in Congress and so forth, is to deal with the issue of access and conflicts that arise between parents or other providers or people who are responsible and so forth. That process is now in place. And that can deal with the conflicts on the practice side of things, which is where I think it's at. I'm not sure as I see it that the practice of medicine was meant to be influenced by 504. Perhaps the access was.

COMMISSIONER DESTRO. I'm not sure that that really addresses the question, but I think I'll await the other questions of the other Commissioners before I come back to it. There's something that leaves me a bit uneasy about the distinction that these are all handicapped children so, therefore, we are not focusing in on the handicapped in order to make decisions about their future. I'm a little troubled with that, but I'll defer to the other Commissioners.

CHAIRMAN PENDLETON. Mr. Abram.

VICE CHAIRMAN ABRAM. Ms. Ahern and gentlemen, the Chairman correctly, I think, identified the primary focus of the hearing, and also he did it on the basis of the notice given as to the purpose of the hearing in the *Federal Register:*

> The primary focus of this hearing is the role the Federal Government should play in ensuring Section 504 rights of handicapped newborns. Preliminary considerations will be given to whether Section 504 affords coverage to newborn infants in hospitals, including whether Congress intended Section 504 to apply to decisions made in hospitals about the treatment of newborns and whether considerations of family privacy or parental rights or medical practice outweighs any Section 504 interests of the newborn.

Let us assume that the Supreme Court takes the case from the Second Circuit and rules as a Second Circuit that 504, the discrimination statute that we are concerned with, does not apply to newborns. Question—and maybe you can just answer yes or no. Would you favor Congress enacting now a statute or an amendment to 504 saying that it does apply to newborns? Dr. Boyle.

DR. BOYLE. Mr. Abram, we believe that the Congress has already spoken to that issue.

VICE CHAIRMAN ABRAM. You would not like any further legislation?

DR. BOYLE. We believe that what has been done is something that needs to be in place, needs to work.

VICE CHAIRMAN ABRAM. Your answer is no, then?

DR. BOYLE. Part of the legislation is that the HHS should evaluate this. I think all the things are in place that are needed.

VICE CHAIRMAN ABRAM. At least at this time the answer would be no?

DR. BOYLE. Yes.

VICE CHAIRMAN ABRAM. Dr. Strain.

DR. STRAIN. I agree the academy would say no.

VICE CHAIRMAN ABRAM. Dr. Little.

DR. LITTLE. No.

VICE CHAIRMAN ABRAM. Mr. Nickels.

MR. NICKELS. No.

VICE CHAIRMAN ABRAM. Ms. Ahern.

MS. AHERN. No.

CHAIRMAN PENDLETON. Could I just follow up on that? It seems to me that we have had a situation exist where we had a Supreme Court decision on Title IX in the Educational Amendments Act of 1972. The Supreme Court ruled how Title IX applied to other statutes, including 504. The legislation before the House of Representatives now is to say or reaffirm what Congress' intent was in 1972. And the idea is to broaden the coverage considerably over where we were in 1972 with respect to Title IX and the like.

It does seem to me that the question asked by Mr. Abram and your answers of no, that one would want to be prepared for any eventuality. It just seems to me that a categorical no doesn't give rise to the question that maybe somebody will. And it's not that you have to answer that question, but I do think that the way things are going now, if 504 is considered to be a response to discrimination—and I read somewhere in these papers here where someone—I forget the organization—thought it only applied to employment decisions as to the handicapped and not to what we are talking about here. But I would suggest to you that the mood on the Hill right now might be to do something different.

MR. GERSON. Mr. Pendleton, the collection of bills that are pending under the rubric of the Civil Rights Restoration Act of 1985 are not intended to increase the substantive sweep of any of the four affected statutes, only to affect the remedies and clarify the issue of program specificity. Nothing would change the scope of coverage of 504 or any decision that 504 did not apply because the infants are not otherwise qualified within the terms that Congress intended.

CHAIRMAN PENDLETON. The majority of the Commission would agree with you, I think, in that respect, but I think one should not find comfort in the fact that if the Supreme Court says it does not apply, that Congress would just abide by that decision. That's the point I'm making.

DR. STRAIN. Mr. Pendleton, just a comment about that. We'll have to cross that bridge when we come to it and we certainly are going to think about what we'll do in that situation.

I guess my feeling about the whole thing is that the academy and other medical groups worked very, very hard on this legislation. We were joined by the right to life groups as well as the disability groups in coming up with some kind of a workable solution to the oversight responsibility of caring for handicapped newborns.

We think we have a workable law, and we think we can make it work at the State level, and our plea would be to give it a chance, and let's see how it works. We, the medical profession, have a good relationship with child abuse agencies in the State. We have worked closely with them in the past. Of course, the reporting many times of child abuse comes from physicians.

So we do have a good working relationship, and I think we can enhance that and develop something that really is workable at the State level if it's just given time. I think it needs to be reviewed in a year or two, but we feel it's a workable law and regulation.

VICE CHAIRMAN ABRAM. I just wondered whether you'd rather have had no law or the regulation.

DR. STRAIN. We don't think the problem is great. As an academy—and I think I speak for most neonatologists and those caring for children—in most instances, parents make the right decision; they make it for the right reason.

VICE CHAIRMAN ABRAM. Does that mean you would rather have had no law?

DR. STRAIN. I would say to begin with we thought we'd rather have had no law. But in the face of all of the discussion that's gone on, we felt it was certainly our obligation to develop something that would work.

VICE CHAIRMAN ABRAM. Does anyone disagree with that?

[No response.]

DR. BOYLE. One additional comment, Mr. Abram, not with respect to whether there should or should not be a law, but out of all of this, we believe there has been substantial benefit in that the dissemination of information on this whole issue has been such that it has simply accelerated the increasing sensitivity that people have had to a problem.

The policy of our association at just about every level that you can think of speaks to doing everything that we can to assist the handicapped and the disabled and to protect their rights. We have a report going to our House of Delegates that speaks to admitting the disabled to medical schools and assisting them in getting past some of the admissions committees' criteria that discriminate against people with certain handicaps.

We see individuals who today are able to do so many things, that have lives that are productive and successful, people who are paralyzed from the neck down running their own businesses—all of these things. So the policy of our association is to see to it that discrimination against the handicapped and the disabled is eliminated in every way, not just in employment but everywhere else.

CHAIRMAN PENDLETON. Mr. Bunzel.

COMMISSIONER BUNZEL. I have no questions.

CHAIRMAN PENDLETON. Mrs. Buckley.

COMMISSIONER BUCKLEY. I have no questions.

CHAIRMAN PENDLETON. Mr. Destro, I think, has some questions.

COMMISSIONER DESTRO. During Dr. Koop's testimony and Dr. McLone's testimony, I think they both agreed—and I hope if I'm mischaracterizing it you'll correct me—I believe it was Dr. Koop who said that if you had an infant with Down's syndrome and atresia, and you had an infant who didn't have Down's syndrome and had atresia—if you had either of those situations by themselves, Down's syndrome alone or atresia alone, there would really be no question. But if you had them together is where the questions arose.

And that's why I think I had a problem with the comment that these kids are all in a class by themselves. Would you put the individual with Down's syndrome and esophageal or duodenal atresia in the same classification as an infant without Down's that has the same kind of a digestive problem?

MR. GERSON. Are you asking me that question?

COMMISSIONER DESTRO. Yes. You seemed to put them all in the same category and saying there's no discrimination.

MR. GERSON. I'm not saying I put them all in the same category. I'm saying that they are in the same descriptive universe that the physicians who are the experts in the area are describing. You are comparing a child with one or more handicaps with another child that has that or different handicaps, and you're not dealing with the classic discrimination question of comparing someone with a set of characteristics against someone else who has none of the characteristics.

COMMISSIONER DESTRO. Well, aren't you comparing someone who has a physical disability with someone who has a mental disability and possibly treating them differently?

MR. GERSON. You're comparing people with a range of disabilities to each other, and you are describing a universe where medical decisionmaking has to come up with solutions to deal with them, where the discrimination law mode of analysis gets you nowhere.

COMMISSIONER DESTRO. Would any of the other panelists like to comment on this? Do all of you feel that there is no discrimination at all in any of this or no possibility of discrimination? Would you agree with that?

DR. STRAIN. Let me just say we have been focusing on the question of Down's syndrome, spina bifida, and various malformations. And I should say that there is really a small percentage that fall into this category of children where you have to make a decision about stopping life support. The vast majority in every survey that has been taken have been premature babies, and the complications of prematurity, hemorrhage, lung problems, and so forth. So we're dealing with a relatively small number of people that fall in the Down's syndrome and spina bifida category.

I think, in general, the medical profession deals with those very well. I think that most pediatricians would disagree with the approach taken that was with the Bloomington baby. We don't know all the details, so we can't make a judgment about that. But in general, I think that all of the pediatric literature favors supporting corrective surgery for the Down's syndrome, whether it was esophageal atresia or duodenal atresia.

In the case of spina bifida, I think Dr. McLone's comments about how they're treated—this would be the way most babies with spina bifida are treated. I think they're really going to be a nonproblem very soon. I think the big problem is in the area of prematurity and the complications that arise.

CHAIRMAN PENDLETON. Dr. Boyle.

DR. BOYLE. I want to respond to that also briefly, Mr. Destro. You are dealing with the easy problems in the questions you ask. The problem that you have is the infant with multiple defects, who has had multiple injuries, and now the question is: Is your intervention going to cause that infant to be harmed? Are you going to create a state in which an infant will be forced to live in pain, spasticity, under heavy sedation and narcotics, and all kinds of things, comparable to forcing a patient with a terminal cancer to go on a life-support system to go on living in pain. Those are the tough decisions. The ones that you were talking about earlier are really the easy things to resolve.

COMMISSIONER DESTRO. The reason I asked the question—and perhaps you'd like to address it—is that what I see out there is a decision of the courts of Indiana, in what you'd consider to be the easy case, which takes the position that it's permissible as a matter of law to make a decision based on a handicap not to feed a child. To me that sounds like a case of discrimination, pure and simple.

DR. BOYLE. I cannot comment about that case. I don't know anything about the details of it. I did not see the child. I have not seen the record. I haven't listened to the testimony. I cannot comment on that case.

I can simply tell you that so far as we are concerned, sure, there is an opportunity for discrimination to occur anytime, anyplace, with anyone. But the systems that are in place are ones that will prevent that from happening or at least will see to it that it's corrected if it does.

CHAIRMAN PENDLETON. Ms. Ahern.

MS. AHERN. I'd just like to put that in a slightly different context of 3 years ago, and let's talk a little bit about where we are now and why AHA has done what it's done.

I think the whole universe of discussing ethical problems is very different than it was 5 years ago or whatever. Mr. Abram and the President's Commission have done an enormous amount to bring all the issues to society's attention.

I think, that as far as what the hospitals have seen—although we are conducting a new study because of frequent changes—there are a lot of discussions of either specific ethics committees or more ethics grand rounds, or all kinds of good things where the issues are coming to everyone's attention more and more.

I think it's been our perspective that our role is to help our membership provide the best context within which good decisionmaking can take place and try to give as much information about the kinds of committees, etc., and we have tried to take positions, as we have done in this lawsuit, that would preclude the kind of disruption to provision of care. Therefore, we did also take the position that the clarification of the child neglect and the clarification of the different processes, in the world as it is now, is going to be the right way to achieve what we want to achieve.

CHAIRMAN PENDLETON. Mr. Guess.

COMMISSIONER GUESS. My questions were going to be specifically addressed to Ms. Ahern as it relates to the role of the American Hospital Association in its case against Secretary Heckler and as they relate to section 504. I think she's answered them, but I want to make sure I understand. You said it was the position of the American Hospital Association to actively pursue this regulation in court?

MS. AHERN. Yes.

COMMISSIONER GUESS. And the reason for doing so was to protect the interests of the hospitals and their decisions as to how the resources of the American people who are using those hospitals could best be applied?

MS. AHERN. As far as the section 504 lawsuit is concerned, as we were discussing earlier, you could see we got into some very technical legal grounds on that particular application. But as far as the AHA's position in this issue, as has been all along, it has been trying to provide the kind of context within the hospital so that this decisionmaking can take place. It has been taking place, but I'm just saying as we all progress in medical science, etc.

Now, I'm not sure I understand your question.

COMMISSIONER GUESS. One of the things we are dealing with is the appropriate role of the Federal Government in managing its resources, and I think the only way we can get into the hospital falling prey to this regulation is because of the use of Federal funds.

MR. GERSON. There is some question about that and what the focus is. But let me say that the AHA did two things. The AHA has never said that there is no Federal role. The AHA took issue, as did the AMA and others, with the 504-based regulations because the AHA felt: (1) they were beyond the bounds of 504, that they didn't apply; and (2) because they were compelled to do so by members such as the hospital in Rochester, which is a party to the suit which is based on very disruptive intervention. At the same time, however, AHA was an active participant in the development of the Child Abuse Amendments and the work that surrounded their discussion and promulgation. So AHA has played an active role in defining what it hopes will be determined to be the appropriate Federal role.

COMMISSIONER GUESS. It would appear to me—I think the Vice Chairman has already asked the question as to whether or not there should be Federal legislation in the presence of the court decision to the contrary—and each of the organizations has indicated that it would be the position of their organizations that there should not be.

CHAIRMAN PENDLETON. I think you've probably answered some of what I wanted to ask. Would it be accurate to say that you feel the Federal Government should get out of the way—I'm sorry.

MR. RUBIN. Mr. Guess, to follow up on the context of 504, whether the Congress should deal with it, I think it is important to go back to 1982—

COMMISSIONER GUESS. I wish I could go back to 1982.

[Laughter.]

MR. RUBIN. I understand. Let me take you back there figuratively if not actually. The administration and the Nation were focusing on these issues. The administration, not to put words in their mouth, was looking for a tool in which to focus their concerns. At that time there was no Child Abuse Amendments of 1984; there was no focus. There was no, albeit, the hook by which the Federal Government can get involved.

That situation has now been obviated in that Congress has clearly laid out an appropriate role for the Federal Government in information dissemination in improving the decisionmaking process, and to providing accountability for the decisions being made through the States.

The situations are no longer the same. There is a new factor in there, and that is the rehabilitation act amendments, that were not in place in 1982 when 504 was selected by the administration as the focus of its authority.

COMMISSIONER GUESS. So what then becomes your problem with 504, other than that I understand it's disruptive.

CHAIRMAN PENDLETON. You don't like it. I'm with Mr. Guess on this. What is the trouble with 504, or what do you want us to do, as organizations?

MR. RUBIN. We have no problem with section 504 as it was being interpreted prior to 1982.

COMMISSIONER GUESS. Your problem, then, is with interpretation.

MR. RUBIN. Our problem is the way the administration created a regulatory program addressing specific operations of hospitals, outlining in the regulatory proposals specific medical conditions they intended to deal with and sending in enforcement teams to second-guess medical decisionmaking.

COMMISSIONER GUESS. So as long as you have a 504 that doesn't do anything, it's all right.

[Laughter.]

CHAIRMAN PENDLETON. As long as you have a 504 that does not intrude the way you say the administration did in 1982, then 504 is okay.

MR. RUBIN. I think the Chairman has articulated our view correctly. That is getting into medical decisionmaking inappropriately.

CHAIRMAN PENDLETON. So in terms of what Mr. Abram read from our opening statement, we can safely say that this panel does not think 504 applies in this case—the case of newborn handicapped discrimination, the kind of thing we were talking about earlier—and wishes it would go away.

What you are really saying as a panel, collectively and individually, I would imagine, is that 504 does not apply and should not apply, and you feel as though it should not apply in cases of treatment of the handicapped newborns.

MR. NICKELS. I'd like to clarify that a little bit. I don't think we're saying it should go away. I think we're saying that Congress—

CHAIRMAN PENDLETON. In terms of handicapped newborns.

MR. NICKELS. Congress took a very close look at this, and 504 was on the table just as everything else was. Congress—and we agree with its decision—decided that there is a better way to do business. The better way to do business is the Child Abuse Amendments of 1984. It will encourage States to do certain things; it will facilitate institutional review committees in hospitals. That issue, I think, has been debated quite a bit, and we agree that is a better route to get to what might be the same place, which is protection of handicapped newborns.

CHAIRMAN PENDLETON. Then 504 should not apply in the case of handicapped newborns, which is the point I'm trying to make. In light of this hearing that we are having today, I'm trying to focus in the light of why we are having a hearing on whether 504 should apply. Am I right about saying that it does not apply, as you think about it, and there are other routes?

DR. BOYLE. Mr. Chairman, everyone is aware of the fact that this issue was decided by two courts, that it did not apply.

Now, so far as we are concerned, the interpretation of how you apply section 504 in trying to protect the rights of handicapped or disabled children was such that it interposed itself directly into the day-to-day decisionmaking process in the management of severely ill children, which we believe is an inappropriate mechanism. We believe that the Congress has developed the mechanism.

Now, if someone were to sit down with us and say, "Okay, let us figure out some other way," we certainly would be glad to listen to it. But at least at the moment, if asked the question, we'd say, "Please don't give us another mechanism. We are trying to make one work right now."

CHAIRMAN PENDLETON. On the other hand, if Congress had meant 504 to exclude such newborns, they could have done so when they passed the act of 1984; is that a correct assumption?

MR. GERSON. Let me say this. There was no need for Congress to designate an exclusion when the courts had already decided what was not within the compass of 504.

504—and the Supreme Court reiterated this only a few weeks ago—applies to programs of independent living and vocational training, etc. That's what Congress had on its mind. There was no need for Congress to make an exclusion. What Congress could have done, what it knew full well about, was that the 504-based regulations had been declared unlawful, and that in a sense by the Second Circuit; Congress had been invited to act if it wanted to do so, and it rejected that invitation.

CHAIRMAN PENDLETON. Mr. Destro.

COMMISSIONER DESTRO. That was really my initial question; assuming all of that, assuming the Second Circuit says 504 doesn't apply to handicapped newborns—for whatever reason they said that—what I hear is that even if the question were on the table before Congress, would you prefer to have a 504 way of dealing with this or a Child Abuse Amendments way of dealing with it? The panel is saying they'd rather have the Child Abuse Act Amendments way of dealing with it. Is that a fair characterization?

MR. NICKELS. Yes. And what we are also saying is that Congress had that choice and made the Child Abuse Amendments last year.

COMMISSIONER DESTRO. Now, maybe you could help me. What is the difference between the intrusion level in a child abuse case which looks into the medical decisionmaking from a child abuse perspective and one which looks at it from a 504 perspective? Because I see the intrusion as being precisely the same. It may come from Children's Services instead of the Baby Doe squad, but there is certainly intrusion going on.

DR. LITTLE. Let me try to get at that as a practicing neonatologist who has been through this a little bit.

In the first place, the comment has been made that everybody is trying to do the right thing. The problem that comes up is when you have complex situations of which there is a difference of opinion and you need to have some type of conflict resolution.

As Dr. Koop said earlier, I believe, really the issue was identified, enjoined, I guess, long before the folderol of the initial 504 application. I think we began to see in this country the need to broaden out the decisionmaking process a little bit in certain select instances, and certainly, the Presidential Commission report when it came out concurrently was further evidence that this process was going on in the society at that point in time.

I think in the last couple of years that organizations that are responsible organizations—I sit as a volunteer member of the academy here today, but I've been part of this task force and institutional review committees—have recognized that there is an important issue here; the neonatal part of this is only a point of a huge issue generically across the board in all age groups, and that we needed to move along, as a professional society and institutions and so forth, and we made real progress in a couple of years.

I happen on an individual level to believe—and on an institutional level we have a review committee—that these committees are, number one, rarely employed but, number two, effective, and they do help out with the process.

So what you have, then, is a process which is identified and which is being tested, which has been a help, which employs local experience and competency, local people, broadened out in that sphere, but does not involve people coming in without experience in a local scene, in an intrusive manner, and whose competency is not tested and not known. In addition to that, if that process does not work, you have an identified thing on a regional level and up to the State, and so forth and so on.

I personally feel that that process seems to be working. It's been worked out over a long period of time—at least in my mind, and it had its generation before that. And I think that's better than the 504 route.

And to answer your question specifically, we have something that started a long time ago, has moved along fairly rapidly over the last couple of years, it seems to be working, and that child abuse institutional review committee, awareness of issues, education, responsibility on a local level sort of thing is a better way of doing it than from the top down.

COMMISSIONER DESTRO. In other words, the problem you have with the 504 route is that you don't want bureaucrats from the Federal level coming down and intruding into the process, but if the local child abuse people think that it's worth intruding into, you wouldn't have a problem with that?

DR. LITTLE. I'm not an anti-Federal bureaucrat person. If somebody is going to murder me, I sure as hell hope the FBI steps in if the sheriff isn't around.

COMMISSIONER GUESS. I think the FBI steps in only after you've been murdered.

[Laughter.]

CHAIRMAN PENDLETON. Dr. Strain.

DR. STRAIN. I think child abuse people are more familiar with child abuse problems and medical neglect problems than the Federal Government would be, and I think that's one point to be made. And in general, I think the closer the decisionmaking process is to the patient, the more likely it is to be the correct decision. There are so many differences in babies you can't make a general statement, or when you can make a general statement—certainly, a procedure or protocol can be established by a committee, but there are these gray areas where decisions are very, very tough to make. And it seems to me the closer that decision is to the baby and patient itself, the more likely it is to be a good decision.

That's why the academy supported the institutional review committees. Those are committees that hopefully would represent society's views. That's really what we're talking about. It serves really two functions: representing society's views, making absolutely sure that the care is appropriate for that particular baby, but certainly, we hope that the committee brings to the medical decisions the ethics that are prevalent in the community, and they may change from time to time. But at least it can serve as a sounding board for society as to what we are doing and whether we are on the right track in caring for babies.

I can conceive of the philosophy, if this were an HHS program, for instance 504, that the philosophy might change within the Department, depending on the administration. So I think that there's a better chance of having good decisionmaking if you can have local people helping with the decision, getting society's input in those very tough decisions.

CHAIRMAN PENDLETON. Thank you.

MS. AHERN. May I say something?

CHAIRMAN PENDLETON. Ms. Ahern.

MS. AHERN. May I just say, from the internal hospital's point of view, one of the reasons AHA participated in the Child Abuse Amendments—after filing suit, of course, on 504—was the fact there was a possibility of dealing with these difficult decisions by building upon existing collaborative relationships within the hospital between the social workers and the child protective agency people. All hospitals have some sort of mechanism to deal with child neglect and abuse. So it was to facilitate the smoothest kind of decisionmaking that could occur.

CHAIRMAN PENDLETON. Thank you.

Mr. Bunzel.

COMMISSIONER BUNZEL. My question may very well be answered quite easily and very quickly. I want to be sure I understand, following up on something Mr. Destro was asking: I understand that all of you prefer the Child Abuse Amendments to 504 as a method of proceeding, for a number of reasons that you have very carefully elaborated upon. So your preference here is very clear.

I guess what I want to ask is whether or not you felt or feel that if the choice were between 504, the Child Abuse Amendments of 1984, or neither, would you still say, and did you say at the time, that the Child Abuse Amendments of 1984 were an urgent necessity? Did you advocate it, push it? Did you want it? Or was this a defensive measure on your part to avoid something worse?

In other words, was your position in favor of the Child Abuse Amendments of 1984 one in which you felt, "We need this legislation. We need these amendments now because we have a critical problem and, Congress, we urge you to pass it. It's absolutely necessary." Or was your position at that time not that strong or not along those lines? Can you help me out?

DR. BOYLE. I'll try, Mr. Bunzel.

First of all, the Secretary of Health and Human Services, in her statement on the 1984 Child Abuse regulations, made it very clear, in her words, that only a very small fraction of births involve any serious question of survival, and only a fraction of this tiny fraction would even involve a potential allegation of medical neglect under State law.

It is our opinion that at the present time we have in place, to protect the infant with serious handicap or disability, the physician, whom we presume, except in an extraordinarily minuscule set of instances, is conscientiously serving as the advocate for that newborn infant. The parents, in all but a tiny fraction of instances, are going to have love and compassion and concern for their newborn infant. We have a hospital medical staff structure which is a very formal structure, in which the performance of individual physicians is reviewed on a regular basis to make certain that they are serving the best interests of their patients, and should some physician have deviant behavior that would tend them to impose their biases on parents of newborns who have serious problems, it would become evident and be corrected.

In the States, we have child abuse statutes and child abuse regulations. We have State courts. We have in hospitals now with increasing frequency patient care review committees, in this instance infant care review committees, that involve individuals other than physicians, although up until just a few years ago there was not a committee on ethics in almost any hospital in the country.

You may or may not know that one of my messages, one of my causes during this year that I have been president of the American Medical Association, in traveling all over the country, has been to make certain that we have a dedication as a profession to a medical ethic. And that ethic is the patient comes first, and all the rest of these pressures, 504 or anything else, we shouldn't let that get in the way.

But today there are increasingly committees on professional ethics in hospitals as well as in medical schools. There are increasingly medical ethicists employed by hospitals to try to assist physicians and families and everyone else in facing these ethical concerns.

So the answer to your question is no, we did not see this as a pressing need. If there is one instance of some abuse, it's too many. But we did not see that there was any earthshaking reason for the Federal Government to get involved in the first place. We certainly had the experience of a very heavy hand of a bureaucracy coming down with a meat cleaver, rather than attempting to try to fine tune the system to see to it that some people didn't fall through the cracks, creating incredible disruption, and in their own report where they investigated some 45 to 65 or however many cases, they found not one single instance of medical neglect or child abuse, but all of a sudden establishing signs in nurseries, causing investigators to come in and disrupt the neonatal intensive care unit, causing the patients in the hospital to be upset, causing a big media event. All of these things are our experience of people trying to utilize a statute which we think was not intended to get into the day-to-day decisionmaking in trying to manage severely handicapped or severely impaired infants.

So, no, we would rather not have it come back again. We certainly did participate as an association in the discussions right up until the very last. And in constructing the amendments to the Child Abuse Act of 1984, we are committed to try and make it work. We have very recently sent copies of the final regulations to all of our State medical associations. I have sent letters urging them to become actively involved in seeing to it that the law is implemented in the best possible fashion in their States.

COMMISSIONER BUNZEL. I appreciate that. Is there anyone on the panel who did in point of fact strenuously advocate the Child Abuse Amendments of a year or so ago because it was in your opinion an absolute urgent necessity; you needed it, you wanted it, and you felt it was imperative to have it passed, and that's why you appeared before Congress?

DR. STRAIN. I should say this about the Academy of Pediatrics. I think we became aware, as the discussion went on, that there was a growing need to have something in place. We weren't terribly enthusiastic about this to begin with, frankly. But when it became apparent that there was a good deal of concern—and also as technology advanced—we could see the need for some kind of review process. We felt it was better to get in and make our suggestions to try to develop a law that would be workable. And I think we have that. And we certainly far prefer what has come out of the Child Abuse Amendment legislation to 504. 504 did not work.

COMMISSIONER BUNZEL. I understand that.

DR. STRAIN. It depended strictly on reporting. There was certainly no reason that one would think that through 504 every case would be covered in the United States, because it was strictly based on somebody's perception.

COMMISSIONER BUNZEL. I understand that. I am reminded of the fact that one of the Senators from my State, Senator Cranston, was a strong advocate of these Child Abuse Amendments, and I'm wondering if any of you here were lobbying his office and saying, "You've got to get these passed. We urge you to pass these amendments. It is absolutely necessary. Our position is that we want them, and now is the time"—rather than simply going along and setting up defensive measures. Did you advocate it that strongly, and was it really necessary?

DR. STRAIN. We worked very hard with Senator Cranston on this legislation. I would say we paralleled his activity. If he was that concerned about it at the time it was passed, I would say that he would certainly have our support and full cooperation.

MR. NICKELS. An important fact to remember is that of the first 64 cases investigated by HHS under the old Baby Doe regulations, they found no abuses. So our position was that there is not this horrible thing going on out in the real world and that some of those concerns were unfounded.

However, and I'd like to break the Child Abuse Amendments into two parts because I think that's important, the guidance review committees—

we, ANA, have advocated review committees, and I think some of the other organizations have, for several years now. So as far as an advocacy role on that concept, the answer is yes.

As far as the regulations regarding reporting requirements, it seemed to us we perceived very clearly that there was a mood in the Congress that there should be some process by which reporting could occur. And we condoned that. We agreed that there's nothing wrong with some process. We got involved because we wanted to have a say in how that process worked to make sure that it was not as disruptive and harmful as the original process was. We had no problem with the concept of having a reporting mechanism within hospitals to State child protective services systems.

MR. WATTON. Let me answer your question, if I may, as best I can—and it's going to be a little indirect but I think you'll understand our position.

All four organizations at this table and several other medically oriented organizations participated about 8 hours a day for about a 6-week period of time with Senator Cranston's office and with the offices of five other Senators. Senator Cranston took the lead on this, as you correctly state.

We worked out a bill together with most of the right to life groups and, I believe it's fair to say, all of the disability rights groups. Many of them are here and they will correct me if I'm wrong, certainly. Unquestionably the groups that ultimately supported the legislation, which is three of the four of us at the table, could have resisted that legislation to the last, and if we had it would not have passed during the last Congress.

COMMISSIONER BUNZEL. I wanted to get this on the record because I think this is actually quite important and very interesting.

CHAIRMAN PENDLETON. Thank you, Mr. Bunzel.

If there are no other questions, we thank you for your participation. Dr. Boyle?

DR. BOYLE. Mr. Chairman, just one point briefly that I forgot to mention at the outset. That is, the Association of American Medical Colleges asked me to inform you that they support our views on this issue. They were not able to be here to testify.

CHAIRMAN PENDLETON. That's on the record.

Thank you very much.

[Recess.]

CHAIRMAN PENDLETON. We will reconvene and reassemble, please.

Welcome, everyone. I have to swear you as witnesses.

[The witnesses were sworn.]

## TESTIMONY OF BUD DANIELS, DONNA AND FRED HINTZE, PATRICIA AND RAY MILLER, AND LORRAINE AND GREG WEIGLE

Ms. Robinson. I'd like to start by having the witnesses all state your names for the record. Why don't we start at your end. And those of you who have children, please introduce your children as well.

Mr. Hintze. Fred Hintze. This is Julie and this is Eric.

Mrs. Hintze. I'm Donna Hintze.

Mr. Daniels. Bud Daniels.

Mrs. Weigle. Lorraine Weigle, and my daughter Diane.

Mr. Weigle. I'm Greg Weigle.

Mrs. Miller. I'm Patricia Miller, and this is my daughter Shawn Miller and my daughter Shermika.

Mr. Miller. I am Raymond Miller.

Ms. Robinson. Mr. Daniels, I'd like to start my questioning with you. You and your wife had a girl who was born with spina bifida, and you came to a decision not to have her treated.

Can you tell us how you reached that decision, what factors you considered, and so on?

Mr. Daniels. We made our decision based on medical advice from sources we considered most competent. The very evening our daughter was born, we consulted with a pediatrician and a neurosurgeon, and they had split opinions on what course of action to follow. In further discussions with the obstetrician, we believed the advice of our neurosurgeon that a course of nontreatment in this particular circumstance probably made better sense. Our daughter was moved from the hospital where she was born to a children's hospital.

Subsequent to that, we talked to a lot of different people and got many, many conflicting points of view and interpretations as to the condition of our daughter to the point where eventually we heard testimony from doctors that the doctors are supposed to be a court of last resort, that if they don't believe in the course of treatment prescribed for a child, they would proceed under legal procedures to have medical treatment. That did happen in our case. As a matter of fact, it was a hospital corporation that took us to court to have a spinal closure and some other procedures that were necessary done.

Ms. Robinson. What did you understand your daughter's life would be like if you did treat her and, again, if you did not treat her?

Mr. Daniels. There were a lot of conflicting opinions, again from many different sources. We must have consulted with about 15 different doctors. I would say that we believed the difference in her life with or without treatment was minimal.

MS. ROBINSON. Did they describe a picture of what her life would be like to you?

MR. DANIELS. Yes. With no action taken at all, there would be a potential of having the child, with all her disabilities, coming home and living with us and all the difficulties that go along with that. The alternative would be the full course of medical procedure with operation after operation, with a projected life span of possibly 12 years.

MS. ROBINSON. That was if she was treated?

MR. DANIELS. That's correct.

MS. ROBINSON. Did they give you any indication of what disabilities they expected she would have even after the surgery?

MR. DANIELS. Severe mental retardation, incontinence, all of the nerve functions from—I don't remember which one of the nerve [inaudible] it was—from about the stomach level on down would not be functioning.

MS. ROBINSON. You alluded to the fact that you were taken to court, and treatment was subsequently ordered for her. After that happened, what alternatives did you examine in terms of what you should do with her?

MR. DANIELS. At that point we had to sit down and assess what the best course of treatment for our daughter would be. It was painful to admit that there were other people who were better capable of handling the situation than we were. We looked into institutionalization for our daughter and couldn't find any place that could handle her disabilities and willing to accept her. We quickly discarded the alternative of letting her become a ward of the court and State. The alternative we found best, finally was to allow her to be adopted by people whom we felt were very competent to handle the situation.

MS. ROBINSON. Thank you, Mr. Daniels.

I'd like to move on now to Mr. and Mrs. Miller.

Your situation was similar to Mr. Daniels, at least in the beginning, in that you had a daughter who was born with spina bifida. Can you tell us what you were told and how you first came to know that she had spina bifida, and how you reached your decision not to have her treated?

MR. MILLER. I was approached first by the doctors and told that our baby did have a problem. At first, I was in a way told that it wasn't as serious as it really was. They immediately said that they couldn't handle the problem at the local medical center where she was born, and that she would have to be transferred to the University of Florida Medical Center.

The doctor tried to explain Shermika's condition to me so that I could understand it. In essence, she had spina bifida, she was born with an opening in her back. He asked for my permission to have her transferred to the medical center. I agreed and went with her.

There she was evaluated by the neurosurgeons. Basically what it came down to is I had to make the decision as to whether or not to have the surgery done. He went over, more or less, the pluses and minuses of her condition and explained the problems with spina bifida. I decided at the time not to go with the surgery.

I had talked to my wife by phone and explained the information that I had received from the neurosurgeons there. She basically left the decision up to me because she was really upset after just having the delivery and so forth. She was rather in favor of my decision, but at the same time had mixed feelings about it. But maybe she can tell you more or less how she felt at that time.

MS. ROBINSON. Do you remember what picture they painted for you of what Shermika's disabilities would be like if you treated her and if you didn't treat her?

MR. MILLER. Well, they explained to us at the time what her condition would be after surgery. They explained all the possibilities as to retardation, as to the paralysis she would have, and the other problems. They more or less explained all the problems that would be associated with spina bifida.

With the extent of the opening in her back, it had a bearing on how much effect it would have on her, which I didn't really quite understand at the time, but later, after speaking with other doctors, I got a better understanding of it.

MS. ROBINSON. Mrs. Miller, what are the disabilities that Shermika has now and are they different from what you had expected when the doctors first spoke with you?

MRS. MILLER. Well, in the beginning I didn't speak with the doctors at the University of Florida Medical Center, so I really didn't speak with the surgeon—she was born on Tuesday—until Friday after she was delivered. And that was a local pediatrician, after they transferred her back to Daytona when my husband made the decision not to have the surgery.

Well, I didn't know what spina bifida really was. Someone locally, who had a son with spina bifida, called me while I was in the hospital. I did not have any idea that that is what my child was born with. She said that someone told her that I had a baby born with spina bifida. She wanted to come and talk to me because she had a son with spina bifida.

She did come and talk to me, but I still didn't have a clear picture because I was so drugged up—my doctor had me so drugged up at the time because I was upset. Later she said if I needed to talk to her to just call her, but I never did because so much happened in between.

Approximately a week after I was released from the hospital, I received a call, 5 o'clock in the afternoon, from the attorney at the HMO [health maintenance organization] that I belonged to at the time, saying that there was going to be a hearing at 7 o'clock—a hearing on my child, about the decision we made.

At the hearing—I was nervous and upset and I didn't know what was going on. When we arrived at the hearing, this is when I heard the pediatrician saying my child was paralyzed from the waist down; she had no bowel or bladder control; she was possibly brain damaged. So, of course, then I didn't know what to think, what sort of life she'd have.

Ms. ROBINSON. What, in fact, are her disabilities now? She's 2 years old now?

MRS. MILLER. Yes. She has some paralysis in her lower extremities—not too good on the bowel and bladder control yet. There is some hydrocephalus, but there is no brain damage. Right now Shermika is learning how to walk.

Ms. ROBINSON. So her paralysis is very low, in the lower extremities?

MRS. MILLER. Yes.

Ms. ROBINSON. Not from the waist down?

MRS. MILLER. No.

Ms. ROBINSON. You alluded to the fact that treatment was ordered by the court. How do you feel now that she has been treated and that you have her with you?

MRS. MILLER. Well, I'm happy that she was treated. I just don't like the way it was done.

Ms. ROBINSON. Thank you. We'll have more questions for you later. I'd like now to move to the Weigles, one Weigle—is there another Weigle?

MR. WEIGLE. There's another Weigle walking right probably outside the door. I can thank my daughter for the opportunity of getting a word in edgewise.

Ms. ROBINSON. I'll give you a chance right here at the beginning.

You have two sons who have Down's syndrome, one of whom is a natural son and the other whom you adopted. Could you tell us what you were told about your natural son when he was first born, what you were told about what his disability would be like, and contrast that with what he is actually like now that he's 7 or 8?

MR. WEIGLE. Five. First of all, just for the record, our natural son is 5½ years old, and we did not have our now foster son at the time he was born.

Our knowledge on Down's syndrome was minimal at best.

Christopher was born at Fairfax Hospital locally. I make the point primarily to show he was not born out in Podunk, Iowa, someplace. The head of neonatology at Fairfax Hospital at the time informed me approximately an hour and a half after his birth that Christopher had Down's syndrome, and essentially what that meant is that he would perhaps learn to function throughout his life at an age level of somewhere between 1 and 3 and it would plateau out. He might perhaps, if we were lucky, learn to recognize us. He might or might not ever learn how to smile. However, he did appear to be in reasonably good physical condition, and would I like to tell my wife or would I rather have him do it. Not a terribly terrific picture for a first-time parent, and from my perspective now, having learned a little about Down's syndrome, significantly contrary to what the teaching was at the time of his birth.

With regard to what he's doing right now, he's in a Montessori school locally with his age peers. He is learning how to read. He knows all the letters of the alphabet. He knows how to count easily to 10. He knows how to bug us to death with no problem and watches just until we are mad enough to start to yell at him, and then be sweet.

He is nowhere near the state of, in a sense, nonfunctioning mentally that was painted as a picture at the time. He is very definitely a person who responds to people. He very definitely has an intellect that can be developed to some degree. Whatever that degree is is essentially based on his own abilities, as opposed to a cap that is put on him by this label of Down's syndrome, which is significantly different than in that first little lecture when he was an hour and a half old.

Ms. ROBINSON. Your experiences with your adopted son, how did his circumstances when you adopted him at first differ from how his development was even as little as a year later?

MR. WEIGLE. Well, Nicholas had been institutionalized at approximately age 2 by parents who were divorcing and relatively unable to cope with the situation. To put that in perspective, that was roughly 1971 when that would have happened.

He spent 5 years in a large institution in Lynchburg, Virginia, the basic four walls with a bench and a drain in the middle of the floor as they described it to me. Basically, not a pretty place. He was transferred when he was about 7 years old to the Northern Virginia Training Center, which is the same kind of residential facility, but not at all the same kind of massive institution. And he spent approximately 5 years there until age 12, when Fairfax County ended up suing the parent, who was then the guardian of the child after the divorce situation, to effect a release from an institution. The parent did not wish for this to happen. The county indicated that the person's needs and abilities seemed to exceed what the institution was able to provide.

Nicky came to us as a 12-year-old who could not read or write in any way, shape, or form, with that never having been addressed in his schooling that he was provided in these institutions. And within a year, indeed in less than a year, he knew his alphabet; he was learning to read; he could count.

He had his self-help skills, as they call them, was able to function as an individual when he came to us.

His social skills—you know, when you're raised in a setting where the reinforcement is by being simply the cutest kid among people who are seriously nonfunctional, you learn things about how to get attention, to get recognition, and he still has behaviors that even 4 years later are not gone, to where if he needs something, he will not necessarily ask you for it; he will revert to behaviors and activities that were typical of when he was in that residential institution—a very different kind of situation than we see even with our Christopher right now.

Ms. ROBINSON. What does your experience with both Chris and Nicky tell you about the whole quality of life analysis as it might be applied to Down's kids in the treatment area?

MR. WEIGLE. I consider the quality of life concept to be a little bit presumptious for an individual in an isolated setting to review unless you're particularly familiar with individuals of the condition that you're talking about. For our neonatologist to discuss the potential of Christopher's quality of life, I would consider wholly inappropriate, (a) because he was uninformed as to what the literal potential was and (b) because he is sitting in a position where he is looking at parents and trying to decide, "Can he handle this? Can he handle that?" And I don't consider that to be the initial function of an individual who is giving a diagnosis. And I don't mean to be presumptious.

To me, the initial function is to give good, accurate information. If you can't do that, you ought to get out of your business and do something else. That should be the first thing to address.

Beyond that, if the family or the individuals need counseling or need help on how to deal with the fact that their child may, indeed, not grow up to be President of the United States, that quality of life question then gets into a lot of nuances about what you are able to accept with regard to potential.

And Christopher probably will not grow up to be President. He might be chief instigator someplace. That's okay. I'm really comfortable with that. I accept the fact that there are parents who will not be able to handle that comfortably, that cannot view a seriously different perspective for their child in the same sense that they did when they thought their child was going to be normal. But that should not be, in my opinion, the perspective of that initial diagnosis. That should be a factual thing. And then you evolve from there with a lot of different input. You get input from parents who have gone through this, from social workers and nurses who are somewhat more on a person-to-person level with the parents. And it's a totally different thing than what the doctors, quote-unquote, are able to do.

Ms. ROBINSON. Mrs. Weigle, I got you back in here despite the fact that your baby wants your attention maybe more than we do, to just ask you a quick question: Do you find that raising kids with Down's syndrome is more difficult than raising other kids and requires a level of bravery or courage.

MRS. WEIGLE. That's a question that makes me very, very angry. Whenever you read in the newspapers or magazines about parents of handicapped children, you always hear these super stories. Erma Bombeck writes about how God chooses the special parent. No, it doesn't take a superhuman parent. It takes a parent that is caring, that is willing to learn about that disability, and going from there.

I don't see us putting any more effort into our children than I see my sister putting into her normal children. She still has to worry about their schooling, their riding their bikes, where they're going to go, what they're going to do, and with how they are going to be when they grow up. She doesn't seem to have any different feelings about what she wants for her children than I do about mine, which is just to grow up and lead happy productive lives.

**Ms. Robinson.** Thank you, Weigles, all three of you.

Now to move down to the many Hintzes, Mrs. Hintze, could you tell us what you were told about what Eric's disabilities would be and what, in fact, his disabilities are.

**Mrs. Hintze.** When Eric was born, we had a very supportive pediatrician that sent him immediately about 50 miles from us, and he was treated when he was 24 hours old and then shunted the following day. A neurosurgeon did tell us that he would probably be extensively brain damaged, and if we didn't want him, don't take him home and this kind of thing. But, you know—especially me—he was our baby and we wanted him, and we were going to take him home and treat him like we did our little girl.

He has gone through a lot of surgery. He's had a lot of things that people say spina bifida children do have. He is mainstreamed in a regular school. He is doing well intellectually. He does have some fine motor problems, but nothing major.

They really couldn't tell us at birth what the extent of his disabilities was going to be. I think that's something that needs to be pointed out, that you can't tell when these children are born whether they are going to walk unaided or whether they are going to be in a chair. This you have to find out with time.

**Ms. Robinson.** As the parents of a child who has had some of the problems that some people say would lead to such a low quality of life, that death would be a preferable alternative, how do you feel about that analysis, that the quality of life might be so low that nontreatment would be the better alternative?

**Mrs. Hintze.** Eric does have incontinence problems. He is in leg braces some, but he is in a chair a lot more now that he is in school. But I can't really say that his quality of life is unhappy. You know, he's very happy and has been well-accepted by his peers, maybe because of the mainstreaming at an early age. But I can't really say that he doesn't have a good quality of life.

**Ms. Robinson.** Has raising Eric been more difficult for you than you think raising a nonhandicapped child would be?

MRS. HINTZE. No. Eric was our second child, and I can't say that it was any harder. I think we were given both aspects of it. We were given a gifted child and then we were given a physically impaired child. And I can't really say that either one is harder, because they are both a challenge. But I think, like they say, any child is a challenge.

MS. ROBINSON. Now I have a question for Eric. First I told you I wasn't going to ask you one, and then I told you I was. But then your mother told me that if you were good today you would get to do something tonight. What do you get to do if you're good, and remember you can't do it if you don't tell me.

[Laughter.]

MS. ROBINSON. What are you going to do when you go back to the hotel tonight?

ERIC HINTZE. Swim.

MS. ROBINSON. Do you like to swim?

ERIC HINTZE. I love to swim.

MS. ROBINSON. What else do you like to do?

ERIC HINTZE. Flirt with girls.

MS. ROBINSON. Flirt with girls?

ERIC HINTZE. Yes.

MS. ROBINSON. Eric, do you get a kick out of your life, flirting with girls and swimming?

ERIC HINTZE. Yes.

MS. ROBINSON. Thank you very much.

I'm going to turn the questioning over to the Commissioners now.

CHAIRMAN PENDLETON. Mrs. Buckley.

COMMISSIONER BUCKLEY. If I may, I'd like to ask the Weigles a question. Your child Chris has Down's syndrome?

MR. WEIGLE. Yes.

COMMISSIONER BUCKLEY. Does he have any of the other usually accompanying symptoms that you see in Down's syndrome, such as heart problems or any of the others? Does he have any cardiac involvement in his condition?

MR. WEIGLE. What do you mean by your comment "usual"?

COMMISSIONER BUCKLEY. In most cases of Down's syndrome—

MR. WEIGLE. Forty percent, not most.

COMMISSIONER BUCKLEY. You're telling us about a Down's syndrome child that doesn't seem to have any medical problems. He's mentally retarded, as I understand it, but that's it, and everything else is all right.

MRS. WEIGLE. Yes, we were very lucky he did not have cardiac problems. But Christopher did have a much higher incidence of respiratory problems—bronchitis, that kind of thing. He had tubes put in his ears to aid in the fluid level so he would be able to hear. He also had to have two hernias repaired and his testicles brought down, which is sometimes more common in a child with Down's syndrome. But other than that, we have been very fortunate.

COMMISSIONER BUCKLEY. In your experience as a member of this group—Parents of Down's Syndrome Children—can you tell us what your experience has been as far as how the other parents have had to deal with children with multiple handicaps. Down's syndrome—I recognize what it is, and I don't consider that, in and of itself, that serious. But when it's combined with a lot of other problems, how do they deal with it, or how have they had to deal with it, and what is your experience in that vein as to what they have had to deal with or how they have had to deal with that?

MRS. WEIGLE. As one of our parents talked about her little girl who had severe heart problems, it involved them for the first 2 years of her life. She had five heart operations. And the mother was heard to say at the end of all the heart operations, "Do you realize that Jill's okay, but she still has Down's syndrome?"

It seems that sometimes when the parents are dealing with the medical problems involved with a child with Down's syndrome, they are more concerned with getting the child well versus the retardation level. And certainly with any child who is sick, it does take more of your time and effort, and is much more of a worry than just a child with Down's syndrome with no other medical problems.

COMMISSIONER BUCKLEY. In your experience, and for my benefit, give us an idea—there are all levels of Down's syndrome, trainable and others. They can be taught to do certain tasks; they can learn enough to hold certain jobs. Some of these children can go out and actually earn money in society and survive quite well. But then we have the other spectrum. Can you tell us on the other end, the lower end of the scale? How are their lives, their parents' lives, and their families' lives as far as surviving in more or less harmony with each other?

MRS. WEIGLE. The majority of people born with Down's syndrome can be taught to function at a good level. But just because the kids have Down's syndrome does not mean that they are not prone to all the other problems that people can have. They can be blind; they can be deaf; they can have all the other problems that everybody can.

And that's one of the problems. When we look at people in institutions, we sometimes are looking at people who have been institutionalized since birth, who have other severe medical problems, and then we just hear about the quality of life of people with Down's syndrome, irrespective of the other problems they have.

Very, very few people with Down's syndrome are going to be, as doctors have pointed out, unable to function at all, and what it does to their families is the same thing as with any other very involved illness.

We are finding that you can bring most people out of institutions who have Down's syndrome, and we can train them to live in group-home situations, hold down jobs, and take care of themselves.

Because of the poor advice, the poor reports that doctors and people that we have learned to trust give us, and the way that parents have to fight sometimes for the things that the more informed professionals give them—parents have to fight sometimes just to get a reading curriculum for their child with Down's syndrome. Many of the educators that went to school were taught out of books that had a very simple sentence that has gone on to really affect many, many of our children. It was a very short sentence that said, "Down's syndrome children do not read." One of the center-based programs in our area—the administrator had been taught out of that book—had no reading curriculum for Down's syndrome children.

COMMISSIONER BUCKLEY. These are the ones who are higher up the IQ scale. Tell us more about those that are lower on the IQ scale and have multiple—multiple—things wrong with them.

MR. WEIGLE. Can I jump in here a little bit, and I'll try to jostle her while I talk, and please excuse my standing.

How many parents of individuals born in the District of Columbia can be assured when their kids grow up that they aren't going to end up on the street doing heroin? And how many people in Central America can be assured that their kids aren't going to grow up and be in a guerrilla movement someplace and getting shot at 17 years old?

There is no way, clinical or otherwise, no matter what the degree of extent is with regard to medical complications, that you can tell what the ultimate intellectual or vocational development of an individual with Down's syndrome is going to be. That is not something that you know when the child is born. The child can be born with a heart defect. It could need surgery for 5 years to get that taken care of, and they can go on to be not even moderately but mildly retarded, and they can go on to earn a living and live all by themselves, or they can start out as Christopher did and end up not learning very much at all.

That is not something you are able to tell when that child comes out. It's on that table and you sit there and look at it and say, "Well, this child has Down's syndrome and has esophageal atresia. My goodness, gracious, sakes. This child will never learn to do anything." This is not something that you know.

So it can be harder. But that connection is entirely invalid, that if there are medical complications, you, therefore, have a more difficult life down the road. You do initially, but you don't necessarily down the road.

CHAIRMAN PENDLETON. Mr. Bunzel.

COMMISSIONER BUNZEL. Not at this time, Mr. Chairman.

CHAIRMAN PENDLETON. Mr. Abram.

VICE CHAIRMAN ABRAM. No questions.

CHAIRMAN PENDLETON. I just want to ask one question. We heard a panel of organizational persons. Some of you may have heard part of that panel discussion. What I think we heard was that the doctor is the patient's advocate; that is, the doctor is the person who makes the best decision. If it's something to do with a parent and something to do with a child, the doctor makes the best decision in terms of the child.

From what I have read in the interviews conducted earlier and what I hear here today, I hear something different from what the doctors are saying. I also heard them say in the last panel—I think a couple of my colleagues might bear me out on this—that in a sense they want to be left alone to be the patient's advocate.

Commissioner Destro was trying to get to the issue about discrimination in treatment, and whereas it might not be the kind that we would deal with ordinarily, there does seem to be some difference of opinion about how you feel about doctors and how doctors feel about patients. And if some of you heard the last panel with respect to the physicians and the organizations, I'd like to know how you feel about that. That was two panels.

Mr. Weigle, go ahead.

MR. WEIGLE. I don't mean to interrupt you.

CHAIRMAN PENDLETON. I want to know how you feel about it.

MR. WEIGLE. Do you mind if I stand? She does a lot better, and it will hold the volume down a little bit. I know, from 2 o'clock in the morning.

There are a lot of resentments that you will hear in a lot of interviews with parents that have had to deal with physicians at the birth of their particular child. You learn that not all physicians are like that. And the kinds of people that will often end up in a room like this are not necessarily the individuals they are talking about.

My father has an expression—he's not the most charitable man in the world—he says 50 percent of the doctors out there graduated in the bottom half of their class.

[Laughter.]

MR. WEIGLE. And it's not a presumption of perfection that an individual is an M.D., nor is it a presumption that, indeed, they can't do their job. But the fact of the matter remains, with regard to how they're being an only advocate, you cannot assume, first of all, that the information they give you is accurate because sometimes it's not. And you cannot assume that they are entirely up to date on all the treatments and procedures that will go on with regard to the particular instance of handicapping conditions that you might be running into.

CHAIRMAN PENDLETON. Mrs. Hintze, I read an interview—I hope it's attributable to what you told the interviewer: "The parents are victims at the mercy of doctors who may not know what they are talking about or who have biases about simple disabilities." Do you want to elaborate on that part at all? Did you say that?

MRS. HINTZE. Yes, I said that. I do believe our children are at the mercy of the doctors, and I will say their parents. Like I said before, we had a very supportive pediatrician and an OB doctor that sent Eric for treatment. But I know of a lot of cases where people have not had the supportive doctor or, like they said, the doctor that has the knowledge of, "No, it can't be handled in this small hospital. We do need to send the child for treatment where they have a neurosurgeon."

I feel like our children are at the mercy of the doctors because "The doctors should know." That's what we hire them for.

CHAIRMAN PENDLETON. Just one more question and I'll yield. At this hearing we talked about the role of section 504 and the Handicapped Act as it applied to the treatment of handicapped newborn. Organizational persons didn't like that too much, and they asked courts to make decisions to the effect that it doesn't necessarily apply.

Now we have the Child Abuse Act. I'm not putting words in Mr. Guess' mouth, but we talked about shifting the burden for the responsibility for decisions going to the parents now as opposed to where it was someplace else before.

How do you feel about having to take that decision on your own, if that comes under the rubric of this omnibus, if you will, Child Abuse, Child Neglect Act. Did you have a chance to testify in Congress at all on that act? Do you know of any parents that did? How do you feel about it? Anyone may answer. Go ahead.

MR. WEIGLE. I don't mean to hog the floor here. If anybody else wants to speak, please jump right in.

It's sort of a perspective comment, having been a parent, and after an hour and a half of having Christopher alive having this news put on me.

I am very uncomfortable with the thought that had someone come to me 10 minutes after I had learned that and said, "You have this option. You can institutionalize the child. He's going to be incredibly difficult to raise and are you sure you are capable of this? If not, you know there are families that will take them who are used to dealing with this kind of thing."

That parent at that point in time is no longer blissful. You are no longer in this euphoric state of your first child or your whichever child that has been born. And I am not certain it's the best time in a parent's decisionmaking process to be the individual with sole responsibility for the welfare of that child.

I think, indeed, you need to be involved in the process, but unless you have received good, accurate information, unless you have sat down with someone who knows what the entire scope of the situation is, you can be instantly prejudiced to a point of not necessarily making a good decision, if that addresses your question.

CHAIRMAN PENDLETON. I'm concerned about the shift in the responsibility for treatment or nontreatment going to the parents, if you will, under this Child Abuse, Child Neglect Act. When somebody says at 5 o'clock, "We're going to have a hearing at 7 o'clock, and we want to tell you you are abusing your child by withholding treatment," that seems kind of strange to me, that you have to make those kinds of decisions and that there is a law on the books that says you could be responsible for whatever happens in the ensuing time period.

That's the point I want to get at. I hope I'm being clear in what I'm trying to ask.

MR. MILLER. In effect that is what happened in our case. They were saying that we were depriving the baby of her civil rights by not allowing surgery. We didn't feel we were depriving her of her civil rights. We felt we were helping the baby. From the information we'd gotten about her condition, we felt it was best not to go with the surgery, not because we knew, in effect, it wouldn't necessarily be an easy job of raising the child, but we were thinking more of her well-being, her health, her quality of life. That's what we were thinking about at the time when we refused surgery.

Although it ended up she did receive surgery, and we are happy about it, I think that kind of reflects on—well, with me it's a matter of having faith in God that everything would work out for the best. If I had the decision to make again, I would go with the surgery strictly on my faith. Speaking to the doctor, as far as her condition was concerned, everything was more or less negative. And like I said, if I had to make the decision again, I would go with the surgery, considering there was a possibility that things would work out as well as they did or possibly better. But you don't know that at the time.

CHAIRMAN PENDLETON. Mrs. Hintze, do you want to comment?

MRS. HINTZE. I don't think it should go completely back to the parents to make the decision. I think it should be shared. You're upset and, like I say, we are sometimes at the mercy of the doctors. I think there needs to be laws that do protect the child. We're not talking about how the parents feel or how the doctors feel. We have to keep in mind we're talking about the newborn and what their rights are and what will life be like for them 20 years from now. I believe that it can be very difficult in many cases for parents to make the appropriate decision when they are in a nervous and upset state.

CHAIRMAN PENDLETON. If the doctors didn't go and say, "We want this law," and as parents of handicapped newborns you didn't, who wanted it?

COMMISSIONER GUESS. Can I ask a question?

CHAIRMAN PENDLETON. Go ahead.

COMMISSIONER GUESS. I'd like to ask a question of Mr. Mann—even though I am reminded that like physicians, 50 percent of lawyers graduate in the bottom half of their class.

[Laughter.]

MR. MANN. I admit nothing.

COMMISSIONER GUESS. Are we dealing here with a question of liability? If we are talking about assuming responsibility for making certain decisions, if that burden falls to the physician or it falls to the hospital or it falls to some third party and the decision is subsequently proven to be wrong, does then the parent have a right to bring an action against the decisionmaker?

MR. MANN. Well, that remains to be seen. For example, Dr. Gross, who was to be one of our witnesses in the panel this morning, declined our invitation to appear because he has been named in essentially such a suit. There have been some other suits that have been filed. I don't really know if any have been resolved yet. Some people believe there is such a theory of liability. It only stands to reason, given the theories of liability the courts construct for everything else, that there should be such a theory of liability here.

COMMISSIONER GUESS. And something similar to the Good Samaritan rule, acting in good faith?

MR. MANN. I think the idea would be that there should be some type of relationship between the physician and patient, and that the doctor must act in the best interests of the patient. And in such cases where the doctor gave a negative impression, the doctor may have felt he was upholding his duties.

I think Ms. Robinson may be able to comment further on that.

COMMISSIONER GUESS. I think the question I was asking was: Would it be safe to assume as a result of that reasoning that that may be one of the reasons the organizations take the positions they take?

MR. MANN. There is no question that they want to shield themselves from as much liability as possible. In fact, the panels tomorrow and the day after tomorrow will illustrate that theme further. We will hear from heads of neonatology units and hospital administrators. And I think if you examine some of the actions they have taken, it is with exactly such lawsuits in mind. But we'll go into that more later.

MR. WEIGLE. If I could address—I think the Chairman stepped out for a moment—his question of if the doctors didn't want it and the hospitals didn't want it and the people didn't want it, who wanted the regulation, who wanted this law to exist?

The initial regulation as handed down by HHS didn't have anything to do with child abuse laws. But the concept of the law, the concept that, indeed, the rights of the newborn were not adequately protected under the current status, whatever that was, was addressed in extremely blunt fashion by that first regulation. And the evolution of how what we have today transpired can be addressed very clearly by some of the folks in the next couple of days.

I suggest you ask Diane Crutcher of the National Down's Syndrome Congress, who has been intimately involved in the evolution, from point one all the way through, as to why certain laws were drawn upon as opposed to others. It was very much a compromise situation, "What will you accept? How can we make this work?" And, indeed, we may not have an ideal situation, but at least we have addressed the concept that not in every setting are the rights of the newborn adequately protected. We have some mechanism. If it needs refinement, all well and good, but better to have it than to have dead kids.

COMMISSIONER GUESS. Is it safe for me to assume that the situation you are describing is one where all the parties who had an interest in this process agreed to a process, and then one of the parties brought suit to challenge the process? I mean, as a matter of public policy, I understand how that happens on a fairly regular basis.

MR. WEIGLE. My recollection of events—and this does stand to be corrected by the people more intimately involved—is that the regulation was handed down first by HHS. There was a lawsuit second by hospital groups that said, "No," and they attacked it initially on procedural grounds, there wasn't enough notice, and that sort of thing. And at that point in time there began this back and forth. So the initiation was that from somewhere there was pressure for some kind of a delineation of how to handle the situation. You folks are probably a lot more exactly aware of what transpired, but it was something that needed to be addressed.

COMMISSIONER DESTRO. Jack, do you have any questions?

COMMISSIONER BUNZEL. No.

COMMISSIONER DESTRO. Let me just see if I can ask Mr. Mann if he can respond to my own impressions of some of the liability. I don't mean to pull a technical question out of my hat, but let's assume, for purposes of addressing this point on the record, if in fact 504 did apply to a doctor or a hospital which received Federal funds, and if in fact it did apply to the question of nontreatment decisions for handicapped newborns, what would be the possible penalty for the hospital under 504, do you know?

MR. MANN. My able counsel, Ms. Robinson, will answer the question.

MS. ROBINSON. All that section 504 does, as you know, is prohibit recipients of Federal funds from discriminating on the basis of handicap. The penalty for a violation of 504 is termination of the Federal funds, and you know how frequently that occurs.

The penalty vis-a-vis an individual doctor who is not a recipient of Federal funds is nonexistent under section 504.

COMMISSIONER DESTRO. That's right. As long as you're a recipient, aren't you also subject to injunctive relief in case you're a recipient? In other words, they can issue an injunction that says, "You will not discriminate anymore on the basis of handicap."

MS. ROBINSON. That's correct, which would be applicable to the recipient. The doctor could take his or her patients off to some other hospital and continue whatever practices the doctor was undertaking.

COMMISSIONER DESTRO. In other words, for the hospital or the organizations, there certainly is an impact if you take a 504 route, which hits them institutionally, if you will, as opposed to the child abuse route which hits the parents more then it does the doctor, and the doctor just becomes a participant in the process.

MS. ROBINSON. That is correct.

COMMISSIONER DESTRO. Just a couple of brief questions. One for Mr. Daniels and Mr. Miller because of the decisions you made.

Did you feel that the doctor in your case, Mr. Daniels, was an advocate for your daughter?

MR. DANIELS. In retrospection, no, I don't think so. I believe he was more adapting to the reactions of myself and my wife.

The same thing occurred with several other doctors in this whole spectrum. The only person in the entire medical and legal processes that we went through that I had any respect for after the entire process was done was an attorney who was appointed guardian to protect my daughter's rights. He was a marvelous individual.

COMMISSIONER DESTRO. Mr. Miller, the same question for you. Do you think the doctors advocated for your daughter?

MR. MILLER. Not really, not to a real strong extent. I say that because with respect to a decision as to have the surgery or not, they did not try to influence me one way or the other. They more or less gave me their knowledge of the situation and more or less left the decision up to me and my wife. But they became more of an advocate when the HRS got involved. It was easier for their position to go ahead with the surgery; at that point they became more of an advocate.

COMMISSIONER DESTRO. If you can think back, you said that if you had it to do over again you'd probably opt the other way.

MR. MILLER. Yes.

COMMISSIONER DESTRO. Can you remember what it was that finally influenced you to opt the way you did before the hearing?

MR. MILLER. To what?

COMMISSIONER DESTRO. Not to have the surgery done. You said it was in your daughter's best interest.

MR. MILLER. Because of the information I received as to her condition and the quality of life she would have. It was kind of a no-win situation. If they did the surgery, she had the possibility of paralysis and—many of the other problems that are involved with the spina bifida which they went over with us and it just didn't look like a pretty picture. And it seemed that by not going with the surgery was the easiest way out in a way.

COMMISSIONER DESTRO. Did it look any prettier, in your judgment, once the children's services got involved? You said earlier that the doctors seemed to be more of an advocate once the children's services got involved. Did the picture look any prettier than when you heard the same doctors talking at the hearing?

MRS. MILLER. We only had the pediatrician at the hearing. We didn't have the specialist there. Our pediatrician didn't have much knowledge of spina bifida. He had to get it from someone else. But he's the one who contacted HRS when people started calling him and asking him what he was going to do for the child. And in order to get the pressure off him, he contacted HRS.

Once HRS got involved in the case, then he started looking for specialists, which in Daytona Beach, there are few. When we talked to a different neurosurgeon, things looked better. He told us that Shermika had feelings in the upper portion of her legs. She wasn't paralyzed from the waist down. But before we could make a decision, HRS had already found a place to have the surgery done.

COMMISSIONER DESTRO. You said that you're glad that it was done, but you didn't like the way it was done.

MRS. MILLER. No, I didn't.

COMMISSIONER DESTRO. If you could come up with what you would think would be the best of all possible scenarios, given the scenario you were stuck in, how would you have liked to have seen it done?

MRS. MILLER. We were called at 5 o'clock, and I didn't even think about HRS getting involved in the case at the time. Because this is a shock to you. You think your child is going to be born healthy, and then something like this happens. If that is not a difficult decision to make—it's the most difficult decision I ever had to make.

So at the time I was thinking, well, maybe she should have the surgery; maybe it's not all bad. Maybe we shouldn't put so much faith in these doctors. They were not trying to convince us to have the surgery.

But, the way it was handled, we weren't even part of the decision. I wouldn't have known she was being transferred to Orlando Medical Center if someone from the hospital at Daytona Beach had not called us and said, "Your daughter is going to be transferred at 8 o'clock to the spina bifida clinic at the Orlando Regional Medical Center."

And I said, "What?" So I immediately went to the hospital. They had made the decision the night before. I said, "Why wasn't I contacted? Why wasn't I a part of it? Even though you made the decision to have the surgery, I feel I should have been part of it," because I wasn't going to give my child up to anyone. I think the parents should be made part of what's going on.

COMMISSIONER DESTRO. In other words, you didn't even get a chance to participate that much?

MRS. MILLER. They contacted almost every hospital in Florida that dealt with spina bifida. The other hospitals would not perform surgery without the parents' permission. That's the way it was. So they found a spina bifida clinic that would accept her. But we were not part of it. It was 8 o'clock in the morning she was to be transferred. I didn't know where she was going. They could have transported her there without my knowledge. That's what I mean by I didn't like the way it was handled.

COMMISSIONER DESTRO. Did you feel the same way, Mr. Daniels, when you were in the process, kind of left out?

MR. DANIELS. No, my wife and I were involved in the process all along. The two things that I remember most from the whole process that I found most distasteful was that it took place in a very public arena and they gave us no notice that they were taking any action. It was, "We are doing this to you now. We're taking you to court and we'll see you there in 45 minutes." There was no opportunity to explain why our decision was made. And the worst part of it was having the members of the media present.

CHAIRMAN PENDLETON. Mr. Bunzel, you had a question?

COMMISSIONER BUNZEL. My question may be one that Mr. Daniels or Mr. or Mrs. Weigle may have already answered and it may be redundant in a sense.

Mr. Daniels, let me ask you first, perhaps restating what you have said in part already. What kind of lessons have you drawn from your experience which, were you to advise a friend, would constitute precisely what you would want to say as a consequence of your own experience? There must be a variety of "advices."

MR. DANIELS. There are several. I was going to respond to an earlier question of, I believe, Mr. Abram, but let me start by answering your question. I think parents, anytime soon after the discovery that their child who is newly born has a handicap, are totally unprepared to make decisions. They are extremely vulnerable listening to people who they must put their trust in to make decisions.

My first advice would be to call in some folks you trust, people who know you personally, and discuss the situation with them before you make a decision.

COMMISSIONER BUNZEL. Not experts but friends?

MR. DANIELS. Friends, priests, ministers, your best friend in life.

COMMISSIONER BUNZEL. Not because they have any particular expertise, but because they are friends with whom you can consult?

MR. DANIELS. That's correct, to give you a more solid emotional basis to get you more on track with what you really feel about the situation.

COMMISSIONER BUNZEL. Does this mean that the kind of conversation you'd want to have with friends—and I'm assuming here you're talking about close friends, people who know you and your wife and so on—does this mean that you want your wife in the hospital as well as yourself to be able to have them come in and sit down at the bedside and talk about some things that are leading to decisions?

MR. DANIELS. Absolutely, absolutely.

COMMISSIONER BUNZEL. One of the things we hear from time to time is that any experience at birth tends to leave a mother for a short period of time, perhaps longer, in something less than the most attentive situation.

MR. DANIELS. To quote my wife: "She's good peasant stock."

COMMISSIONER BUNZEL. In this situation, though, you think that this would not be an additional burden, this would be a blessing, something that would clear the air and be of comfort?

MR. DANIELS. Absolutely. A second point I'd like to make, and following up on your question, is that there should be a representative for the child, not just a parent or doctor. I don't know that an attorney as a guardian *ad litem* is a good idea. It gets you into the legal system automatically too fast if you do it that way. Maybe a hospital person, a social worker, at some point, after you have established a solid basis for making a decision, should come in and explain what the child's position is. A social worker as an advocate of the child might say, "I must consider these things for the child that you may not have thought of in making your decision for the child."

COMMISSIONER BUNZEL. Can you speculate at all, whether had you had this kind of procedure—friendship, community, and various other forms of advice and consultation—would your outcome have been different?

MR. DANIELS. That's pure speculation. My guess is, based on the information we had at hand, no.

COMMISSIONER BUNZEL. The information you had at hand was from the experts, the medical people?

MR. DANIELS. Yes.

COMMISSIONER BUNZEL. And that guided your decision?

MR. DANIELS. Yes. Of course, we tried our best to be rational decisionmakers at that point. I don't know if that is a contradiction in terms.

COMMISSIONER BUNZEL. Mrs. Weigle, does any of this make sense to you? After listening to what we talked about, are there any kinds of lessons that you haven't already discussed, you and your husband, in terms of what you might advise, in a similar situation?

MRS. WEIGLE. Since the birth of our son Christopher we have become very much a part of an organization of parents of Down's syndrome children. What we do is go out and talk with nursing units, talk with the doctors, and the hospital staff calls us immediately after a child with Down's syndrome is born so we can, if the parents of the new child would like it, go to the hospital and talk to the mother and father about what it means to have a child with Down's syndrome. We can at that time tell them about the specialists in our area who deal with different problems and get them pointed in the right direction. If the parents do decide that they don't want to raise their child, we have also helped parents place their children in adoptive homes.

We have a counseling service, and we train through the Association for Retarded Citizens. We do this in hopes that what happened to us doesn't happen to other people, that terrible feeling of emptiness, the denial that goes along with the diagnosis. And we were lucky to have a child who was not very sick. But for the parents who do have a child that is very sick, we can put them in touch with other parents who have gone through the same problems, and we try to match them up as closely as we can so they can make the best educated decision.

COMMISSIONER BUNZEL. This feeling of denial that you're talking about, I assume that this is the kind of problem you have talked over with other parents in similar situations who have gone through the same type of—as you. Are we talking about a common theme? Are the problems that surrounded your situation very much likely to surround similar situations?

MRS. WEIGLE. Yes, very much.

CHAIRMAN PENDLETON. Mr. Guess.

COMMISSIONER GUESS. I have one final question.

Mrs. Miller, you indicated that you were informed at 8 o'clock in the morning that your child was to be transferred to a spina bifida center, that the State had made the decision to do so.

MRS. MILLER. Yes.

COMMISSIONER GUESS. And in retrospect, were you offended that you were not informed or were you offended that you were not allowed an opportunity to participate in that process? And in retrospect, would you suggest, as we talk about advocates for the child, that it would have been appropriate for the State to intervene?

MRS. MILLER. I was upset for both reasons, I was not informed that she was to be transferred, and also because I wasn't a part of the decision.

I'm glad in a way that they did find a place to have the surgery. And it was the best place. That is one good thing I can say about it; it was the best place. This is where we got all the information that we should have gotten in the first place. They had a counselor to talk with us. When I found out she was going to be transferred, they said, "You can go with her." They had a counselor there waiting for us to explain Shermika's condition, which made me feel 100 percent better about it.

I think there should be someone in the hospital, someone at the time of the birth of the child, which we did not have in Daytona Beach at the time but we do now, to explain to the parents the condition of the child so that the parents can feel comfortable in making a decision.

Like I said, I don't know why the doctors just don't go ahead and do it in the first place instead of leaving it up to the parents, because it's such a difficult decision to make.

They said closing up her back wouldn't change her condition, so I said, "Why don't they close it up anyway if it's not going to change her condition? Just close it up." At the time they didn't tell me it would prevent her from getting an infection. I thought the child was going to die in 10 days. So I think there should be someone there who is knowledgeable and can explain the situation.

COMMISSIONER GUESS. So there is a very delicate balance.

MRS. MILLER. At the time I didn't know about my rights. They were not explained to me at all.

CHAIRMAN PENDLETON. In the absence of any further questions, Eric, we want you to be able to go swim and flirt.

I will not speak for my colleagues but I can't tell you how impressed I am with the kind of support system that the children have in this situation and the kind of forthrightness with which you come and testify before this Commission. I wish that other parents could be around to hear what it is that you have had to say, and I think you deserve an awful lot of thanks, tributes, and commendations for being knowledgeable, being aware, and for certainly giving us this information that we can perceive through these very touchy hearings. I can't thank you enough.

And I thank the little ones for being here so quietly all the time. Even though that one was not quiet then, she is now.

MR. WEIGLE. She is now asleep.

CHAIRMAN PENDLETON. If there is no other business before the Commission, we will recess until 8:30 tomorrow morning.

COMMISSIONER BUNZEL. Mr. Weigle, this isn't the first time this Commission has put people to sleep.

[Laughter.]

MR. WEIGLE. We thank you all very much.

[Recess.]

CHAIRMAN PENDLETON. Can we convene, please? I would like to swear the witnesses.

[The witnesses were sworn.]

## Neonatal Practice

### TESTIMONY OF CYNTHIA BARRETT, M.D., DIRECTOR OF NEONATOLOGY, UCLA HOSPITAL, LOS ANGELES; KENNETH N. ROSENBAUM, M.D., DIRECTOR, CLINICAL GENETICS DEPARTMENT, CHILDREN'S HOSPITAL, WASHINGTON, D.C.; ANTHONY SHAW, M.D., PEDIATRIC SURGEON, CITY OF HOPE NATIONAL MEDICAL CENTER, LOS ANGELES; AND K.N. SIVA SUBRAMANIAN, M.D., DIRECTOR OF NEONATOLOGY, GEORGETOWN UNIVERSITY MEDICAL CENTER, WASHINGTON, D.C.

CHAIRMAN PENDLETON. Good morning, and thank you for coming.

As the agenda so indicates, the first panel will be on neonatal practice. It is our custom at the hearings to start with Counsel's questions, and then the Commissioners will have questions later and then we will have some exchange.

MS. JONES. Thank you, Mr. Chairman. My name is Christine Jones. I'm an attorney in the General Counsel's Office of the Commission on Civil Rights.

I would like to start by asking each of you to state your name and present position for the record. Let's start with Dr. Rosenbaum.

DR. ROSENBAUM. I am Kenneth N. Rosenbaum, M.D. I'm the director of clinical genetics at Children's Hospital in Washington, D.C.

MS. JONES. Dr. Shaw.

DR. SHAW. Dr. Anthony Shaw. I am director of pediatric surgery at the City of Hope Medical Center, and clinical professor of surgery at the University of California, Los Angeles.

DR. SUBRAMANIAN. My name is Siva Subramanian. I'm a pediatrician and neonatologist and director of the nursery at Georgetown University Medical Center in Washington, D.C.

DR. BARRETT. I'm Cynthia Barrett, director of the Newborn Intensive Care Unit and head of neonatology at UCLA Medical Center.

MS. JONES. Thank you.

The first question I'd like to address to all of you, starting with Dr. Rosenbaum: We'd like to know whether you have ever recommended or approved the withholding of treatment of babies in the Baby Doe categories and, if so, under what circumstances?

DR. ROSENBAUM. That is a question that may require a lengthy response, but I'll keep it brief and I'm sure we will get into this later.

As part of what I do daily, I see the large majority of children in the Washington region with major birth defects, and because of the nature of malformations, in many cases lethal malformations, not medically or surgically able to be remediated, we have in the past recommended or gone along with parental wishes not to proceed with therapy in those situations.

MS. JONES. We are interested in knowing what kinds of factors you take into account in making these decisions.

DR. ROSENBAUM. I would say the overwhelming factor is the particular malformation. If we are dealing with something that by its natural history does not allow for survival, then we can make that decision, things like anencephaly, major chromosomal abnormalities like trisomy 13 and trisomy 18.

CHAIRMAN PENDLETON. We are going to have to ask you to repeat that. We're having difficulty hearing.

DR. ROSENBAUM. I was saying that the most likely category for decisionmaking like that is a child with a lethal malformation. And in Washington that is a frequent occurrence, as it is anywhere else in the country. And certain categories like anencephaly and major chromosomal abnormalities like trisomy 13 and trisomy 18 are some well-known examples of lethal malformations.

There are many, many others, and I'm sure we don't have time to go into those right now. There are many conditions that don't allow survival, irrespective of the type of intervention that occurs. You may temporize, but you will not be able to change the condition.

MS. JONES. Can you give me an estimate of how many cases you're talking about, in your experience?

DR. ROSENBAUM. In Washington we estimate that two to three babies every day are born with a major birth defect. That would be, of course, about 100 a month, let's say, 1,200 or 1,500 babies a year. In that category we are probably talking about 50 to 75, maybe 100 babies, with lethal birth defect conditions, different syndromes, in this area.

MS. JONES. Dr. Shaw, could you respond to that question, too.

DR. SHAW. Yes. As a pediatric surgeon, I see a somewhat different population of babies. I don't see necessarily the very low birth weight babies where some of these questions arise where further medical supportive treatment are needed. I see babies who require operations for life-threatening conditions, such as tracheal esophageal fistula, duodenal atresia, which are commonly associated with Down's syndrome. I see babies with other forms of bowel obstructions associated with severe mental retardation states. I see babies who require surgical procedures to allow them to be fed, for instance, babies with such severe brain damage that they can't eat or drink, and other situations where a surgeon may be called in.

And through the years there have been situations where the parents and the physicians together have felt that surgical procedures to maintain life in certain situations was not in the baby's best interest, and we have refrained from proceeding with operations under those circumstances.

I must say that, over the years, our perception of the value of surgical procedures has changed as various other supportive treatment has come into play to improve prognosis in certain groups of children. So the sort of situations that we might have accepted as a nontreatment situation 15 years ago, we wouldn't necessarily accept as a nontreatment situation today.

Ms. JONES. We understand that you developed a mathematical model that was used to make treatment decisions adopted by the hospital in Oklahoma. Are those the kinds of factors that you take into account in making a recommendation to parents of nontreatment?

DR. SHAW. I'd like to talk about that—that requires more than a yes or no answer—if I may.

Ms. JONES. Certainly.

DR. SHAW. Let me give you a little background on this formula that appeared in the article from Oklahoma, somewhat to my surprise. I can't defend the use of that formula in that article, nor can I attack it, because I don't really have the facts beyond what I read in the article itself. It is my understanding—and I understand some documentation of this is going to be sent to me soon—the formula was discovered by the authors of the article after they had already done the research and put together the material based on the treatment of those babies without the formula having been used at all, and the formula was put in later.

But the concept of this formula is this: The formula was to define—and when I wrote this in the Hastings report it was entitled "Quality of Life—a Formula Without Numbers," and the idea was that one doesn't assign numbers to this. The idea of the formula was not to set a numerical level of a quality of life above which a baby would be treated and below which the baby would not be treated.

The point of the formula was to point out: What factors other than the natural endowment, the mental and physical capability of the baby, at the time of birth were important in determining the future quality of that baby's life? And in that formula, which is $QL = NE$, natural endowment, times $[H + S]$—$[H + S]$ had to do with those things given to the baby from a loving and concerned family and a loving and concerned society—it seemed to me perfectly obvious that, given anyone, whether it's a handicapped infant or any individual at all, the quality of life of that infant will depend to a large extent on what the family and society at large is willing to do for that person. The quality of life goes down certainly for a handicapped person if society withdraws resources from helping such an individual, particularly if that person is disabled to begin with. And the quality of life goes up if society makes a contribution to that person's.

I put together this formula for the first time at a meeting about 15 years ago as part of a discussion I was asked to give on proxy consent for handicapped infants. And it was my feeling that a good proxy for a handicapped baby was someone who would maximize those factors that would improve quality of life, and maximizing those factors means supporting families who have to take care of such infants and supporting services in the community to families and to such infants if we are going to make the medical efforts required to salvage such infants.

So my idea in presenting the formula was a very positive one in terms of looking at the future of many of these infants optimistically in terms of what we can do for them.

As I understand it, in the University of Oklahoma series they used the formula to say, "Well, if society and the parents are not going to do this for the baby, the quality of life is going to be poor and we might as well do nothing." That was not my intention when I put the formula together.

CHAIRMAN PENDLETON. Excuse me. I forgot to do something. Let me interrupt you. Are there persons here who are hearing-impaired? We need to ask that in case there is. If not, we don't need to have the interpreter here.

[No response.]

CHAIRMAN PENDLETON. Could you give us for the record the formula we are talking about? It would be important in terms of putting the transcript together that the formula as it exists be a part of the record now.

MS. JONES. Would you mind repeating that, Dr. Shaw?

DR. SHAW. This appeared in the Hasting report in 1977. It was QL, which is quality of life, equals NE, representing the mental and physical endowment of the infant, natural endowment, if you will, times (H), representing those factors contributed to the infant by the home, plus (S), those factors contributed to the infant's welfare by society.

When I wrote this, I thought it was a pretty obvious truth that I was stating. I still think so. I think any formula, whether it's that or the one that Einstein recognized relating to mass energy, can be used in destructive ways as well as constructive ways.

MS. JONES. I'd like to move on for a moment. I'm sure the Commissioners will return to that.

I'd like to ask Dr. Siva—that is what you are called, Doctor?

DR. SUBRAMANIAN. Yes.

MS. JONES. —if he could comment on his experience in making those kinds of treatment or nontreatment decisions and explain the kinds of factors that he takes into account.

DR. SUBRAMANIAN. I think it's very critical to give a little background in terms of how decisions are made. Also, we have to look into the evolution of the field of neonatology itself. I'm just going to touch briefly on both of them.

If an infant is admitted to the intensive care nursery with any malformations, after a thorough history and physical examination, he will get a complete workup. This workup will include chromosomal analysis, genetic, neurologic, and developmental consultations from various subspecialists. And once we have the information available from the examination and the consultants and the prognosis is confirmed from the available data and the literature—and this is where it is very critical to understand, that there is information that we know for sure that the prognosis is very bleak, and other where we know for sure that the prognosis is good, and there are gray areas where we are not 100 percent sure because the evolution of the data is not available for making such categorical judgments in terms of whether this prognosis is poor or not.

But if on the basis of given data on that particular infant—and this is why it's very critical to say on an infant-by-infant, patient-by-patient basis—and the available literature, the judgment is made that there is no medical intervention available that will help or improve the chance of this particular patient, this is then discussed with the staff, social workers, residents, and the parents, and further discussed in the pediatric ICRC, as it is called now; and the decision to withdraw extraordinary life support, such as respirators, is made only with parental consultation.

In all these situations, when we make a decision in terms of withdrawing extraordinary comforts of life, the basic comforts of life such as nutrition, hydration, and warmth are always provided to maintain the dignity of human life. At the same time, we have to take into account the pointless prolongation of the dying process, which may not be morally justifiable.

So in terms of this background, I wanted to give you what is done, and in terms of the whole component of the field of neonatology, as the previous two physicians mentioned, it is evolving. There are areas where the gray areas are getting defined, and as they are defined will give more information as to the prognosis.

So any judgment that is made at that time is made with information, data, that is available in the literature and the information gathered from the patient himself or herself.

Ms. Jones. Thank you.

Dr. Barrett, what is your experience? What kinds of factors do you take into account in your practice in making these decisions?

Dr. Barrett. I think, like all neonatologists, my practice actually begins before a baby is delivered, and particularly with the very immature baby in whom we know, for example, that in many instances survival is improved by cesarean section and by fetal monitoring, there comes an age at which this really does not increase the benefit to the fetus about to become baby. And the area in which we first become involved is with the obstetrician in speaking to the parents about chances of survival alone and whether or not the parents wish to undergo cesarean section for delivery of, let us say, a fetus at 24 weeks or 25 weeks, and the age at which we do begin to monitor and recommend cesarean sections has dropped now to about 26 weeks of gestation, at which age we now have 30 to 40 percent survival with some really good babies coming out of this.

The other instances in which we deal with this kind of decisionmaking, as you have heard from Dr. Rosenbaum, are babies with bad chromosomal malformations, and for this we really only will include initially those babies with trisomy 13 or 18.

Within the course of therapy of a baby, as we watch the course evolving in which viability becomes absolutely impossible, we are good enough now to prolong life for weeks. And at that point if we see that a course is irreversible—and this, again, we base on our medical knowledge, our reading, discussion with parents—we will, again, offer them the option to withdraw care.

MS. JONES. I would like to ask each of you, beginning with Dr. Shaw, to explain whether or not you believe the recently enacted Federal legislation requiring State child abuse agencies to consider as medical neglect instances where treatment is withheld from handicapped newborns—do you believe that to be a viable solution to the problem?

DR. SHAW. Do I favor the provisions in the amendments to the child abuse legislation?

MS. JONES. Yes.

DR. SHAW. Yes. I think the amendments as written, with the new guidelines, are quite workable, and I think will perform the function for which it is designed, to protect infants against inappropriate decisions which might possibly be made, and to allow physicians and parents flexibility to make decisions which are in the best interests of the baby.

MS. JONES. Do you think that decisions made in accordance with that legislation and the regulations under it are in accordance with the quality of life formula that you just discussed?

DR. SHAW. I'm not sure that it really addresses the quality of life formula. I think what would address the quality of life formula is the support that the Federal Government then gives to the families of babies who are treated and kept alive by modern technology, who need help coping with these infants later on. I don't believe the current law addresses that aspect of it, which the formula does.

MS. JONES. Dr. Rosenbaum.

DR. ROSENBAUM. The language of the current legislation I may not be as up on as I should be, but I'm pretty familiar with the process. I think there are benefits to such legislation and some disadvantages as well. I think the benefits the current law provides for is equalization of some standard of care throughout the country so that babies born in any part of the country can have the same type of care as babies born in major metropolitan centers. I think it's also helpful in making doctors and families more aware of how to make decisions and perhaps improving the decisionmaking process.

The disadvantages I see—and again, my knowledge of the most recent language is not as good—is that it still places legislators and other individuals in the midst of this parent-physician-child relationship. And that is difficult, especially if decisions have to be made during the night and on weekends when it is hard to get institutional review boards together and so on. Each institution, I know, faces that in its own way. But I do a lot of work at outlying hospitals at all times of the day, and I know that usually there is not much chance of getting a group together at those hours.

So there is certainly reason to have such legislation for the reasons I listed.

Ms. Jones. Dr. Siva.

Dr. Subramanian. I basically do not dispute the principle that all infants, including handicapped infants, should receive all the necessary care and treatment that they deserve. So in that way the child abuse prevention law, after a lengthy process and compromise with various organizations, has dealt with this reasonably in terms of intent and principle.

But what I would dispute is that in situations which are highly charged with significant emotion, distress, anguish, frustration, anger, guilt in the family, which is being dealt with with the specialist, the medical nursing, social workers, and clergy, it is a delicate process. During this process, an intervention by any outside agency, whether it's the Federal Government or State, as an ultimate arbiter of what is appropriate care for that infant, I feel is inappropriate.

Ms. Jones. Did you say inappropriate?

Dr. Siva. Inappropriate.

I think also the provision of the Child Abuse Prevention Act, the suggestion of creating infant care review committees, where the local institution with this multidisciplinary routine would then fill the informational and educational gap, which was one of the accusations in the past, among perhaps the particular physicians making the decision—I think this will fill the gap and provide a forum for discussion and input whereby a decision that is made will be fully informed. And I think it's appropriate.

I would like to go one step more and mention—this, I think, was in an editorial in one of the papers which I would like to mention. I'm not quoting it, but I'm just mentioning it. The intent was that if the day comes where we start believing the medical, nursing, social workers, clergy, and the local people cannot form a viable alternative, which is obviously flexible, to these handicapped newborns, I think any amount of law and regulation is not going to help. I think there has to be a group of people who can get together and make such policies or guidelines at this stage, and I think it should be at a local institutional level.

Ms. JONES. Dr. Barrett.

DR. BARRETT. I think the language, at least as expressed in the April 15 *Federal Register,* is very viable. I see it as putting primary emphasis upon parental responsibility and physicians, with backup, advice, input from an infant care review committee, with recourse to the child protective service agencies in the State should the other areas fail. I think that from my practicing standpoint it will work.

I will say that one possible advantage that is our biggest problem is not our wishing to discontinue care, but parents wishing us to discontinue care. Our major conflicts are when parents come to us with the request to stop respiratory support of their babies when we have no indication that this baby will grow up to be anything but normal. I think that having the recourse to an infant care review committee prior to calling the juvenile court and saying, "Will you make this child a ward of the court for us" will reduce the hostility that in that occasion will arise between physicians and families.

Ms. JONES. Thank you. I don't have any more questions.

CHAIRMAN PENDLETON. Thank you very much.

Mr. Abram.

VICE CHAIRMAN ABRAM. May I first express my appreciation for the opportunity to hear from such a diverse group of neonatologists, and forgive me if I use the opportunity to educate myself further in this interesting field. To begin with, I'd like to ask whether or not the materials that we have before us represent the practice as you see it.

Dr. Shaw, I'll start with you. In 1973, Duff and Campbell, as you know, in the *New England Journal,* published the results of their study of 299 deaths occurring in the special care nursery of the Yale-New Haven Hospital. They reported 43 such deaths. Fourteen percent were related to the withholding of medical treatment. Dr. Lawrence K. Pickett, the chief of staff at Yale-New Haven, was later quoted as saying that allowing infants with serious handicaps to die was accepted medical practice at other hospitals.

When Dr. Duff, testifying before a Senate committee in 1974, was asked by Senator Kennedy to estimate how many severely handicapped babies each year were left to die in the United States, he reportedly replied, "I'm sure several thousand."

Is this survey and the material I have quoted to you congruent with your experience and opinion?

DR. SHAW. Mr. Abram, I had an article in the same issue of the *New England Journal of Medicine* called, "The Dilemmas of Informed Consent."

VICE CHAIRMAN ABRAM. Yes.

**Dr. Shaw.** As a matter of fact, I never had an article accepted by a journal so quickly. I sent that in to Dr. Ingelfinger of the *New England Journal of Medicine* a few weeks before it was published. He telephoned me saying he had just received an article on a similar thing from Yale and he wanted to publish them together.

My article also indicated that there were such egregiously impaired infants that decisions by parents and physicians together for nontreatment were done and were reasonable. I'm talking about the late sixties and the early seventies now, and we're talking about infants that at that time had perhaps a worse prognosis than we would think now.

But I would confirm what Dr. Duff wrote at that time and what he subsequently said in his testimony, that it was not uncommon for such decisions to be made.

On the other hand, we have really no good statistics on the incidence or, indeed, on the kinds of infants or handicaps that fulfill the requirements for nontreatment in the view of neonatologists and pediatric surgeons in those days, or even now.

**Vice Chairman Abram.** Moving away now from the underweight baby, which I suppose a lot of these must have been because, as you say, technology has advanced very rapidly, to the case of the Down's syndrome child, which I suppose presents a different problem. It isn't really whether or not the child will survive, but it's the parent of the child.

We have a reference to this particular quote: Dr. William Bartholomew, senior assistant resident, Johns Hopkins, and a doctor in charge of the case—speaking of a Down's syndrome case—said "similar life and death decisions are made at least twice a week in the hospital."

And Father Richard McCormick, who is a Jesuit theologian, said that "instances like this happen frequently."

*Time* magazine, we are told, reported that doctors have long withheld life-saving medical support from grossly malformed infants, allowing them to die at birth, and only telling the parents that the babies were stillborn.

How does that comport with your experience?

**Dr. Shaw.** I think the latter practice is something we would all regard as unacceptable, and I think it's been perhaps years since that might have been routine practice of doing this sort of thing at birth, mostly in cases where medical science had nothing to offer in any event.

When we were writing articles like this around the end of the sixties and early seventies, the options for parents and families with babies with Down's syndrome were very meager also in that group. For most of them, the advice was they should be institutionalized. Educational resources for them were very meager. About a third of these babies had congenital heart disease which at that time was not remediable anyway, and it didn't make sense to correct an intestinal obstruction when the baby had a congenital heart lesion which was going to kill the baby within a few months. The advances in cardiac technology are at the point now where cardiac lesions in Down's babies are now correctible.

So again, I think we are looking at statements that were made 15 years ago that I think we might considerably modify today.

VICE CHAIRMAN ABRAM. Then we have the statement: "The widespread acceptance of withholding of treatment received some documentation in the studies published in '76 and '77."

And this is one that I'd like to have you comment on: "In one study, 61 percent of California pediatricians polled said they would not perform surgery to correct a life-threatening intestinal obstruction in a Down's syndrome baby." That was published in a Hastings Center report.

DR. SHAW. I think that was in a situation where the parents refused consent for surgery, and I think that that was true. We took a survey nationwide of not only pediatric surgeons, but also neonatologists, chairmen of departments of pediatrics, and geneticists. This was a nationwide survey which was published in *Pediatrics* in 1977, and which I undertook with my colleagues at the Academy of Pediatrics Surgical Section in 1975, which came up with very much the same sort of statistic. It was in response to the question of where the parent refused to consent to surgery, which was a relatively small number of cases in those days. Most parents did consent to surgery. The question was what one does in the situation where the parent refuses to sign consent.

VICE CHAIRMAN ABRAM. You would all agree that the physician has an enormous role in this in that he is the authority figure.

We have here the Massachusetts study that found 51 percent of pediatricians surveyed would not recommend surgery for a Down's syndrome baby with an intestinal blockage. That figure was derived from an article published in 1977, and there hasn't been much improvement in the skill with which that intestinal blockage is removed.

So we have now a status in which the technology has not really changed, and the question is an attitudinal change, if one has occurred. Would you say that a Massachusetts study done today would find that 51 percent of pediatricians surveyed would not recommend surgery for a Down's syndrome baby with an intestinal blockage? Dr. Barrett, maybe you'd like to comment.

DR. BARRETT. I haven't worked in Massachusetts since I was a medical student. I would say in the time of my internship, which was the 1960s in Seattle, we universally recommended it, and at the time I became a faculty member at UCLA, we universally recommended it.

I can also add that on one occasion where the parents refused to give permission, a juvenile court judge in the County of Los Angeles went along with them and would not give me a court order.

VICE CHAIRMAN ABRAM. I understand. I'm not trying to pass judgment on you.

DR. BARRETT. No, I know you're not.

VICE CHAIRMAN ABRAM. Let me ask the panel what it thinks would be the current recommendation. I would again ask each of you. The Massachusetts study of 1977 found that 51 percent of pediatricians surveyed would not recommend surgery for a Down's syndrome baby with an intestinal blockage. Dr. Rosenbaum.

DR. ROSENBAUM. I have no doubt in my mind that if that poll were undertaken now, the numbers would be very different. Our approach to Down's syndrome is so different, as Dr. Shaw was indicating, and physician education, I think, is also very different, so that the numbers are likely to be in the other direction. I personally have provided care for 700 babies with Down's syndrome, and I know the decision not to intervene is a very infrequent decision, and I'm sure that is now true in Massachusetts as well.

DR. SHAW. To add to what I said before, the statistics you are asking about should be available very shortly. Dr. Tuddress, head of neonatal anesthesia at Mass General Hospital, who conducted the survey in 1977, has just undertaken a new one, asking the same questions of, I believe, the same population of pediatricians in Massachusetts. I believe the results of that survey should be available in the very near future.

I had an opportunity to query a group of pediatric surgeons at an American Pediatric Surgical Association meeting 2 years ago and threw out the question generally that we had asked in our survey almost 10 years before. And as Dr. Rosenbaum mentioned, the attitudinal change is considerable. The surgeons who had responded that they would not operate or would not request the family to allow permission for such an operation on a Down's baby now feel that such a baby should be operated on. And this is not just under the pressure of Baby Doe regulations or legislation. There has been an attitudinal change.

VICE CHAIRMAN ABRAM. Why the attitudinal change, do you think?

DR. SHAW. For several reasons. One, I think the options that were available—physicians are very sensitive to the total family situation where a handicapped baby is born and presented to the family. Back in the seventies, particularly early seventies, late sixties, many of us were discomfitted by the idea that we as pediatric surgeons could operate on these babies and open up their intestinal tract so that they could eat, and the parents would then through their own decision or suggestion to them by family, friends, pediatricians or whatever, turn the baby over to an institution. And those of us who took the trouble to look at these institutions were by and large horrified at the conditions that existed and the way babies were subsequently managed.

VICE CHAIRMAN ABRAM. Was that entered into the quality of life formula that you used?

DR. SHAW. This has a lot to do with the quality of life. My feeling was, "My God, if the family is going to do this to these babies, why are we trying to salvage them?"

I think there has been a tremendous change in the perception of what can be done for these babies and what society's and the family's obligation to them is since then, which has given us a great feeling of optimism about doing something for them in the first place.

VICE CHAIRMAN ABRAM. Dr. Siva.

DR. SUBRAMANIAN. I think one of the major reasons is the change of available technology. There is a significant increase in our ability to keep these babies alive.

VICE CHAIRMAN ABRAM. Not in the case of a Down's syndrome baby with a simple intestinal blockage.

DR. SUBRAMANIAN. I would say definitely there has been a change in attitude. And the attitude changes, I would say, are related to two areas.

One, traditionally physicians had the philosophy of what is called an ethical theory of patient benefits; that is, they will act in the best interests of the patient. I think that has increasingly changed in the last 10 to 12 years—which has nothing to do with the infants; it is the whole doctor-patient relationship—to the autonomy of the patient. So there has been a switch over the last 10 to 15 years from the totally patient benefits model to a respect for the autonomy of the patient.

VICE CHAIRMAN ABRAM. The child has no way of expressing its autonomy. You mean the autonomy of the parent?

DR. SUBRAMANIAN. The change in attitude is autonomy of the patient. But in the situation of infants, the question is the infant cannot articulate, and it becomes what is called familial autonomy in terms of the family as a unit, and the parents in the best interests of the patient will be able to express their opinion in terms of autonomy.

In terms of the attitude of Down's syndrome, with respect to recommending surgery, I would absolutely have no question in terms of saying the recommendation at this point by any survey of neonatologists would be to do the surgery.

CHAIRMAN PENDLETON. Just to follow up, if I may: Could you explain to us, who are not as well-versed as you are in these conditions, what is wrong with doing the surgery, the abdominal surgery, on a Down's syndrome baby? I don't understand the connection between the two. You have two conditions. You say you don't operate on one because the baby has Down's syndrome and some other sort of blockage or atresia or whatever. Why can't you do that? What is wrong with doing it? Anyone.

DR. BARRETT. Nothing.

CHAIRMAN PENDLETON. We have heard that when there are multiple conditions involved, perhaps the newborn should not be treated.

Dr. Rosenbaum. The issue was in the past Down's syndrome was a common cause of severe mental retardation, and usually residential or institutional placement, so that qualitative decisions were made. Although the surgical technology existed, the ultimate outcome of that child was not as good as someone would have liked. That attitudinally has changed. So we know that children with Down's syndrome can lead very productive lives, and the surgical technology is the same as it was.

Chairman Pendleton. When you talk about attitudinal change, I can understand that. But, Dr. Siva, I think I heard you say—or maybe it was Dr. Shaw—that you carry these babies along so far, and Dr. Barrett said that you have gotten good enough to prolong life. And at some point during this continuum of treatment the parent decides, "I don't want to go through this anymore." It seems to me that presents quite a dilemma for you, having practiced your specialty, if you will, of trying to prolong life. When it gets to that point, with the Child Abuse, Child Neglect Act as it is on the books now, are you open to neglect suits?

Dr. Subramanian. You mean neglect by the parent?

Chairman Pendleton. No, by the physicians. You've gone along so far in this process. Do you have a problem later on down the line if the parent says no? Can they sue you or can you sue them, or what?

Dr. Subramanian. The question, I think, is in terms of it's very critical to realize—you are absolutely right, as neonatologists, with our technology and skills, we could sustain life as long as possible. But I think we also have to make the assessment in terms of the patient: Will this treatment bring more pain and suffering without any benefit for that patient, will it be gravely burdensome to the patient?

I think in a situation where it is gravely burdensome, the extraordinary life support that we give to the patient, I would have no problem in terms of discussing with the parents withdrawing life support.

Chairman Pendleton. What I am saying is there's a child neglect law now on the books and child abuse, and treatment of handicapped newborns comes under this rubric of the law. Who can sue whom, or is there potential for that to happen in this process, where one can sue the other for neglect?

Dr. Subramanian. Even without this law, I think traditionally there has been on the books, in terms of physicians pursuing in the court, of possible child neglect—in situations where it is definitely felt the medical treatment is in the best interests of the patient, like transfusions, surgeries, and situations where the pediatricians and other physicians have gone to the court to require that that should be performed. So I think that is already in existence. I think the question is in terms of whether the physicians would be afraid of legal suit; is that correct?

Chairman Pendleton. Certainly. There is a law on the books now, and Mr. Bunzel asked the question yesterday: Did the physicians fight or did they lobby to have the existing law on the books as it exists today? Did they really want that law on the books? Does it help them? And yesterday we got some answers that it was sort of like "take this or it will be something else" so they took this. The question becomes: How does that affect your practice?

**Dr. Subramanian.** I don't think it can be answered on a single-institution-by-single-institution basis, but generally, I would say any additional regulations—in situations where this delicate process of decisionmaking is involved, is not very helpful.

**Chairman Pendleton.** Dr. Barrett, do you want to say something about this?

**Dr. Barrett.** We are always at risk of lawsuits. With good education, and good communication with the parents, there is less of a problem. There is a fear among the medical community, however, that there will be criminal charges rather than a regular civil malpractice suit raised against them in this situation.

I can give you an example that is very recent in my mind of a baby for whom this decision was ultimately made on Saturday night. This baby was born profoundly depressed and quite premature on December 30. He spent his entire life on a respirator.

In March his parents came to me and said, "Jacob is on 100 percent oxygen. Do you think it's time to call it quits?"

I said, "As far as I know, if he can survive his lung disease, he can grow up to be an entirely normal child."

He had been paralyzed much of his life, sedated virtually all of his life, and finally his lungs failed late last week, and with appropriate studies and discussion with the parents, we removed respirator support when it was clear that he would die within the next week or 2 weeks, but was really suffering in the process.

From my standpoint, we complied with the guidelines of the current rules. It is possible that by someone else's standpoint we did not. I'd be very surprised if anyone reported us. I think we could prevail were this to happen. But it is a real concern.

**Commissioner Bunzel.** Would you have handled that case differently if there had been no guidelines?

**Dr. Barrett.** No.

**Commissioner Bunzel.** So what are you telling us about the guidelines?

**Dr. Barrett.** Either that I am brave, foolhardy or, as I stated earlier, I think the guidelines are not inappropriate as written today.

**Commissioner Bunzel.** Are they redundant from the point of view of what you see and how your committees and hospitals and consultants handle this? They are not inappropriate you say. Are they functionally necessary? You say you have lived successfully and professionally without them.

DR. BARRETT. I do not see my standard of behavior changing in any real way based on the new guidelines. The benefit I see from them is that I have an advisory board when parents do not wish me to proceed with medical care. I think most physicians view death as defeat, and it is very hard for us to admit we have failed. Therefore, when a parent wants to let go, it is very hard for us to do so—and I think probably inappropriate until we are medically certain that we have, as it were, failed. I think having an advisory board to mediate, communicate, educate us and the families will be of benefit to us.

COMMISSIONER BUNZEL. I did not mean to interrupt you.

CHAIRMAN PENDLETON. I'm glad you did.

You mentioned something about criminal charges. Would you expand a little bit on that?

DR. BARRETT. Child abuse is a criminal offense. And under the new guidelines, when we inappropriately fail to treat a patient, the charges are not civil but criminal. And I think this is a major concern of many practicing physicians.

CHAIRMAN PENDLETON. Mr. Destro.

COMMISSIONER DESTRO. Dr. Barrett, would you expand a bit—you said that one of the problems you've had is not so much your decision to go ahead when you think it is appropriate, but the parents saying it's time to stop, even though in your medical judgment you might think that the child is going to grow up to be entirely normal. Would you tell us in your experience what factors the parents use to make a determination that they don't want to continue?

DR. BARRETT. The emotional cost to a parent of having any degree of handicap of a child, a very premature child, a child requiring respiratory support, is very, very high. The expectations of all parents when they have a baby is it's going to be a 7½ pound wonderful child, and they'll take it home and it will grow up to be whatever—a doctor, lawyer, commissioner.

When this does not happen, their emotional costs are very high. They see a child over whom they have no control, whom they cannot carry, handle, nurture—a bunch of strangers is nurturing this child. They see this baby often as someone who cannot grow up to be anything that they would perceive their child should be.

And although we try to educate them, show them the growing babies, let them talk to parents who have been through this, it doesn't make much difference to them. They are really grieving over this, and appropriately so.

The financial cost is inordinate, and parents are responsible for at least a portion of the medical costs.

And I think the various tensions are what make many parents ready to give up when physicians think that they should go ahead.

COMMISSIONER DESTRO. You indicated that in one case—correct me if I'm wrong—you went ahead and filed for a charge of neglect, and the Los Angeles County judge upheld the parents. What were the factors that went into that decision? What were your reasons? Can you tell us a little about that case?

DR. BARRETT. This was a baby with Down's syndrome and duodenal atresia. It was about 8 or 9 years ago. And the juvenile judge refused to give me consent to perform an operation on this child.

COMMISSIONER DESTRO. What were the parents' reasons for not wanting surgery done?

DR. BARRETT. A child with Down's syndrome wasn't in their expectations of a child.

COMMISSIONER DESTRO. Do you have any doubt that if the child had not been Down's, but it had the same condition that they would have gone ahead and had the surgery?

DR. BARRETT. Absolutely; absolutely. It's corrective surgery.

COMMISSIONER DESTRO. In the same vein, let me ask Dr. Siva, because you raised a question—and I want to address some of the same kinds of questions to Dr. Shaw—you mentioned a move in the direction of family autonomy, and Dr. Shaw raised the question of proxy consent, which is in this case identical. Do you consider yourself an advocate for the patient in that process, or do you consider that it is to be left up to the family?

DR. SUBRAMANIAN. I think it's a very interesting question. If you will look at the patient-doctor relationship, it is basically a question of where the physician provides not only just medical treatment, but support for the patient, and in this situation for the entire family.

So in one sense the physicians, the nurses, and the support who are taking care of the patient are also patient advocates in the newborn situation—with the parents. So specifically in this newborn situation, yes. But if you take this beyond the newborn situation, it is more of an interaction, and the parents have by tradition acted in the best interests of the child.

COMMISSIONER DESTRO. In terms of your interaction with the parents, how do you envision yourself? Do you envision yourself as an information provider basically for the parent and then the choice is up to them? Is that a fair characterization? Or do you provide information and then, in effect, almost like an attorney would, argue your patient's case for them?

DR. SUBRAMANIAN. I think it's much more complex than that. I think in situations where you have a newborn patient in the intensive care nursery, you establish a tremendous amount of rapport with the parent. So there is an ongoing conversation and information that is being given to the parent about the infant, about the progress, and what is going on.

So I think it is not a question of abruptly one day you decide to say, "There's a problem. We'll talk to the parents about what the information is." I don't think it's in that abrupt fashion. It is a continuum, so they already have a lot of information about this.

And I think you give the information to the parents in terms of what are the options and what things are there, but if they come back with a decision which, in your best medical judgment, is inappropriate, which is what Dr. Barrett was speaking of in the Down's syndrome situation with duodenal atresia, you would then argue for the patient, for the baby, and say, "At this stage this is not appropriate."

And I think, in the majority of cases, if there has been good rapport, discussion with the parent should be able to resolve the situation. So it is not a situation of simply giving information and stopping there, but once the information comes up and in the medical judgment various decisions are consistent, I think there should not be any problem.

COMMISSIONER DESTRO. What about if in this process and in this rapport you find out that the parents are considering more than the individual child's best interest; they are thinking about the family and everything else, and you feel that the child's interests are getting a little lost in the process. What would you do in a situation like that?

DR. SUBRAMANIAN. I think I would be looking out for the child's interests primarily at that point. As a person in neonatology who has been trained to take care of infants, in the best interests of the child, again, I would try to provide more information to the parents for their understanding.

COMMISSIONER DESTRO. Dr. Shaw, what would you do in a situation like that?

DR. SHAW. I think I would agree generally with everything that Dr. Siva said. I think as physicians we have to consider the impact of what we are doing on the families as well as on the infant, but I think, by and large, we consider ourselves advocates for our patients, and the patient in this situation is the baby. I think we need to separate the interests of the baby from the interests of the parents, and I think we need to require the legal mechanism to do so. I think in States where it is not difficult or there is no punishment to the family to give up a baby, where there are options which will allow the baby's interest to be protected and the family's interests to be separated from that, then I think we should have those options available to us. And I think this is by and large where the infant care review committee and the hospital mechanism that is permitted under the new legislation can be very valuable and very useful at that particular point.

COMMISSIONER DESTRO. Let me just ask the panel as a whole: What kind of training did all of you get or do you get now in terms of dealing with the disabled or the handicapped? Do you get any formal training? Are there any rounds that you get in medical school? Do they give it in medical school? And how much?

Dr. Barrett, do you want to respond?

DR. BARRETT. I don't recall having this as a course in medical school. When I was a house officer, we ran the Northwestern March of Dimes Clinic, and our house officers probably spent 25 percent of their time dealing with handicapped patients, particularly those with myelomeningoceles, and were really very well educated, and positive, in the outcome of children with this handicap.

As a faculty member, we spend more time teaching than getting educated. We certainly have grand rounds devoted once or maybe twice each year to subjects similar to this.

But I think that medical schools are just now beginning to understand that this is a basic responsibility in their education of medical students, and that in the next 4 or 5 years we will see a population of house officers that is much more sophisticated in this area.

COMMISSIONER DESTRO. Dr. Siva.

DR. SUBRAMANIAN. Basically, I would agree with Dr. Barrett that in medical school you get primarily theoretical background in terms of anatomy, physiology, malformations, and such. But I think that the majority of training is during the period of house staff where you actually deal with patients as a resident and fellow and think process of decisionmaking during that time—and I think that the many conferences that are held within a teaching hospital, in addition, is very educational and extremely helpful.

COMMISSIONER DESTRO. Dr. Shaw, let me modify the question a little bit and rephrase it in terms of the kinds of information that medical students and doctors have with respect to long term outcomes, things we might call vocational rehabilitation for handicapped infants when they grow up, the long term prognosis and treatment. Is there any training in that?

DR. SHAW. I think when these various entities are described and taught and discussed during medical school, one tries to be as comprehensive as possible in teaching about them. That would include the prognosis in a number of different situations. When one is studying Down's syndrome, one tries to learn about the implications of that for a baby, and this obviously has changed over the last 15 to 20 years, particularly with respect to spina bifida. When I was a medical student, most babies with spina bifida died, most of them because they got hydrocephalus; and the neurosurgeons were just then fooling around with shunts and mechanisms for relieving the intracranial pressure which developed when their backs were closed.

So there has been an enormous change. There are things that can be done for people with cerebral palsy, for instance, which was a hopeless situation when I was a medical student.

I think medical students now are being far better educated in these areas, particularly with respect to long term outcome, particularly what can be done in a multidisciplinary way. This is a relatively new thing over the last 10 or 15 years, the idea of having teams of doctors, each representing a different discipline, working with babies with, say, spina bifida, the children with cerebral palsy, the mentally retarded.

If I could come back to a question Mr. Abram asked me before, the change in perception with respect to the Down's child is partly based on a change in technology, not just a change of perception. In the last few years there has been a change in technology that has affected Down's children, and over the next few years, it will be even more so. There has been a Down's center established, for example, at the City of Hope where I am, which is involving the resources of ear, nose, and throat, dentistry, ophthalmology, and so on, recognizing that a lot of the deficit of Down's syndrome children that has been thought to be congenital related to their chromosomal defect, is indeed related to hearing impairment, visual impairment, and things that can be corrected and, hopefully, adjusted early in life to allow them much greater potential in terms of their development.

So it's the recognition of these things and new surgical techniques applied to the Down's child that are being developed that also improves their prognosis to the point that where doing the early things to salvage them makes much more sense, perhaps, than it did 15, 20, or 25 years ago.

COMMISSIONER DESTRO. So basically what you are saying is that the training they are getting now or the things that are available mainly are approached from the perspective still of the treating doctor and not so much of the long term, what somebody else can do.

DR. SHAW. Oh, no. I'd say much of it in medical school has to do with what the treating doctor can do because that's the basic science of taking care of patients. This is what they have to learn. But they also have to learn what is available in the community that will help these patients in the long run and, as physicians, what changes they can and should help to bring about in the community that will help their patients do better subsequently. And I think this is definitely going on in medical schools now.

COMMISSIONER DESTRO. Dr. Rosenbaum, let me start with you and just ask a definitional question.

[Discussion off the record.]

COMMISSIONER DESTRO. We discussed the question of what is a handicap yesterday with some of the representatives of the medical associations, and one of the attorneys told me that as far as he was concerned we really weren't dealing with handicapped infants, that you had a range of medical problems. Is there some understanding that you or the members of the panel may have as to what we are talking about when we speak of handicapped infants?

DR. ROSENBAUM. I think that's an important area, and I think each of us on the panel and the ones who will sit here in the next few days have their own idea as to what a handicap is all about. We have two neonatologists, we have a pediatric surgeon, and a geneticist, and each of us has a little different view.

Some people may say that a chronic disability is a handicap. The American Academy of Pediatrics a few years ago looked at chronic disabilities in the pediatric population and found that the percentage of children below the age of 17 with a chronic disability was 3.8 percent of the entire population. That included chronic seizure disorders, asthma, diabetes. So it may not be all malformations, the types of things that most of us are used to dealing with. I had a chance to read the regulations a few minutes ago—it doesn't detail by name what a handicap is.

I have always been antilist because you always leave things out, but maybe that has to be done, since from my view I'm talking about malformations that are handicaps, but babies who are premature may well survive with visual or physical handicaps and they need to be considered as well. Burn patients who survive have handicaps also. It's not just the newborn with malformations.

I don't know the answer to your question.

COMMISSIONER DESTRO. I was just trying to get your impressions of what the answer was. I had a little difficulty with the answer yesterday. I just wanted to know what practicing physicians felt about this.

DR. ROSENBAUM. I have difficulty with it as well, as you see.

CHAIRMAN PENDLETON. Commissioner Berry.

COMMISSIONER BERRY. Thank you, Mr. Chairman.

First of all, could any one person on the panel tell me what an ethicist is?

DR. SUBRAMANIAN. I think you can get a better definition from Dr. Fletcher who is on another panel.

COMMISSIONER BERRY. I asked because apparently, from the interview process, you have an ethicist on your review committee, Dr. Siva. You, Dr. Shaw, seem to think that it's all right to have them. And you, Dr. Barrett, have a review committee, but there are no ethicists on it from what I read.

DR. BARRETT. No, we have one.

COMMISSIONER BERRY. And you, Dr. Rosenbaum, talked about how you were a practicing ethicist.

We had some discussion about it yesterday, and I just wonder if anyone can tell me what it means to you, as a physician, when somebody says you're going to have an ethicist on your committee. Anyone?

DR. SUBRAMANIAN. If you're looking for a pure definition, it's a little different than the definition I will give you. An ethicist is probably one who is qualified or has a theoretical grounding in ethical principles in any area. Then you can narrow it down because you have ethics in law and institutional ethics, and then you can narrow it down in terms of biomedical ethics, who is a person who is grounded in the theoretical principles of biomedical ethics.

So when I refer to an ethicist, I usually refer to a biomedical ethicist in terms of one who has theoretical grounding in the principles of biomedical ethics. There could be physicians who have excellent knowledge in the area of biomedical ethics who can serve as ethicists as well.

COMMISSIONER BERRY. Excuse me, Dr. Siva. Perhaps I haven't framed my question correctly, because I'm not getting an answer that I can understand, at least. All I really care about is: If you have a review committee, do you care if someone says there is going to be an ethicist on it? Do you worry about what kind of ethicist that is, or do you feel that one ethicist is as good as another ethicist?

DR. SHAW. That's like saying one doctor is as good as another doctor. You'd like someone with a background in ethics who addresses the kinds of problems you're going to see. For instance, an ethicist on this committee you'd like to see is one who has a background in biomedical ethics, specifically with some practical experience with the kinds of problems one is going to see. We are all familiar with a number of people who are qualified in this area who we would recognize as ethicists. Some have medical backgrounds; some have legal backgrounds; some have theological backgrounds; but all of them have had special training and interest in this particular area with some practical application of it, either making rounds with physicians or spending time in the hospital working with these particular problems.

COMMISSIONER BERRY. I only asked the question because years ago I was a philosophy major as an undergraduate and I took courses in ethics. As I understood it—I haven't taken courses since—there were different theories of ethics and approaches to ethics. So it would depend on which kind of ethicist you got unless the field has changed since then.

DR. SHAW. We would certainly want someone who is familiar with all the different theories of ethics.

DR. SUBRAMANIAN. I think of it in terms of referring to the utilitarian and deontological components as being the two major components. And I think it is in terms of the basic concept of utilitarian is in the best interest of society, whereas the deontological is in terms of the principles of autonomy, respect, trust telling, promise keeping, etc. I don't think it makes a difference in terms of what is the broader goal of the ethicist, but I think in terms of the basic good knowledge of both utilitarian and deontological principles.

COMMISSIONER BERRY. That helps me a great deal.

The other thing I wanted to ask Dr. Shaw was about the experience you described with Down's when you responded to the questions of the other Commissioners about how technologies, perceptions, and so on have changed, and in the old days how a physician would think about the fact that the parents were going to institutionalize the child as a consideration. Did that experience teach you anything about what physicians ought to do when they make decisions about treatment?

In other words, did that experience teach you that physicians ought to make decisions based on what they can do technologically without concerning themselves about whether people are going to be institutionalized or not or how the technology is going to change years from now, just at the time when they're making a judgment, whether it's intestinal blockage or whatever can be done, just do whatever they can do at the time they can do it? Is that a correct inference to draw from what happened in the history of Down's and how it's handled then and now?

DR. SHAW. Not altogether. I think we still must make decisions based on the times in which we live and what else is available. One example I might pick is the child born without any intestines. We hope some day intestinal transplants will be feasible. Whether it is reasonable at this time to put a baby on total intravenous feeding knowing the child is going to spend a lifetime on total intravenous feeding, and we do this very often with the idea that intestinal transplants will occur perhaps 10, 15, 20, 25 years from now, I don't think it's reasonable for us to do that. I think we have to consider what we have to offer the baby now. We can save that baby. We can plug in an IV. We can't transplant the intestine. We know what the complications are of long term intravenous feeding which need to be presented to the parents.

My own feeling, for instance, in that situation, as opposed to the Down's syndrome situation vis-a-vis institutionalization a few years ago, I feel parents should have the right to decide whether they want that baby maintained on long term intravenous nutrition in the hope that eventually something will be found that will enable them to be taken off it.

So I think those kinds of considerations are reasonable today in light of what can be done today as they were 10 or 15 years ago, in the light of what could be done then.

COMMISSIONER BERRY. What is there in the training of physicians that makes them responsible for deciding not only what they can do as medical experts, but for deciding also what will happen to people after they've left the hospital and, therefore, they should or should not do something to them?

For example, if my doctor decides that he ought to operate on my foot or not, based on whether I'm going to go out and play tennis and break it and come back again, as opposed to whether he can fix my foot—I'm asking this quite seriously—what is it about your training, then and now, which means you have to consider what is going to happen to people when they leave and all of that rather than what you can do?

DR. SHAW. You have the option of whether you want your foot operated on or not. The physician has to tell you, "If you go out and play tennis, you're just going to do this again to yourself." And then you may decide, "Well, maybe I don't want to do that," or, "I don't want the operation," or, "I don't want to play tennis." You can make that decision. But the physician has to know, for example, what you're going to do after he does the operation so he can advise you and you can make an intelligent decision based on that. If he just goes ahead and fixes your foot and doesn't tell you, "If you go out and play tennis you're going to ruin your foot again," then he's done something very bad.

COMMISSIONER BERRY. Sir, that was not my point. I may not know whether I'm going to go out and do it or not. I may or may not. But he knows how to fix my foot.

In the case of the Down's child we were talking about, parents may have said they were going to put him in an institution, in those early days you were talking about. They may not. Or now they may or may not. Or they may put him in for a while and take him out again, for all we know. But why is it necessary for you to make a judgment about whether there will be surgery based on the fact that now they say they will put them in or won't put them in or they may be there forever? Why not just do the surgery you know how to do?

DR. SHAW. In those days, by and large, I did the surgery I knew how to do because most of the time the parents said, "Fine, go ahead and do the operation." In the situation where the parents didn't want the operation done and said I'm going to put this child in an institution, and knowing that most of the infants that went into those institutions with that condition would be dead within a period of a few months because of an infection, I would tend in those days to go along with the parents' decision.

COMMISSIONER BERRY. Dr. Barrett, you talked in the interview, at least, about not worrying about economic factors because all the women who had babies delivered in hospitals had subscribed to an insurance package, so all necessary postnatal treatment is without additional cost. Is that substantially correct?

DR. BARRETT. No, that isn't substantially correct. I said that there is good funding for children who require intensive care. In the State of California it is not now as good as it was when Ms. Hanrahan was on the West Coast talking to me.

It used to be that California Children's Services, which I assume is similar in most States of the Union, would make a contract with parents so that their responsibility would be equivalent to twice their last year's State income tax in my State, which most parents could handle reasonably well.

At that time the upper limit of income for which they could be eligible was $125,000 a year. Most of our families were eligible.

Since then the State has cut the maximum income of the parents to $40,000, and now significant numbers of our parents are not eligible for California Children's Services until they can demonstrate that they have spent 20 percent of their last year's income in cash on the care of this child, and economics is becoming a major problem.

But it would never be a factor in my decision whether or not to treat a child, but it is becoming a very real factor to the families of many of our patients.

COMMISSIONER BERRY. Thank you, Mr. Chairman.

CHAIRMAN PENDLETON. Mrs. Buckley.

COMMISSIONER BUCKLEY. First of all, what I want you to consider is only those children with severe multiple handicaps. When you talk about Down's syndrome with intestinal blockage or esophageal atresia, that's not the child I am talking about. I'm talking about a child with severe multiple defects, some of which can have corrective surgery.

Thinking about these kids, can you tell me when section 504 came about, and all the furor about applying it to the handicapped newborn—can you tell me the difference between how the treatment of these children was viewed and how aggressive your treatment of these children was after this interpretation came out? And can any of the four of you tell me, excluding your colleagues' experiences, if there was a difference, and if you were more aggressive in your treatment? Did it help the child in total? Was it better for the child that you were more aggressive in your treatment or not? Did it make a difference on how you viewed their treatment or not?

DR. ROSENBAUM. I might just start very quickly. Dr. Bunzel asked a similar point and I want to get to that for a minute.

I think it is important for the Commission and everyone to understand that most of the panel members are at major academic centers. Dr. Bunzel asked a few times, "What difference has it made?"

At most academic centers the difference is probably small, if at all. That is not to say it is not different somewhere else, in a level one or level two nursery, where there is now more attention to issues like this.

So in the academic centers, in my mind—and I expect my colleagues would echo the same thing—this has made little difference in the approach to the child with multiple severe birth defects.

I was also glad to hear you exclude the child with Down's syndrome because babies with Down's syndrome have been caught in the middle of this and probably shouldn't be.

COMMISSIONER BUCKLEY. Anyone else? Or is that the experience of all of you?

DR. SUBRAMANIAN. I think Dr. Rosenbaum put it very nicely in that we all represent primarily academic teaching institutions, and we have gone into this discussion about the entire problem, and the availability of the multidisciplinary teams of consultants to look into these factors. So I don't know whether this would significantly influence our decisions, although it is unlikely.

But I think definitely, from what I read and from talking to other physicians in different institutions, it did influence them in terms of prolonging the dying process in terms of these infants.

COMMISSIONER BUCKLEY. Yesterday in hearing some of the parents speak, some of these parents were not in these nice centers where everything was available and all the specialists were there, and they didn't leave one with the impression that they were very pleased about how knowledgeable their doctors had been and how useful their advice had been.

In your experience, when you come in and look at a newborn with multiple defects, how reliable is your prediction as to their level of mental retardation or their degree of problems? In seeing them after surgery and after treatment, how reliable was your initial prediction?

DR. ROSENBAUM. From my standpoint as a geneticist—and I think that's true for everyone on the panel and all specialties—it really is an experiential difference. If you took a practicing pediatrician, even a very senior pediatrician, he may well have taken care of one or two children with Down's syndrome in his entire practice. And he can read the literature and talk to people, but he may not have the personal experience that some people on this panel have. So it really comes down to what someone's experience is.

I think there is a trend nationally towards involving these specialty centers more and more, so that if you're born 100 miles from a major metropolis, there's much more likelihood of involving some of those specialists and making those decisions even long distance, and that will certainly be to the benefit of the child.

But these decisions are experiential decisions. And to answer your question directly, I think if we face a problem enough times our own predictions are pretty good. If we don't, then we're human like anyone else, and we have to look at the probabilities and try to work that out.

I'm sure Dr. Shaw, as a surgeon, has some feelings as well. But in terms of accuracy of prediction it really comes down to the experience of the individual.

COMMISSIONER BUCKLEY. Dr. Barrett, from your interview we understand you said you used as a criterion whether a child had the ability to know his environment. How do you go about assessing this? If I'm going to say this is what he has to be able to do, how do you do this with a newborn?

DR. BARRETT. You cannot test it absolutely, and again you have to go, as Dr. Rosenbaum was saying, on your experience with any given malformation.

For example, the babies with trisomy D, with trisomy E, who we have been discussing as examples of multiple major malformations—there is a considerable amount of information, (a) that the majority are dead by 1 year of age, and (b) that those who survive do not almost universally acquire cognitive function, the ability to recognize their environment, to recognize their surroundings, their parents, the people around them. And this is the category of patient about whom I was talking.

We often make mistakes, not in these babies so much as it is in the preterm baby who may have had an intracranial hemorrhage, and our predictions there may be way off. There are babies who have major hemorrhages who may grow up with cognitive function, and there are babies with what we think are fairly trivial functions who grow up without cognitive function, although that is relatively rare. In the major malformations we deal, again, on the experience and the literature which we have acquired.

COMMISSIONER BUCKLEY. In these babies that you treat that have multiple surgeries—five, six, seven, eight—that wind up with paralysis or colostomies or problems with bladder and problems with bowel, that have mental retardation, what kind of life expectancy do these patients really have? Do you see them throughout this period of time? Do you see them until their death if they die or if they don't die? Do you see them after the first month or 2?

DR. BARRETT. I do not anymore. When I was a house officer, I certainly followed them. I was a house officer for 4 years. At that time we dealt with patients with spina bifida up to the age of adulthood because the adult physicians weren't interested at that point.

But their survival in the examples you spoke about is basically related to several things. One, if there is a shunt, can they be maintained free of shunt infections? This is much easier now that a peritoneal shunt is used rather than a vascular shunt. If they can manage bladder evacuation and don't get a lot of kidney infections, they should be able to survive to adulthood. Beyond that I'm ignorant.

COMMISSIONER BUCKLEY. What about the rest of you? What is your experience on the life expectancies of these children? After you do all these surgeries and all these things to them, can they go out of the hospital and live for how long?

DR. SHAW. There is a great variability there. It depends on a number of factors.

COMMISSIONER BUCKLEY. Those with severe defects.

DR. SHAW. It depends to a large extent on the care they get subsequently and what's available to them. We know the children raised at home who have access to tertiary care centers, multidisciplinary teams, for example, do better than those, for instance, who are put in rural institutions. So, again, it depends on what is going to be done to support these infants and their parents. The viability of the baby and life expectancy, as well as quality of life, if I may come back to that, depends to a great extent on the resources available to that family after they leave the hospital. It is very easy for the surgeons to do these simple operations, and most of us never know what happens to these babies later on. Sometimes when we find out, we wonder whether we really should have done that little simple thing that we did. So it really depends on many other factors whether these babies survive or don't survive.

COMMISSIONER BUCKLEY. Do you have any idea how many years? Adulthood?

DR. SHAW. It depends so much on the condition. If you take a baby with cystic fibrosis, one can say what the average life expectancy is. If you take some of these trisomies that Dr. Barrett mentioned, we know they don't live beyond a year. So as genetic knowledge expands and we follow more of these infants into later life, we have a better idea of what the average life expectancy is.

CHAIRMAN PENDLETON. I'm reminding my colleagues we have about 5 minutes left for the rest of the questions. Mr. Bunzel.

COMMISSIONER BUNZEL. My question will take about 2 hours, but I want to follow through on something my colleague, Commissioner Berry, began with. We were thinking along the same lines here.

Ethicism is almost becoming a cottage industry. I have a feeling now that we can rent an ethicist. And I'm curious about something that I really would prefer to ask of physicians than I would later on of the self-styled ethicists who will be with us later on in the afternoon.

I would like to ask, but I will pass over it: How are ethicists chosen? Because ethicists differ. I was not entirely satisfied with the response that was given to Commissioner Berry's question. So let me try to flesh this out a little more provocatively for the sake of the argument and see how you will respond.

Could you have, in your institution, an ethicist, or an ethics consultant, who might believe that because of various behavioral developments the right to life really begins at 3 months? Now, the argument here is that neonates have no real capacity for thought and, therefore, should not be regarded or treated as a full person. Now, that is a very strong view held by a very responsible group of ethicists, and I am wondering whether, as physicians, that kind of question, the question as to whether that kind of ethics consultant has ever come to your attention, and would that kind of ethicist be the sort of ethicist you would seek out? Because it does not confirm any of the arguments any of you has made today, that is, that ethical viewpoint in perspective is a different perspective.

But would you be comfortable with that kind of ethicist? Is that the sort of perspective you could live with? Is that the kind of ethicist that would serve a function on an ethics committee? Dr. Barrett, let me begin with you.

DR. BARRETT. No.

COMMISSIONER BERRY. They told me they'd take any kind of ethicist they could get.

COMMISSIONER BUNZEL. Yes, and I wasn't too satisfied with that answer. I thought if we fleshed this out we would find that in fact there wasn't really a feeling that six of one and half a dozen of another would do. Could you embellish a little bit on your negative view about this particular ethicist?

DR. BARRETT. I think to neonatologists, reasonable and appropriate care needs to be given, as I stated earlier, before delivery. We care very much about the last part of pregnancy, no matter how short it is. We care very much about the fetal well-being during labor and the delivery.

I think to have someone giving us advice, as ethicists tend to do, with the attitude that nothing important happened until they were able to smile and coo is absolutely inappropriate. I would reject such a person out of hand.

COMMISSIONER BUNZEL. Whether or not that's a fair description of the cooing of ethicists as a cooing group or not, what I am listening to you say, by my inference, is that either implicitly or explicitly there must be some kind of test, if not a litmus test, that would pass or fail the application for consideration of ethicists; that in fact, as we now hear it, they are not all the same, that it isn't true that one is as good as another. There are a variety of groups, and in point of fact what you have just said is a very good response to suggesting that a particular point of view and underlying philosophy is necessary because of some of the reasons that you have advanced.

If I may simply push this a bit further, the reason I raised this is because I am of the opinion that many of these ethical considerations do have a very significant role to play in terms of whether, for example, an ethics committee will consider only one factor, namely, whether the infant had a significant chance of survival, or whether an ethics committee would also consider the quality of life factor, and should it equally, on an equal basis? Or should the cost of treatment, for example, be a factor?

Now, these are only some of the questions, and they don't go to all of the theological points and positions. Having been brought up in a family with a physician—I can only speak for myself—physicians don't like to think and talk in theological terms, and not always in the deepest ethical terms. But the implications of an ethicist and an ethics committee has much to say about how you would regard and whether you would regard the patient as well as the quality of life and the family all on the same plan.

That is why I am suggesting that perhaps there needs to be a reconsideration as to whether all ethicists are equal, because in point of fact some of them are perhaps more equal than others. Dr. Shaw, does this make any sense to you?

DR. SHAW. Yes, it makes very good sense to me. I have encountered ethicists whose opinions I would not find acceptable, as I have encountered doctors and lawyers whose opinions I wouldn't find acceptable. And I wouldn't consult with doctors and lawyers whose opinions I would reject because I know it comes from a philosophy which I can't accept, any more than I would an ethicist who has a particular bias that I feel is incorrect and unacceptable.

COMMISSIONER BUNZEL. Then who picks the ethicist and by what criteria? How are they chosen? They aren't just delivered like infants. How are they chosen?

DR. SHAW. Chosen for what? To participate in infant care review committees, or in what capacity?

COMMISSIONER BUNZEL. I think they vary in different respects. I don't know whether we are down to the point of having itinerant ethicists or not.

DR. SHAW. We do have itinerant ethicists.

COMMISSIONER BUNZEL. Is an ethicist who would come to your committee for consultation and participation in the committee from a neighboring hospital acceptable because he or she comes from a neighboring hospital? Or would you be concerned before he or she arrived that he or she was of the proper perspective?

DR. SHAW. I would be very much concerned about the particular point of view of a particular ethicist who was going to participate in deliberations affecting the treatment or nontreatment of newborn infants.

COMMISSIONER BUNZEL. So there would be a philosophical test of some kind.

DR. SHAW. I would hope so. And particularly if this person were going to participate regularly in these kinds of deliberations, I would feel the general point from which this person is coming needs to be known to the members of the committee, and as the other participants of the committee, the same sort of thing. Their general orientation, I think, is an important part of their acceptability to participate in such a review committee.

COMMISSIONER BUNZEL. Who would draw up the criteria by which you would decide that this ethicist passes and this ethicist flunks?

DR. SHAW. Again, it seems to me it depends on the situation in which the ethicist works, and how much the ethicist has to say about what actually is happening.

COMMISSIONER BUNZEL. Let's assume that he says as much as your committee wants him or her to say and plays the role that you have set out, but what you need to know first is whether this person's philosophy is acceptable to you. How do you determine it? What are the criteria, and who sets those up?

DR. SHAW. I don't know. It differs from institution to institution. In institutions in which I have been, we have had a number of ethicists participating in panels and discussions about these issues. And I think that over a period of time, one or another would appear to reflect a philosophy, or at least a background, that would make that person work better in a committee situation that has decisionmaking powers than others.

CHAIRMAN PENDLETON. It seems to me that maybe Dr. Bunzel is looking for a new role for himself on the West Coast.

[Laughter.]

DR. SUBRAMANIAN. Commissioner Berry addressed the question, I think, in terms of the major components of philosophy and ethical theories. And obviously, like physicians, ethicists also have different theories about the decisionmaking process in terms of what is in the best interests of the patient and what are the things to respect. But in terms of looking at the infant care review committees, the first component, if you are talking in terms of weightage, I think, is what is in the best interest of the patient: What is right and medically correct for the patient?

The reason for getting the counsel of the multidisciplinary team, as I said, is only in situations where there is a gray area. In defining the problem, we are talking about less than 0.7 percent of the babies that are born who are going to have multiple severe problems.

So we are not talking about a large percentage of babies where they need consultation. Even in this 0.7 percent, the information that we have, for example, is more than 50 percent of them are in the ranges of Down's syndrome, we have eliminated that as a consideration in the decisionmaking of whether to have treatment.

So we are talking about a small number of infants where the question comes up, after considering the medical indications and judgment in terms of what is in the best interests of the patient, then the consultation by the two components that you mentioned in terms of the quality of life—and I think I agree with Dr. Barrett that at this point I don't think the consideration of cost comes into it in terms of decisionmaking whether to support or not support.

Like Dr. Shaw mentioned, I am exposed to very many ethicists in terms of the number of ethicists available to my committee. Ethicists that are available to us have different perspectives in terms of what is best.

COMMISSIONER BUNZEL. I could make the argument that an ethicist really ought not to be in a position simply to ratify the committee's opinion or the doctor's decisions—

DR. SUBRAMANIAN. I agree.

COMMISSIONER BUNZEL. —but rather ought to be there to raise all the kinds of disturbing questions that disagree with, perhaps, those views and premises of the physicians. And if that's the case, then perhaps in Dr. Shaw's committee there is, in fact, room for an ethicist who does not start out with the same premises and assumptions, but challenges and makes the physicians and the whole committee regard a lot of issues which they may not simply consider. And it may well be that the role of the ethicist is to challenge fundamentally the "givens" of the doctors.

DR. SUBRAMANIAN. I would agree that this is their role. I think that they are not interested in terms of what is the decision of the physician or what the prejudices or biases are that they may have, but in terms of clarifying the principles of what is in the best interest or under conditions what ethical aspects should be looked at. More often than not, they are in the process of challenging the whole discussion and looking at different aspects of it.

DR. SHAW. I think the litmus test of a good ethicist is the unwillingness to make decisions himself. The ethicist is not the person who is going to make the decision for the ethics committee. The ethicist is the person who is going to stimulate discussion and bring up points of view and considerations of the physicians and others that have not been thought of and, as Dr. Siva says, to challenge their concepts and ideas.

COMMISSIONER BUNZEL. I am not entirely certain why the particular example of an ethicist that I mentioned could not serve that function, even though he or she came from a different pew in the church. You started off by saying—and so did Dr. Barrett—that there are certain ethicists that are not acceptable. What I'm asking you is, based on what you just said, whether that nonacceptable ethicist couldn't, in fact, perform very well the function that I'm laying out because, in fact, he or she comes from a different philosophy.

DR. SHAW. I have a feeling that an ethicist who feels that life begins 3 months after birth is not going to perform the kinds of functions that we would find useful. I think that particular bias would make the kind of challenges and discussions that such an ethicist brought forth—perhaps they could do that, but I think it's unlikely. I think their initial bias and their initial assumptions would make it unlikely that they would be open-minded with respect to the other kinds of discussion we'd like to have.

CHAIRMAN PENDLETON. We have just two other short questions here. Mr. Abram has one and the Acting Staff Director has a couple of questions. We are over time so we will delay the next panel a little bit.

VICE CHAIRMAN ABRAM. I wouldn't intervene except that I am really troubled by some statistics and also conflicted by the gratitude that I have for the advances in neonatology. But my question really runs to the issue of whether what we can do we should do.

Now, statistics show—and you may challenge them, but I guess they're about right—that babies whose birth weight is between 500 and 1,000 grams, of that 68 percent die. Of those who survive, 30 percent are handicapped.

Should neonatology, of which you are great examples, be trying to get this birth weight down further and further and further? Was there a moral purpose in showing how much we can do at the verge, at the edge, to the point now, when resources are difficult to come by in the home and in the public, and we know that something like, just say, 60 percent die after heroic efforts, and of those who survive, the handicapped will at least be something around 30 percent—and these are neurological and other handicaps. We don't know the psychological handicaps yet—handicaps of being kept from the mother, kept in a sterile environment with the lights on all the time, not being cuddled. We don't know. We don't have the experience yet.

So my question to you is: Are we on an exercise of proving what technology and science can do? And, if not, is "can do" equivalent to "should do"?

CHAIRMAN PENDLETON. You said "get the birth weight down," so we might have something like a 200-gram baby surviving as opposed to 1,000.

VICE CHAIRMAN ABRAM. It's down pretty far already, and the consequences are there.

DR. BARRETT. I can speak to that from my own perspective, and this is very important in our discussions antenatally with parents.

We personally do not recommend to them a cesarean section or fetal monitoring at less than 27 weeks of gestation, which is approximately 800 grams.

In our fiscal year '83-'84, which is our most current year since we're not through '84-'85, we had in my hospital 15 babies born who were less than 800 grams. Fourteen died. And the 1 survivor out of the 15 was, as far as we can tell now, at a year and a half of age, normal. However, between 800 and 1,000 grams, we had 13 born and 1 died, and we had a survival of 92 percent. And of those babies, as far as we can tell now, about 40 or 50 percent—as far as we can tell—are going to be completely normal.

VICE CHAIRMAN ABRAM. Forty or 50 percent?

DR. BARRETT. As far as we can tell.

But I think that going back to try to save every 23-, 24-, and 25-week fetus or newborn is irresponsible on our part. I'm not out for a world record on the smallest surviving baby. I'm out for a world record on the most normal survivors or reasonable survivors of the tiny babies.

DR. SUBRAMANIAN. Let me address that question. I can give you some statistics the same way, but there are differences.

I have a different perspective in that I don't think it's purely a medical judgment or a medical decision in terms of how far you go. I think it is in terms of the societal judgment, in terms of taking all points into consideration.

For example, in England and in Sweden, the decision has been made at the societal level that infants less than 750 grams will not have any extraordinary support of life other than the basic comforts, unless there are some other factors that require intervention. So the society there has made the judgment in terms of 750 grams as the lower limit at which extraordinary measures will be applied. I believe at this stage—it is not written anywhere, but I think it's basically accepted that 500 grams as the lower limit, good or bad, can be replaced, rather than the 750 grams as the lower limit.

One of the components that you have to look at is there has been a change within the last 10 years or 15 years. Infants who are more than 1,000 grams have now a 95 percent rate of survival, and over 90 percent of them are completely normal. Whereas the same statistics, if you look at babies who are less than 1,000 grams, if you're looking at 10 years ago or 12 years ago, the survival statistics were less than 40 percent, 30 percent, and the percentage of the babies who were normal was also much lower.

But with continuous aggressive management, starting prenatally with the obstetrician and the neonatologist, those numbers have changed, like what we are learning about Down's syndrome, about the prognosis, about the future. We are at this point in a state of flux. I think the whole technology, skills, and attitudes—all of them are changing because of rapid changes in this process.

I think that's probably why when one of us mentioned parental opinions—the problem is the whole field of neonatology is changing so rapidly I don't think it's feasible at this point to medically say that this is something we can fix as a lower limit clearly, that subjectively we can do something about it.

I think that the parents as well as society, at this point, are caught in a state of flux because of the rapid changes. As you mentioned, we are hitting the lower limit. And I think with continued aggressive approach we will be able to have increased normal survivals. But that is in terms of the medical judgment, but the total issue is not purely medical.

CHAIRMAN PENDLETON. Max.

MR. GREEN. You had testified about the changing attitudes of physicians towards the treatment of newborns with handicaps. What about the attitudes of the parents? Has there been any change in that? Has there been a greater or lesser percentage of parents who now want their newborns with handicaps to be given surgical treatment?

DR. SUBRAMANIAN. I can speak for myself. I have perceived over the last 15 years a change in the attitude of the parents as well, in terms of the infants with or without handicaps. There has been the same educational process of the society taking place, in terms of the knowledge and availability of services, and the potential, I think, has changed the attitude of parents in terms of surgery or anything else.

CHAIRMAN PENDLETON. Thank you very much.

We will take a break and summon our next panel in about 10 or 15 minutes.

[Recess.]

CHAIRMAN PENDLETON. Now that we have a quorum here, I'd like for my colleagues to pass this resolution that deals with a hearing subcommittee, what we had at the affirmative action hearings. It is to form a subcommittee for the purpose of conducting the hearing, in case all of us are not here. So before everybody runs, we've got to have a subcommittee.

VICE CHAIRMAN ABRAM. I move the resolution.

CHAIRMAN PENDLETON. Is there a second to the resolution?

COMMISSIONER BUNZEL. Second.

COMMISSIONER BUCKLEY. Read the resolution for the record.

CHAIRMAN PENDLETON. It will be in the record. I'll give it for the record.

[The resolution is as follows:]

## RESOLUTION FOR HEARING SUBCOMMITTEE

WHEREAS, section 6(f) of the Civil Rights Act of 1983, 42 U.S.C., section 1975d, authorizes the Commission, or on the authorization of the Commission, any subcommittee of two or more members, at least one of whom shall be of each major political party, to hold such hearings as the Commission or such authorized subcommittee may deem advisable for the purpose of carrying out the provisions of the act; and

WHEREAS, the Commission deems that it may be advisable that said hearing be conducted before a subcommittee of the Commission; it is therefore,

RESOLVED that the Chairman be authorized to appoint any appropriate subcommittee for the purpose of conducting said hearing as he shall deem advisable.

CHAIRMAN PENDLETON. I appoint Commissioner Buckley and Commissioner Destro as a subcommittee to conduct these proceedings in the event that our colleagues are called elsewhere.

Let me announce at the beginning that Mr. Smith is the executive director of the Spina Bifida Association of America, and the agenda mistakes him as the president.

I do want to say to the people in the audience, I've had some conversations with some of the people in the media, and perhaps some of my colleagues might want to make comments on this issue. Whenever the Commission conducts a hearing, it does not mean that there is something wrong. It means that there is an issue that deserves public attention as we conduct our work under the civil rights statutes. All we are doing here now is gathering information about a situation that we think is of importance to the administration and to the Congress and to the broader public.

I do not want the assumption to get out like some press people have had. They have asked, "Do you have a lot of complaints? Has somebody been to your office? Have you investigated? Have you seen things wrong?"

That is not the purpose of this hearing at all. It is to gather information and, if necessary, to pass that on as policy recommendations or policy guidance to the administration and Congress, and certainly we will publish the results of these proceedings and have some final report. The thrust of my comments is to disabuse you of the fact that something is wrong at the present time. We are just trying to find out what the situation is, primarily under our monitoring responsibility.

We will now go to the next panel. This is the one on "Scope of the Problem: A Disability Perspective." I will turn to General Counsel, who will begin the questioning.

## Scope of the Problem: A Disability Perspective

### TESTIMONY OF DIANE CRUTCHER, EXECUTIVE DIRECTOR, NATIONAL DOWN'S SYNDROME CONGRESS; HARLAN HAHN, PROFESSOR OF POLITICAL SCIENCE, UNIVERSITY OF SOUTHERN CALIFORNIA; AND KENT SMITH, EXECUTIVE DIRECTOR, SPINA BIFIDA ASSOCIATION OF AMERICA

MS. GEREBENICS. Thank you, Mr. Chairman.

Beginning with you, Mr. Smith, would each of you state your full name for the record and your organizational affiliation or present position.

MR. SMITH. My name is Kent Smith. I'm the executive director of the Spina Bifida Association of America.

MS. CRUTCHER. Diane Crutcher, executive director, National Down's Syndrome Congress.

CHAIRMAN PENDLETON. I'm sorry. I need to swear the witnesses in. Strike all of that.

[The witnesses were sworn.]

MR. SMITH. Again, I am Kent Smith, the executive director—thank you for giving me the extra opportunity to correct the agenda—of the Spina Bifida Association of America.

MS. CRUTCHER. Diane Crutcher, executive director of the National Down's Syndrome Congress.

MR. HAHN. Harlan Hahn, professor of political science and director of the Program in the Study of Disability in Society at the University of Southern California.

MS. GEREBENICS. Mr. Smith, could you briefly tell us about the Spina Bifida Association, when it was founded, and its purpose?

MR. SMITH. Yes. The Spina Bifida Association was really founded as part of a meeting with the National Easter Seal Society in 1972. In 1975 we established our charter. It took 3 years to really set our goals, our priorities, where we wanted to go, and to set the issues that we felt we should address ourselves on a national level.

In 1976, during our annual conference in Cincinnati, we actually moved into much more of a professional organization, and my involvement as an advocate, parent, involved with a local chapter, they asked me to start moving into a national involvement, and I became the volunteer executive director. That was more formalized in 1979 when I helped establish the central office in Chicago.

Our organization started out with 24 chapters, a chapter being basically a family-oriented, consumer-oriented type of a group around a hospital support unit. We have now grown to 106. We are trying to develop 60 additional chapters in other hospitals and in other areas.

We are primarily a grassroots support unit for each other, but also to bring to the forefront issues that concern us all as parents and consumers, and then to bring them one step further and to advocate for them.

MS. GEREBENICS. One thing we're looking at in this hearing is we're trying to get a grasp on the nature and extent of the problem nationwide, and I wondered if you had any thoughts on the practice of withholding medical treatment from handicapped newborns.

MR. SMITH. Each month in our central office we are dealing with roughly three cases of nontreatment—and I put quotes around those words—nontreatment cases where families have been given information or encouraged not to treat, and through a process that can vary from someone saying, "Well, I know this individual that has spina bifida; maybe you'd better talk to them," and then they get through a chain of command that finally ends up in our central office. We are able to bring certain resources, volunteer-type resources, back to provide them with good information, also professional-type information, and put them with resources and people that are actively familiar with the care and treatment of spina bifida on the professional side as well the parent-consumer side, and do this with people in their area.

MS. GEREBENICS. The other issue we are addressing in this hearing is the appropriate role of the Federal Government. I wanted to get your organization's perspective on the recent Federal activity including activity under section 504 and the recently passed Child Abuse Amendments.

MR. SMITH. We have been an organization that has joined with Down's syndrome and several other groups in helping to bring to the attention of Congress our requests and needs specifically on that point. We were very much involved in the original posting—I call it posting regulations—the original Baby Doe regulations when they first came out. We found ourselves very surprisingly sitting on the opposite side of the table from the medical profession, who are the people that provide the health care to us and to our children.

I think, through the process that developed from that point, it did open up a form of negotiations where for the first time our organization and our parents were viewed as a type of viable and acredible people with a point of view to be considered, and that point of view is the compassion, the firsthand knowledge of a specific case that sometimes is lost in the clinical approach or technical approach from the professional field.

We do not say we know the technical side of a particular medical care, but we do know the human side. And after certain support to adjust, I think our organization represents people that feel very strongly in the raising of children with spina bifida in the home.

Ms. GEREBENICS. And how does the Federal Government fit into that scenario?

MR. SMITH. We were very much involved as trying to bring action, starting out with section 504. As we view it, section 504 does and should be applicable in a situation like this. And we were very much involved in that process.

I think as negotiations continued, as the views were discussed back and forth, other avenues were pursued, and we helped very much in having input into the drafting of the Child Abuse Amendments.

We are hopeful that the Child Abuse Amendments will answer the questions that we have. And the questions that we have from a national sense are: How will it apply, and will equal treatment apply from one State to another? How can we change those attitudes?

We are not sure, but we are willing to try to work within the regulations that have been established. But there still are some questions and some concerns that we as an advocate organization will continue to monitor.

Ms. GEREBENICS. Thank you.

Ms. Crutcher, could you tell us a little bit about the Down's Syndrome Congress and its purpose.

Ms. CRUTCHER. The National Down's Syndrome Congress was formed in 1973. Its primary purposes are parent support and public awareness. It has under its auspices approximately 600 parent groups across the United States that are really its grassroots, its workers. The NDSC is merely an extension of its 600 local parent groups.

All of our parent groups on the local level as well as on the national level are primarily parentally involved. Our 21-member board of directors has 17 parents. There are four professionals that are not parents of children with Down's syndrome. However, many of the 17 parents are also professionals somewhere in the field, most of them having become involved after their child with Down's syndrome was born.

Ms. GEREBENICS. Can you give us any idea of the nature and extent of the practice of withholding medical treatment from infants born with Down's syndrome?

Ms. CRUTCHER. I was very curious to hear Kent's comments because it stimulated some thoughts in my mind regarding the number of calls that we get regarding things that I had not considered to be nontreatment. Initially, when what we call the original Baby Doe was born in April of '82 and upon his death, we got considerable calls in our central office, anonymous calls, from people saying they were representing a nursing field or a consumer of some sort, sometimes medical practitioners, doctors, saying this had happened in their community, in their facility—most of them not wishing to say any more than that, but saying, "We want you to know that this kind of thing goes well beyond Bloomington, Indiana."

We were caught somewhat naive at that time and didn't keep as good a records as we should have in our central office. However, since then we have been keeping better track of things, and we have kept our ear closer to the ground of what's going on regarding treatment of people with Down's syndrome.

As was stated earlier this morning, we have seen an increasing awareness regarding the quality of life of people with Down's syndrome and their response to services, and the fact that they should not be judged according to the diagnosis of Down's syndrome.

So the threat of withholding treatment to individuals with Down's is certainly diminishing. We still get reports of people who have been given the advice, but not forced in any fashion, not to provide their child with any particular kind of treatment or, if nothing else, to just institutionalize him. That still happens.

Ms. GEREBENICS. Could you address the same question I asked Mr. Smith, with respect to the appropriate role, if any, of the Federal Government, and whether you believe the Child Abuse Amendments are and will be an effective means of addressing this problem.

Ms. CRUTCHER. The ultimate role of the Federal Government from our standpoint is that of the ultimate protector.

As I said, we were caught somewhat unaware. We were very, very appreciative of the medical profession, have always been so. I think that's just part of our society's point of reference. And 3 years ago we found ourselves with the reality that perhaps they were as human as every one of the rest of us, and that there were some of those that had a great deal of prejudice and bias towards individuals with mental retardation.

We, at that point in time, began working closely with the medical professionals to see if we could alleviate some of this prejudice and bias, and although those things are still ongoing, they have been very positive. We see the Federal Government's role as one that will ultimately protect individuals with Down's syndrome and other forms of mental retardation from prejudice and bias when it cannot be overcome in any other compensatory fashion.

MS. GEREBENICS. Do you think the State child protective agencies are equipped to handle these problems?

MS. CRUTCHER. I don't believe that the State child protective agencies are currently able to handle the load that they've got right now, prior to the load that was put on them by the Child Abuse Amendments. However, we are very supportive of the amendments and have been.

504, by the way, which you brought up, is to us the civil rights of all individuals. Whether they have mental retardation or not has nothing to do with it, and whether they are 1 hour old or 100 years old has nothing to do with it.

MS. GEREBENICS. Thank you.

Dr. Hahn, could you put into perspective the controversy regarding the treatment of handicapped newborns as it relates to the community of disabled adults?

MR. HAHN. Let me begin by pointing out what I think is an irony here in that I appear to be the only token disabled adult at this hearing which is located in a facility which is at least partially inaccessible. That, I think, is reflective of a general problem that has plagued the community of people with disabilities for a long period of time.

We are, in fact, a minority group. We are, however, not a minority group that is determined or defined genetically. And as a consequence, we lack, often, a sense of generational continuity. Yet, we have understood, as disabled adults, that we have an important responsibility to the rights of disabled infants and disabled children, and that these rights must be protected at all stages of the life cycle.

People with disabilities cannot be granted legal rights or rights involving an attempt to provide relative equality only to the age of 3. If you seek to protect the rights of disabled infants, which I strongly endorse, you must also give corresponding attention to the rights of disabled adults. There is, in fact, a lifelong commitment created thereby.

At the present time, people with disabilities do not have civil rights. We do not have equal rights in employment, in social welfare programs, in education, in all areas of community activity. We have what is perhaps the highest unemployment rate in the country. We have one of the highest rates of welfare dependency in the country. And we face a society which, because of institutional structures and architectural barriers and other restrictions, is even more rigidly segregated than racist governments practicing apartheid. We are denied equal rights in housing, transportation, employment, education, and public accommodations.

And I feel that it is important to view the problems of disabled infants within this context, to understand that we are dealing with, in this case, the youngest members of a minority group who are going to be compelled throughout their lifetimes to struggle with a society in which their main problem is not their functional impairment or the particular diagnostic category into which they may fall, but in which their main problem is the prejudice and the discrimination to which they are going to be subjected by the remainder of the society. And that is my concern about this issue.

Ms. Gerebenics. What effect do those particular aspects of disability have, do you think, on the decisionmaking process in the treatment of handicapped newborns? Do you think that is a central issue?

Mr. Hahn. It is obviously a central issue.

I think the one thing we are neglecting or ignoring in the analysis of this controversy is the fundamental fact, which many of us may prefer not to acknowledge but which is amply demonstrated by abundant empirical evidence; people with disabilities are subjected to attitudes of aversion, avoidance, and rejection. And this is a form of bias, discrimination, and prejudice which is an integral part of our cultural values.

So I would submit that it is impossible for a physician or a nondisabled parent, or anyone in a decisionmaking position vis-a-vis a disabled child, to view the circumstances of that child, to view the potential of that child, in the absence of the biases which are created by these cultural values.

People with disabilities comprise a minority group for some very fundamental reasons. And I think we have to go back to the problems of definition which were discussed this morning.

We understand that the definition of disability is changing from an essentially medical view of functional impairment to an economic view of vocational limitations, and finally, now to what I would term a social-political perspective on disability which understands disability as the interaction of the individual and the environment. And from this perspective the fundamental problem is not the functional impairment or the vocational limitations. The basic problem is that that individual is located in a disabling environment.

When you view the problem from that kind of nonclinical, holistic, more comprehensive perspective, you begin to get different answers to the questions that are raised about the treatment of disabled infants. And I think we have to understand some basic components of this approach. First of all, I'm saying that the fundamental problem is attitudes of aversion, avoidance, and rejection. Secondly, I'm saying that we live in a disabling environment which is fundamentally molded and shaped by public policy. Thirdly, we have to acknowledge that public policy is a reflection of predominant or prevalent attitudes and values.

So from that perspective, the fact that we live in an environment which is inaccessible and disabling to people with a wide variety of disabilities may not be accidental or coincidental. We may be dealing with an environment which was created to perpetuate attitudes of aversion, avoidance, and rejection toward people with disabilities. And that's the fundamental problem. It's a problem of bias and prejudice, which is in the mind of the physician, and in the minds of all those who are nondisabled who are viewing the potential life circumstances of a child with a disability.

Ms. Gerebenics. Thank you.

I'll turn the questioning over to the Commissioners.

Chairman Pendleton. Commissioner Destro.

Commissioner Destro. Mr. Hahn, let me start with you, and I'd like to get the views of the other panelists as well, but you've touched on it the most in your comments.

Yesterday in questioning representatives of the medical organizations, I got the answer from the attorney that this really wasn't a civil rights problem at all. It was really just a range of medical problems.

Would you address the question—and certainly it came up within the Commission—why is the Baby Doe issue even on the agenda of the Civil Rights Commission? Could you give a specific answer to that, and then we'll get into questions about 504.

Mr. Hahn. Specifically, I would say that probably the most fundamental right that any individual has is the right in some sense to live, the right to have the opportunity to pursue a life. But once that right is established, then you must begin to extend it, to recognize, to fulfill principles of equality and freedom which are a fundamental part of American traditions. And those principles have been denied to disabled adults.

The problems of disabled infants are simply a kind of microcosm of the problems of disabled adults who do not receive adequate health care, who do not receive adequate education, who are denied employment opportunities, who are faced with segregation in housing, transportation, and public accommodations.

This is only one small aspect of the problem. And, as I say, it is politically irresponsible and morally reprehensible to be in a position of saying that people with disabilities should be granted legal rights to provide them with relative equality only to the age of 3.

Commissioner Destro. Mr. Smith, is this a discrimination issue to you?

Mr. Smith. At this point I think I would look at it in that light also. We believe that every child with spina bifida is entitled to medical treatment, and that this should be the sole purpose of their medical care, and we should do this irrespective of the quality of life.

We became a participant in the principles of treatment of disabled infants and signed onto that agreement, along with the other disability groups and the American Academy of Pediatrics, and also the American Coalition of Citizens With Disabilities and other groups, including the university-affiliated programs and children's hospitals organizations.

In that phrase is this phrase that we very strongly believe:

> When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer

the infant to an appropriate medical facility, and considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care.

This statement we strongly believe in. And I think the disability groups that were involved in it added this statement and felt that an individual's medical condition should be the sole focus of any decision.

COMMISSIONER DESTRO. Let me just ask, in following up, why do you think that quality of life considerations should even come into all of this in the context here? It doesn't really come in when we are dealing with other minority groups. Why does it come in here? Anyone can answer that.

MR. HAHN. Could I respond to that?

I think it reflects a fundamental assumption, which is prevalent in this culture, that anyone with a significant or severe disability cannot possibly enjoy a life of reasonable quality. I think that we are dealing here with the assumption that people with disabilities are fundamentally biologically inferior. And that's the same kind of stereotyping and stigmatizing to which other minority groups have been subjected in the past.

There is a sort of cultural value that disability represents a personal misfortune which reflects, I think, in part a smug self-righteousness on the part of many nondisabled people. I think people can contribute important valuable things to society with a wide range of mental, emotional, and physical characteristics. And, if I may, to cite an example of that, I might refer to some athletes.

MR. SMITH. I think I would add to that, too. I believe that there is prejudice and bias that has been expressed in society, in the professional field, and if that is not solely dealt with by the professional community, by the physicians, that this carries over in the attitude when you first approach a new parent and tell him that his child has a disability.

COMMISSIONER DESTRO. Ms. Crutcher, what prejudice do you see from your perspective? Can you give a thumbnail sketch of the prejudice itself? How would you describe it?

MS. CRUTCHER. Relative to Down's syndrome?

COMMISSIONER DESTRO. Yes.

MS. CRUTCHER. I think that there is, indeed, a lot of prejudice. In fact, Down's syndrome is probably one of the few groups of disabilities in which there is an extreme stereotype and generalization, even to the point of physical characteristics, hair styles, and hair texture, let alone the fact that everyone with Down's syndrome is just assumed to fall in the moderate to severe area of mental retardation and cannot possibly provide any enjoyment to their family's life, let alone enjoy a life themselves. So I think it's one of the prime areas of stigma as far as MR goes.

I do have a couple of comments regarding the civil rights issue relative to people with mental retardation, particularly Down's syndrome. And that is that in the Constitution of our country, nowhere do I find in there any rights contingent upon ability level.

Beyond that, certainly, civil rights—the inherent right to life is the ultimate civil right, and that is the one we, in fact, demand for people with Down's syndrome.

CHAIRMAN PENDLETON. Ms. Crutcher, on Commissioner Destro's point I just want to go a little further.

Yesterday we had a panel of organizations, and my colleague Mr. Bunzel raised the question did they really support and request that the Child Abuse Amendments be passed. I think we surmised from the conversation with them that they had not really worked for it to be passed, but it was probably the best compromise they could look forward to.

I was discussing with Commissioner Berry—yesterday we heard 504 really doesn't apply because of some court case that is being discussed now in the Supreme Court. But we look back in the law and find out that 504 is back in the law.

Now, it does seem to me that perhaps that is the only protection we have in the Federal domain for handicapped persons, whether they are before 3 or after 3. That's all we have on the books right now in terms of specifically applying to the handicapped. Would you agree, Mr. Hahn?

MR. HAHN. You're talking about 504 being the only law that applies to people with disabilities?

CHAIRMAN PENDLETON. No. I'm saying it's the only law that we have right now on the books that is specific to the handicapped.

COMMISSIONER DESTRO. You mean nondiscrimination.

CHAIRMAN PENDLETON. With respect to nondiscrimination on the books right now.

MR. HAHN. It depends also on your interpretation of the equal protection clause of the 14th amendment.

CHAIRMAN PENDLETON. I'm considering all of that. I'm saying in terms of where we are in the Federal presence by which we've given these Baby Doe cases under 504. We asked yesterday what would be a substitute for 504, and some of them said this act would be a substitute for 504. But this also includes 504.

My question to you is: Do you believe that 504 is sufficient to cover the issues that you are concerned about? What would you do different from 504? How would you amend it? What would you do with it?

We talked yesterday about the purpose of the hearing was to find out whether or not 504 was the best route to take in protecting the civil rights of the newborn handicapped. And that's where we are in these proceedings. It is not the other issue, but where are we with 504? How do you feel about 504's applicability?

MR. HAHN. My concern is that 504 be enforced.

I'd also call your attention to section 127 of the Child Abuse Act which says that nothing in that act has any particular relevance or it would not affect 504, which is something that was not pointed out yesterday; ironically.

CHAIRMAN PENDLETON. That's the point I'm making, that it didn't come out yesterday; in other words, 504 was almost discounted yesterday by the organizational persons.

MR. HAHN. Well, 504 is almost discounted by the people who are supposed to enforce it.

COMMISSIONER DESTRO. The medical groups said yesterday that Congress spoke on 504. Maybe Mr. Smith or Ms. Crutcher could address this. Why didn't the disability groups just move to amend 504 and make sure that the Second Circuit's feeling on all of this didn't stand for what it's worth?

MR. SMITH. I'll take the first one. We felt that there was a viewpoint that we should compromise with the medical people. They felt more comfortable working with the child abuse regulations. And early on there was agreement that that was the avenue we would go. It was not exclusive of never working on 504, but the point was we wouldn't try to go with that respect because that seemed to be a point that the medical community looked at and said, "This does not apply and we feel very strongly about that."

CHAIRMAN PENDLETON. What do you want to recommend to this Commission with respect to 504 that gets to a resolution between where you are and where the medical groups are? What can we tell the Congress and the administration?

MS. CRUTCHER. We feel that 504 is the ultimate civil rights protection for people with disabilities.

CHAIRMAN PENDLETON. Is there anything else you want to do or say about that? I recognize the enforcement problem that Mr. Hahn is talking about, but what else about 504? Just enforce it?

MR. HAHN. I think that's the principal issue on the agenda. But it's not only 504. There is other legislation that should be enforced as well. P.L. 94–142 should be enforced and implemented and adequately funded.

The problem seems to be here in a variety of areas that there is a tendency on the part of many people in public life to say that they support the rights of people with disabilities, on the one hand, and then, on the other hand, they fail to provide the financial resources which are necessary to implement those statements. That kind of contradiction can't be tolerated any longer. It is the same kind of contradiction that's entailed in saying that we will only extend legal rights to people with disabilities up to the age of 3.

COMMISSIONER DESTRO. If the Supreme Court denies *certiorari* in the Baby Jane Doe case, would it be your position as organizations that you would recommend that 504 be amended to throw out the Second Circuit's decision? Would that be your recommendation, that we should take the position that 504 should be construed to include these cases?

Ms. Crutcher.

MS. CRUTCHER. I can only speak for our national organization relative to Down's syndrome, but I'm certain that the other major disability groups relative to MR would be very active in working for some kind of an amendment to 504 to make sure that it did, indeed, address the issue relative to Baby Doe.

CHAIRMAN PENDLETON. What kind of an amendment would you have to 504? Based on the court decisions that are out, based upon the concerns that you all express, understanding now where the medical community, organizations are, what should be amended, or should it be amended? I'm just at a loss right now as to what we should be recommending based upon what you say.

MR. SMITH. It is my understanding that the child abuse regulations have a great deal of voluntary participation in them in the establishment of the infant care review committees. Let's look at that and realize that there are only a few infant care review committees that are currently in existence. More are being formed. But that is a new process and that is a process that is ongoing. Currently, there are, I'm under the impression, in the low percentile, less than a third, maybe even 20 percent, and that may be a high estimate.

So that the hospitals do not yet have in place good, solid infant care review committees. They are moving in that direction because, I believe, of pressure from the voluntary groups and the consumer population.

COMMISSIONER DESTRO. Is that the case in the big medical care centers? Wouldn't they have review committees anyway? Or is what you're saying that they don't exist in the smaller communities, or that there are just a few of them, or what? I'm not understanding exactly. The doctors seemed to indicate that they had a lot of committees.

MR. SMITH. But they were representative, I think, of the major centers, and I don't think that that kind of review process exists outside of many of the major centers, and I would question that the makeup of some of the committees is really fully in existence at even some of the major centers. Oklahoma would be an example.

COMMISSIONER DESTRO. Are you talking about committees that are internal to the hospital that there are a lot of, or are you talking about the more broadly based committees that the Child Abuse Amendments seem to envision?

MR. SMITH. I'm talking about the broadly based committees.

CHAIRMAN PENDLETON. Mr. Hahn had a point.

MR. HAHN. You asked a question about 504, and I wanted to respond to that.

I think the first thing you do is to enforce and implement it, not only 504, but 503 and other parts of Title V 505 of the Rehabilitation Act of 1973. You also, I think—you were asking what the Commission can do, and I realize this is contrary to a position which the Chair has taken previously—

CHAIRMAN PENDLETON. What was that?

MR. HAHN. Yourself, sir.

CHAIRMAN PENDLETON. And where was that?

MR. HAHN. At the hearings in Los Angeles, on the Restoration Act.

CHAIRMAN PENDLETON. I was in Los Angeles?

MR. HAHN. That is my understanding, sir.

CHAIRMAN PENDLETON. No, sir.

MR. HAHN. Okay. My apologies if I'm in error.

CHAIRMAN PENDLETON. Please, I get enough as it is and I only want to be counted when I was there.

MR. HAHN. That is an important issue, and that is an issue that is high on the agenda of the disability rights movement, the passage of the Civil Rights Restoration Act of 1985. That is something that can be done specifically to extend the rights of people with disabilities, and it is totally consistent with the approach that I mentioned earlier, which is in terms of altering the environment so that people with disabilities can achieve at least relative equality within the society, which is denied to them at the present time.

CHAIRMAN PENDLETON. I'm told by my colleagues that you're talking about my opposition to the act of '85. Yes, that is true, but that's not what I'm talking about in this case. I'm talking about the enforcement of 504 as it exists, but not in terms of where we are with the Restoration Act.

MR. HAHN. Well, the Restoration Act is an attempt to restore rights that had been provided previously to people with disabilities under section 504.

CHAIRMAN PENDLETON. I thought we already had 504 and it couldn't be restored. 504 is still on the books.

MR. HAHN. 504 is still on the books, but the court interpretations have whittled away at the applicability of 504.

CHAIRMAN PENDLETON. I see.

MR. HAHN. And as I say, that is important because we have to deal with the environment. We have to create an environment that is conducive and that accommodates the interests and the needs of people with a wide range of abilities and disabilities.

CHAIRMAN PENDLETON. I see.

MR. HAHN. And we cannot work toward the rights of disabled infants or disabled adults until we create an environment that is appropriate to more than just a small fraction of the population.

As a colleague of mine says, at the present time we create an environment that is appropriate only to the average person, plus or minus half a standard deviation. We have to extend that so that we have an environment in which people can function and can contribute to the society on an equal basis regardless of their impairments.

CHAIRMAN PENDLETON. I agree with you.

MR. SMITH. That's support for restoration.

CHAIRMAN PENDLETON. That I don't agree with.

Commissioner Berry.

COMMISSIONER BERRY. I'll ask Mr. Smith or Ms. Crutcher: What do you think has caused this great interest in providing legal protection from the Federal Government? As I heard you testify, you emphasized the necessity for the Federal Government to do something on the issue of handicapped newborns at a time when, if the public opinion polls are to be believed, the American people generally seem opposed to expansion of Federal authority and talk in terms of cutting back on Federal protection in a number of areas. That seems to be the ideology of the times. So why is this an exception in terms of the problems of handicapped newborn infants? What do you think accounts for it?

MR. SMITH. I don't believe that the polls reflect an attitude toward treatment of newborns. I think that is a separate entity.

COMMISSIONER BERRY. That's why I'm asking. Why is there this exception? The polls indicate generally—and I don't know if the polls are right or not, but after the last election I believe them. But the polls seem to indicate an emphasis on new federalism, giving the power back to the States, get the Federal Government out of this, that, or the other. One of the themes of the last campaign was getting the government off people's backs.

I just wondered why there is some receptivity and leadership at the political level on the issue of expanding Federal protection in this one particular area and not in others, and at the same time, as Professor Hahn points out, we don't see very aggressive efforts in terms of enforcing 504 generally for adults who have disabilities. But this emphasis on newborns—why is that so popular?

MR. SMITH. I think the emphasis on newborns is, (a) because there has been a great deal of medical improvement in the last few years, and consequently, that information, that education, has to be carried over into the general public. And very few people know that.

One of the major objectives of our association is public awareness. We spend a great deal of time and effort educating people of the new medical advances that are being made in the care of spina bifida, as is Down's syndrome.

COMMISSIONER BERRY. Ms. Crutcher, do you have a comment?

MS. CRUTCHER. Yes, I do. I think our society in this country is one that is extremely humanitarian for the most part, and I think we try to pride ourselves on that kind of a society.

I think many people were caught unaware when the Baby Doe situation came to light 3 years ago, and that people were outraged and appalled by the fact that those kinds of things were going on, and going on amongst people whom we have always emulated and respected, the medical profession whom we had trusted our very lives to.

Mr. Hahn. If I may respond also, I think there is a more fundamental problem here, and that is that, unlike other minority groups, the predominant attitude toward people with disabilities is one which is highly paternalistic. So it is appropriate in one sense for the public to oppose or seem to oppose the extension of civil rights, and on the other hand, to be concerned about disabled infants, because to most members of the public we are children that never grow up. We are still seen in a predominantly paternalistic context.

And I might add, in some sense that is why I welcome the opposition of those who oppose rights for disabled people because I think it allows us to establish a constructive dialogue. I think for so long people with disabilities have labored, have been burdened, by predominantly sympathetic attitudes which prevent us actually from achieving our rights because people fail to recognize the inherent hypocrisy in that kind of sympathetic paternalism.

Commissioner Berry. The other question I have is the financial resource problem. I asked some questions of doctors about it, and they seem to be concerned, but thought it ought not to be a consideration in terms of making treatment decisions.

What about the financial resources of families to pay for the medical care, in terms of making decisions about what to do about these children, in terms of what happens to them over their lifetime, and all the rest? Are you concerned at all about the financial resource problem either at the time the treatment decision is being made or later on as these children grow up, some of them disabled? And who ought to pay for it?

Mr. Smith. I would say we are very much concerned with it because of the treatment issue, but we also don't hold that as a reason for nontreatment.

We see an alternative to nontreatment, by the way, and that alternative is adoption. Both our organizations are working with informational programs to try to help place in receiving homes children with our respective disabilities. We find—and I know this to be the case in Down's syndrome—we have a waiting list of parents, and we have placed those infants and newborns in the homes. We don't have the children to supply all the parents.

I think you should also realize that once we talk about adoption as an alternative, we have entered now a third element—treatment, nontreatment, and possibly looking at nonparenting or placing the child up for adoption.

When that third alternative is raised, it is almost like a whole different perspective is brought back to the natural parents because we have introduced an approach that there are adoptive parents that would wish to take that infant, that there is value in that child. And that possibly may be the first time the parent realizes there is value in that disabled child.

Based on that, you can almost see right in front of your eyes the new parent starts to take a different approach to his or her attitude toward his or her infant child with this disability. And we have found that when we talk about adoption, literally three-quarters of the parents decide that. "Maybe I'll reconsider my approach not to treat," and will go back and make themselves much more open to raising that child and certainly become very excellent parents.

COMMISSIONER BERRY. What if the parents want to keep the child, but don't have the resources? Do you support any kinds of programs or activities?

MR. SMITH. Yes, we do. I think there are also resources through the Federal Government through the maternity and child health programs that come down to the States, to the respective States' crippled children's services division.

COMMISSIONER BERRY. Is there enough money available in the programs you're talking about?

MR. SMITH. There is always some question. Sometimes when you get near the end of the year and there needs to be additional funding, but generally those fundings are available. I think that, working with physicians and the medical community, we are finding they are also working toward shorter hospital stays so some of those medical costs are coming down.

CHAIRMAN PENDLETON. Excuse me, Commissioner Berry, on your point about resources, to be a bit more pointed: From your association's point of view, how much does it cost to care for a child with spina bifida? And is the Federal appropriation enough? Should it be more? Once the child goes home, what is that cost going to be to the parent?

I think it's important that we understand what those costs really are. It's not to say whether they should or should not be paid, but what are those costs going to be?

MR. SMITH. I think that question is very hard to pinpoint, obviously, because you're dealing with spina bifida, and there are varying degrees.

CHAIRMAN PENDLETON. Can you give us some ballpark figure?

MR. SMITH. On the average, I would say that raising a child to the age of perhaps 4 or 5 could cost close to $100,000 in medical care. But that is not necessarily the average. For many, it does not cost that much.

COMMISSIONER BERRY. If that's the case, where do they get the money to pay for it?

MR. SMITH. Usually through third-party insurance programs.

**COMMISSIONER BERRY.** What if they don't have insurance?

**MR. SMITH.** Then they would turn to the welfare programs or the division of services for crippled children.

**COMMISSIONER BERRY.** And there is sufficient money in those programs, as far as you know, to take care of all the problems?

**MR. SMITH.** It does vary from State to State. I come from a State where there is not that major a problem.

**COMMISSIONER BERRY.** Which State is that?

**MR. SMITH.** Illinois.

**COMMISSIONER BERRY.** But you don't know nationally whether that is the case or not?

**MR. SMITH.** If you're asking for a specific number, no, I do not. I do know that there are insufficient funds at times, and we try to advocate very much to make sure that the families get the necessary medical care and payment that is needed. Sometimes hospitals have to pick up the cost themselves or write it off.

**COMMISSIONER BERRY.** Ms. Crutcher, could you just give me some general answers to the same line of questioning? Do you worry about the money? Who's going to pay? Is there enough money?

**MS. CRUTCHER.** Most babies with Down's syndrome are born without life-threatening conditions, and therefore, we don't face the same kinds of problems that parents of children with spina bifida face, particularly during the first 4 years that Kent was referring to. We also find that the expenses involved in raising that child are very near the expenses that one has with a typical child that has a myriad of colds and other relatively unimportant problems.

When we do have a child that has a very serious problem, perhaps a heart condition, and there is no insurance available to the family, our discovery has been that most often there was also no insurance available for other children in the family, and therefore, the cost of raising those children, or correcting their medical problems, was also extremely high and a burden on that family. So it wasn't relative to Down's syndrome. It was relative to the family's impropriety in not having insurance coverage or some kind of method in which to take care of their children overall.

However, our local parent groups, the 600 across the country, do make a point of supporting the families within their unit as best as they can particularly when one comes into financial crisis.

**COMMISSIONER BERRY.** One of the physicians who was here this morning comes from a center where they do something about corrective surgery involving Down's syndrome children in California. And he was talking about multiple defects and putting together teams of people—ear, nose, throat specialists, and the like—and discovering that many of the problems of retardation were related to those defects that could be corrected. Do you think that is generally accurate? If so, who pays for all that surgery?

MS. CRUTCHER. At City of Hope, which is where Dr. Shaw is from, it is a service that they provide free of charge, as I understand, or contingent upon one's ability to pay. So it is an extremely reasonable service that they perform. And there are several of those across the United States.

Yes, certainly people with Down's syndrome have more ear problems probably than the standard population. They certainly have more respiratory problems than the standard population. However, they are easily controlled with antibiotics and just good medical care, and parents watching over this child as they would any normal child. So it's not a staggering fee that one needs to pay in order to get tubes put in their child's ears because they have middle ear fluid.

COMMISSIONER BERRY. I see. So your association concerns itself with the outlay from the parent, but not necessarily with who's paying for all that treatment at the City of Hope since someone has to pay for it. Obviously, it's not free.

MS. CRUTCHER. City of Hope does fundraising in order to cover the expenditures and these services for far more people without Down's syndrome than with Down's syndrome.

COMMISSIONER BERRY. I see.

Mr. Hahn, do you have any comment at all on any of that?

MR. HAHN. Yes, I do.

I think there is another way of looking at that. That is, if you accept the assumption that the problem is essentially a problem that stems from a disabling environment, and if you accept the additional assumption that it is, in fact, possible to design and create an environment which is appropriate and can accommodate the needs of everyone regardless of their level of abilities or impairments, which the Chair acknowledged was possible, then it seems to me that there is a collective societal responsibility to offset the costs that are imposed upon individuals and families because the environment as it is presently constructed is disabling and was designed almost exclusively for the interests of nondisabled people.

Let me just cite one quick example of that. In addition to the costs of accessibility and of creating an environment that is appropriate for people with disabilities, we also need to consider the costs on people with disabilities for creating an environment which is appropriate to nondisabled people. I noticed, for example, that today I am one of very few people who was considerate enough and reduced the financial burden by bringing my own chair.

[Laughter.]

MR. HAHN. There are many different modes of communication that are possible for people with sensory disabilities. We need not rely exclusively on the transmittal of information by words written on pieces of paper or even by words alone. We can use alternative modes of communication.

And the cost, as I say, I think should be viewed as a societal responsibility because of the constricting effects of the present environment.

I just want to add one additional comment, and that is that I really think that we should try to avoid discussions of disabilities strictly in terms of diagnostic categories. We have to realize that disability is a continuum which encompasses people with a broad range of impairments and that from this perspective the fundamental problem is discrimination.

COMMISSIONER BERRY. Thank you.

Mr. Smith had his hand up.

MR. SMITH. I wanted to add to the point that many of our chapters reach out in their own communities and supply and provide that necessary funding in the form of picking up the costs of braces, orthopedic shoes, catheter supplies, emergency funds for families. We are working also with a variety of different groups that frequently will even help provide transportation for the mother and the child back and forth to hospitals. Those are part of our chapter services and part of the role that many of our chapters do provide to those families and individuals that find themselves in this situation.

COMMISSIONER BERRY. Thank you.

CHAIRMAN PENDLETON. Mrs. Buckley.

COMMISSIONER BUCKLEY. Ms. Crutcher, what percentage of children with Down's syndrome are born with life threatening conditions?

MS. CRUTCHER. If one considers duodenal atresia, esophageal atresia, esophageal fistula—as to life-threatening conditions, it's about 4 percent.

COMMISSIONER BUCKLEY. Only 4 percent?

MS. CRUTCHER. Yes. Approximately 33 percent of the children born with Down's syndrome do have cardiac problems, and many of those cardiac problems do require surgery. However, statistics show that 90 percent of those cardiac problems are correctible now through surgery or medication.

COMMISSIONER BUCKLEY. In your experience, what percentage of these children with Down's syndrome would be the ones that have no real perception of the environment, no response to stimuli, no movements, that parents have to take care of 24 hours a day?

MS. CRUTCHER. Extremely minimal. Over 90 percent of children with Down's syndrome born in the last 10 years, that have first of all, had the opportunity to live and, secondly, had the opportunity of good loving homes, better preschool and primary school programs, secondary education—just better public attitudes—are functioning in the mild-to-moderate range.

COMMISSIONER BUCKLEY. Children less than 3 years old—would you say that there are more of these children less than 3 years old being allowed to live longer than before with severe handicaps? That would be after the time of section 504 when these cases came to light and possibly more of them would have been treated and consequently more would be alive now. Is the percentage significant? Can you see that as a difference?

MS. CRUTCHER. Well, I have to bring another option in here, and that is that children with Down's syndrome, people with Down's syndrome—I referred a while ago to the stereotyped stigma surrounding Down's syndrome and generalized ability of their skill levels. They are very, very easily trained individuals, always have been. Therefore, the statistics that people have seen and heard that make them feel that individuals with Down's were functioning in the severe range were really contingent upon those individuals being placed in institutions and receiving very little to no stimuli, and at best they learned how to compensate in an inadequate environment. Therefore, individuals with Down's syndrome who appear today to be able to function at a higher level are really just those individuals who have had all of the opportunities that I referenced before.

Yes, children under 3 years old that have had the opportunities of early intervention, infant stimulation, good loving homes, better public attitudes—certainly are functioning at a higher level. We are not seeing nearly as many children with Down's syndrome functioning in the severe to profound range.

COMMISSIONER BUCKLEY. Mr. Smith, when you tell us that you have these fundraisers and have these resources available to parents of children with spina bifida, what happens to those parents that are middle income that have already gone beyond the expenditures that insurance will provide, but they still have four or five other children? They still have the expenditures of colostomy bags, two or three colostomy bags a day, the wheelchairs, excessive amounts of antibiotics for all the different things that are going on with them. How do you help these parents with these expenses when they don't come under any Federal program, when there aren't enough fundraising funds to help them? What can you offer them?

MR. SMITH. For those expenses which you have itemized—the program is set up by the fact that you are involved with the association, and you have a need. And the need is that you need equipment, not necessarily your ability to pay.

Generally, we have found that those families that are able to pay will go first to their insurance companies or through the third-party paying procedures, rather than through our voluntary organization, thus leaving our limited funds for those people that do need it.

COMMISSIONER BUCKLEY. Do you have any idea how much outlay your parents do have a year for these children? Do you have any figures at all on that?

MR. SMITH. No, we don't have any specific figures on this. We have tried to conduct some very loose studies, and we find that it can range in the vicinity of a couple of thousand dollars a year. That may be in the form of buying disposable diapers or in buying catheters for catheterization. Yet a supply of 8 or 10 catheters, if properly used—we're talking clean intermittent catheterization; we're not talking sterile procedures anymore, so that you're talking about reusing the equipment after it is properly washed.

CHAIRMAN PENDLETON. Commissioner Destro.

COMMISSIONER DESTRO. Just one last question. Getting back to 504, because that is largely the focus of the hearing, what I was hearing is that you approached the 504 issue, that you already felt 504 covered all this. We now know that at least one court of appeals didn't feel that it did. Was there any reason why, just to preempt the fact that the Supreme Court might agree with them, that you didn't go after 504 specifically?

MR. SMITH. I think it was an attitude that possibly we were very much concerned as to how it was going to be approached. I think with our limited time and effort we agreed to go with the other alternative, child abuse. That does not mean that we do not believe 504 is applicable. Again, we support the legislation that has recently been written and are willing to try to see how it works out, with the idea of it hopefully being successful.

And this is a personal view of mine. I look at 504 and Public Law 94–142 as extensions of 504 in the areas of education. I'm looking at the Child Abuse Amendments as also being an extension of 504, even though there is a very loose tie there. But I'm saying that now we have the mechanisms established, and if you the Commissioners do not feel that the mechanisms are there, then I certainly would do everything in bringing the resources of our organization to try to come up with the proper legislation to make my initial premise available, that treatment be available to everyone that requires it, and we not be faced with a discriminatory issue.

CHAIRMAN PENDLETON. We are not saying that is not sufficient. We are not saying anything at all. We are trying to find out what you think is appropriate. It's not so much what we think. It's up to us to recommend to the Congress, based upon what we get out of the hearing. We are not being judgmental about 504 in this case at all, and I thought I made that remark in the beginning. The purpose of these hearings, again, is to find out what 504 really does in terms of the treatment of handicapped newborns.

MR. SMITH. We felt that it was very applicable and have always felt that it was applicable, and that was our original position. That's why we have gotten involved in this as an organization because, originally, we felt it was applicable.

COMMISSIONER DESTRO. What was your concern? You said that you had a concern about 504. Maybe I'll just rephrase it. Was the concern that you had about 504 the same kind of concern that has been affecting the debate over opening up the other civil rights laws? And what were you concerned about, about getting into 504?

MR. SMITH. I think the concern has been the legal process so far, so far as the judiciary system, and it has not been necessarily upheld. I want to follow that through, the necessary resources that are available, and I want to see what the U.S. Supreme Court rules if it's carried that far. We believe that it is applicable.

COMMISSIONER DESTRO. I guess my point is: What concerns did you have with the legislative process? We know what the judges have done or what they might do. Would you have any problems if the Supreme Court rules against you about going into 504 and asking Congress to do something about it?

MR. SMITH. I would have no problems with that.

CHAIRMAN PENDLETON. Do you think that some of your parents could be sued under the Child Abuse Act for neglect of their children in terms of their treatment process?

MR. SMITH. That is a concern, yes.

CHAIRMAN PENDLETON. What are you going to do about that concern? That law is on the books.

MR. SMITH. Yes. What we have found—and you heard Dr. David McLone speak to that effect—is, that with proper information and presenting all the facts and possibly even using information from our consumer organizations, which are written by people that are familiar with the care and treatment of handicaps, we find that a nontreatment decision is not made. That is, when the decision to not treat is made at those early stages, it's because of lack of information.

CHAIRMAN PENDLETON. We heard parents yesterday say that they were told at 5 o'clock that there would be a hearing at 7 o'clock and that their baby would be shipped off to another city for treatment. Suppose they had refused to do anything? Could they have done that? What do you think would have happened in that case?

MR. SMITH. I think at that point it would have been nice to have someone who was more familiar with them, another parent perhaps. Many of our chapters are starting to develop a parent-to-parent type of group that will meet with the other parent and say, "Look, this is what our experience has been," and to be a resource to these other people.

COMMISSIONER DESTRO. Do you have any fear that under the Child Abuse Amendments the child protection services in the States might use the same kind of criteria that some of the doctors do, the quality of life criteria?

MR. SMITH. If the child protection agencies use the experts that are familiar with the care and treatment of spina bifida, experts in the field, I do not feel that that will be a big problem. I am concerned that we are hearing the equations still presented, because I do not support the equations, and our organization certainly does not either. We feel that the entry of quality of life should not be a factor in the treatment.

CHAIRMAN PENDLETON. I just got word from the General Counsel, I think this afternoon some of the parents have been asked to respond to the financial resources question raised by Commissioner Berry. I'll request that we do it first thing this afternoon. I'd like very much to hear what they have to say about the financial resources.

COMMISSIONER DESTRO. I'm finished questioning, so if you have anything else to add, please do.

MS. CRUTCHER. I'd like to respond to some of your questions on 504. As I said, initially, when we began all of this, we felt that 504 adequately covered the discrimination aspects of Baby Doe so we didn't pursue it.

There was also another reason behind it, however. We felt that 504 rights issues were not particularly popular in recent Congresses, and beyond that there had been some attempt at deregulation, and we just really didn't want to endanger 504 in any fashion at the time.

Then when we got into the Child Abuse Act Amendments, it was more for the specificity of this particular type of discrimination. The Chairman raised a question regarding the parents and the applicability of their being sued. This is the Child Abuse Amendment Act to protect the child. And even though we are parent-support organizations, the person for whom we advocate the most is that child.

MR. HAHN. I would just like to add that there is, I think, an important and appropriate role for disabled adults in this entire process, not only in the development of public policy, but in providing input based on our lifetime experience, for parents faced with these kinds of circumstances.

I am extremely troubled that in the guidelines which have been published thus far for review committees, there is a provision for representation of a single disabled adult, which is again, I think, a reflection of tokenism and raises a serious problem that the experience of people with disabilities, and the rights of parents and the rights of children, are going to be completely overshadowed by the kind of professional intimidation that, as Weatherly has pointed out in a study of the Massachusetts law equivalent to 94–142, is a problem in implementation.

So I would suggest that, in order to adequately provide and protect the rights of parents and children, that disabled adults be part of the process and that some effort be made to prevent the process from being dominated almost solely by professionals.

CHAIRMAN PENDLETON. Thank you very much for your testimony.

We will recess until about 1:30.

[Recess.]

CHAIRMAN PENDLETON. For the record, we are interested in hearing a brief response from the families we heard from yesterday with respect to how they were able to pay for the treatment of their children. I understand that Mrs.. Miller and Mrs.. Hintze are prepared to address the issue, and I asked them to give us 10 to 15 minutes in the beginning of this session. Although all my colleagues are not here, please understand this will be a part of the record of this hearing, and that's the most important place for it to be.

I will not swear you in again. You have already been sworn in, and we will let that suffice for this round.

Either one of you may go first, and feel free to discuss with us, probably absent too many questions, what it costs you and how you paid for it.

MRS. MILLER. As far as financing for Shermika, when HRS became involved in our case and made the decision to have the surgery, they covered most of the initial surgery charges. However, I was billed for all of them, and I went to them and asked who was responsible. They said they would take care of these bills, but in turn they will sue my insurance company, which was an HMO at the time. But when HRS became involved in my case, the HMO dropped Shermika from my policy. So that was an experience in itself. I was wondering where I was going to get the money to pay for this.

HRS did cover most of the initial surgery charge, and then I went to the HMO and asked them to put her back on. It took them 3½ months to decide to put her back on the policy.

COMMISSIONER DESTRO. Did they take her off because HRS had taken custody? Was that why they took her off?

MRS. MILLER. Yes, because HRS took emergency custody, so they dropped her from our policy.

CHAIRMAN PENDLETON. For the record, would you tell us what HRS is in Florida?

MRS. MILLER. Health and Rehabilitative Services.

CHAIRMAN PENDLETON. Health and Rehabilitative Services for the State of Florida?

MRS. MILLER. For the State of Florida.

They dropped her because HRS became involved in the case. And I had to go around with them for months before they would put her back on.

HRS appointed a caseworker to make sure she was getting the proper care. After that they just got out of the case completely and forgot about it.

My point is that, even though they stepped in to get the initial surgery, I thought that I should be helped some other way as far as funding, because that was just initial surgery. They don't know what's involved in the coming years. I mean the expenses have really piled up.

CHAIRMAN PENDLETON. How much has it cost you so far? How much has the treatment cost to date in some round figure?

MRS. MILLER. Because she's only 2 years old, she's just started getting surgery. She just had her first orthopedic surgery since she was born. So far it's probably run about $20,000.

CHAIRMAN PENDLETON. That's cost to you or total cost?

MRS. MILLER. Total cost so far. But like I said, there are going to be other charges because she's scheduled for another surgery in about 8 weeks. She doesn't have her shots yet, and she has to go to get a CAT scan to make sure the hydrocephalus isn't building up in her brain. So that's another $500 charge every time, every 6 months.

COMMISSIONER BERRY. Is it $20,000 for the original work and the orthopedics and the whole thing from the beginning?

MRS. MILLER. Right. HRS gave me a list of people to contact for financial help. They gave me the Children's Medical Service (CMS) and told me to apply for SSI [supplemental security income]. I applied, but because of my husband's and my salaries, we did not qualify. So who else could I go to?

I went to the local Easter Seal program. They said because of our salaries we didn't qualify to get the treatment free. So they split the charge in half and I paid $20. Then they advised me to go to HRS and apply for Children's Development Services. This is based on the child's need, not the parent's salary. She did qualify for that under the high risk category.

Lately, under her reevaluation, the State of Florida has come up with a spina bifida category. But it doesn't cover any medical charges. You get the Easter Seal services free, but that's it.

CHAIRMAN PENDLETON. What is the Easter Seal Service?

MRS. MILLER. Volusia County Easter Seal Service is a service that provides occupational therapy, physical therapy, speech therapy for handicapped children. They now also have a preschool enrichment program for smaller children. They have an early intervention program that Shermika is involved in right now and is receiving all this therapy. She gets this service free because Children's Development Service, which is under HRS, put her under the category of spina bifida, which the State of Florida just included as a category. Previously, they didn't have it as one of the categories to get the services.

Other than that, that's all we get. My insurance pays 80 percent of the medical bills, and other than that, that's the only service we get, because we don't qualify because our salaries are too high.

CHAIRMAN PENDLETON. Thank you.

Mrs. Hintze.

MRS. HINTZE. In the State of Florida, the financial criteria for a family of four is $9,600 a year gross income to be eligible for what is called Children's Medical Services, and this is from birth to 21 years of age. We did not qualify the year that Eric was born because we made $10,000 that year. So we were responsible for his total newborn care. There were no exceptions made.

Since that time—my county does have a Children's Medical Services District, so they did take us on and said they would help us out with what our insurance doesn't pay, and our insurance pays 80 percent. But this still doesn't include diapers, catheters, any general pediatric care. And last month they denied payment for a leg fracture when Eric twisted his leg too far. If he wasn't paralyzed, he would have known he was twisting it too far.

We have had some bills in our house and senate trying to get a lot of these artificial barriers—for instance, if you live in one county, you get help; if you live in another county, you don't.

Our State really needs, I think, better guidelines. In our State our kids don't qualify for SSI because of the parents' income. I think it's important to realize that when these kids get to be adults, there's a lot of needs. I know a 22-year-old boy that needs a special pair of shoes that cost $700. He is not eligible for CMS because he's over age. Medicaid won't pay. It's like no one pays $700 for a special pair of shoes so he can go to work.

CHAIRMAN PENDLETON. He wants to be a taxpaying, productive citizen, in other words.

MRS. HINTZE. Yes, he does, and he can't. Developmental Services won't pay for anything that's a prescription, and Children's Medical Services, because he's 22, will not pay for it. He can't go to work because he can't stand on his foot because it gets sores.

CHAIRMAN PENDLETON. How much did it cost you, Mrs. Hintze, since Eric's birth, the whole process?

MRS. HINTZE. His newborn care was $12,000 for the first 6 weeks, that was 7 years ago. When he was about 6 months old—my husband is a State employee, and the insurance changed over so we went back to zero dollars. And my insurance has paid $101,000, and they pay 80 percent.

I believe the figure now is usually for the first year about $50,000 average, because some of the kids don't require as much as others. But in our case our insurance has paid $101,000.

CHAIRMAN PENDLETON. To get back to Commissioner Buckley's question about the multihandicapped newborn, the cost would be extraordinary, say, much higher?

MRS. HINTZE. Well, Eric was shunted and his back was repaired. But like I said, that was 7 years ago and it was $12,000. So I couldn't tell you what it would be today.

COMMISSIONER BERRY. What would people do if they don't have insurance?

MRS. HINTZE. Probably one of the things that would enter their minds would be to put them in State custody. If I didn't have insurance and we made $10,000 a year, like we did the year Eric was born, there might not have been any other alternative for me, because the State would pick up and pay then. We love our children, you know—

CHAIRMAN PENDLETON. What would happen in that case? Would that be a decision about nontreatment? If you run across parents who decided the cost is prohibitive at this point and, therefore, there should be nontreatment, or if the child happens to expire at an early age—if this "Q" formula goes into effect and you have no money, no insurance, is it a decision sometimes not to do anything at all and just let the child expire?

MRS. HINTZE. I think it would be a factor.

CHAIRMAN PENDLETON. Any more questions?

COMMISSIONER BERRY. Were you going to say something?

MRS. MILLER. I was going to say it would be a factor. I didn't even think about finances at the time that Shermika was born, but I think with some parents that could be a factor. The financial problem is a hardship and causes a lot of problems in the family.

COMMISSIONER BERRY. In Florida do hospitals generally accept patients who have no insurance and no money?

MRS. MILLER. Some of them.

MRS. HINTZE. Some of them do and some of them don't.

CHAIRMAN PENDLETON. I guess we have to stop the questioning someplace, but it seems to me that we heard testimony yesterday that all hospitals don't have the same facilities to treat handicapped newborns. Do you assume or do you know that that has anything to do with whether or not hospitals will accept people who have no insurance or other means of supporting the cost of the newborn? You don't know? I'm probably asking you the wrong question.

MRS. HINTZE. I really don't.

CHAIRMAN PENDLETON. I'm probably asking the right question, but with the wrong people.

COMMISSIONER BERRY. You can always say you don't know.

CHAIRMAN PENDLETON. You don't have to give us an answer.

Thank you very much for your time and adding to our record. I appreciate it.

MRS. MILLER. Thank you.

MRS. HINTZE. Thank you.

CHAIRMAN PENDLETON. Will the panelists please take your seats and I will swear you in.

[The witnesses were sworn.]

## Ethical Considerations

### TESTIMONY OF JOHN FLETCHER, Ph.D., ASSISTANT FOR BIOETHICS, WARREN G. MAGNUSON CLINICAL CENTER, NATIONAL INSTITUTES OF HEALTH; WILLIAM E. MAY, Ph.D., ORDINARY PROFESSOR, DEPARTMENT OF THEOLOGY, CATHOLIC UNIVERSITY; RICHARD McCORMICK, S.J., ROSE F. KENNEDY PROFESSOR OF CHRISTIAN ETHICS, KENNEDY INSTITUTE OF ETHICS, GEORGETOWN UNIVERSITY; AND MARY ANNE WARREN, Ph.D., LECTURER IN PHILOSOPHY, SAN FRANCISCO STATE UNIVERSITY

CHAIRMAN PENDLETON. It is our custom here to start questioning with the General Counsel, since the Counsel's office put together the hearing, and then there will be Commissioner questions later. Mr. Mandelman.

MR. MANDELMAN. Thank you.

First of all, for the record, would you each please state your name and your present position or affiliation.

DR. WARREN. Mary Anne Warren, San Francisco State University, Department of Philosophy.

DR. FLETCHER. John C. Fletcher. I'm assistant for bioethics in the Clinical Center of the National Institutes of Health.

FR. MCCORMICK. I'm Richard A. McCormick, the Kennedy Institute of Ethics, Georgetown University.

DR. MAY. William E. May, Department of Theology, Catholic University of America.

MR. MANDELMAN. Thank you.

Starting with Dr. May and then working across the panel, would each of you first briefly state your views on the selective treatment of handicapped newborns, and just very briefly what each of you considers to be the ethical considerations that underlie your position. And then I'd like to get into some more specific questions.

COMMISSIONER BUNZEL. Do that in about 2 minutes, please.

DR. MAY. I think the basic consideration is that of justice and equity to the newborn. I believe that a newborn child, and even an unborn child, is a member of the human species, is a being who is superior to any animal, who is a being of transcendent worth and significance, and I believe this can be defended on philosophical grounds as well as because of religious convictions.

I believe that it is wrong to kill newborn children, and that you can kill them either actively, by administering potassium cyanide, and you can also kill them by benign neglect. For example, you can kill a child, a newborn, by failing to give the newborn child the treatment that it requires to be rescued from a lethal threat against its life. And I believe that the criteria for selecting newborns for treatment or for nontreatment should be such that they are not predicated upon quality of life considerations by which one would judge that the child would be better off dead than alive and its life is a burden to it, and that there are other criteria that ought to be adopted.

But the main purpose, I believe, of a Commission such as this is to guarantee and to protect the rights of the newborn child to equal treatment and to receive medical treatment to which it is entitled, and that it not be killed by having treatment refused to it because of its condition.

That briefly is my position.

MR. MANDELMAN. Reverend McCormick.

FR. MCCORMICK. First off, let me say that I think we approach the problems of the newborn with a presumption of treatment. We don't walk into the intensive care unit with a dilemma mentality, whether to treat or not. We start with the presumption of treatment.

However, there can be certain infants, in my judgment, whom it would be futile to treat and, therefore, it would not give them any benefit or, secondly, whose treatment would be far too burdensome, given the prospective benefit.

Therefore, in terms of the decision to withhold or withdraw life-sustaining treatment from infants, I believe that the key ethical consideration is the question of the benefit and the burden, the proper calculus to be worked out there. If there is no benefit to the child, then I think the child is better left untreated. Also, if the burdens are overwhelming in terms of either pain, risk, things like that, then I think the same conclusion could be drawn.

MR. MANDELMAN. Dr. Fletcher.

DR. FLETCHER. Mr. Mandelman and Mr. Chairman, I would like the record to show that I am testifying today as an individual. I'm employed by the National Institutes of Health as an ethics consultant, but NIH doesn't have policies or views on the subject before the Commission today. So I am here because you invited me.

My answer to the question is very similar to those who have spoken. I feel that society has a moral and a legal obligation to protect the newly delivered infant, whether the newly delivered infant is delivered prematurely or delivered in due time. Society does have interests in fetal life and in newborn life especially, but in my view these interests of society grow and develop as they increase; and as the interests of the mother, the father, and the family can be differentiated from the interests of the individual, the new individual, society's responsibilities grow and continue. And they continue to grow.

So I agree with the moral statement that lies behind the Child Protection Amendments of 1984. I think that our society has made a statement, if I could paraphrase it, that we are not allowed to bargain off the life of a newborn, even the life of a badly handicapped newborn, for other considerations, namely, a special consideration about the family's competence, the family's income, the lack of available therapy in that particular location that might be available in other places.

Just to emphasize one qualifying theme, however, when there is not a rational approach to therapy and when the burden of the disorder is so grievous, in the language of the amendment, as to render the hope of therapy futile, there is, in my view, a fate worse than death, and that is to be trapped in a kind of lingering technological fix that inflicts much more suffering and burden upon the people involved in the problem.

But my views are essentially the same as my colleagues, perhaps with the exception of a steadily increasing obligation of society to protect the life of the unborn and then of the newly born individual.

MR. MANDELMAN. Thank you. Dr. Warren.

DR. WARREN. I believe that from the moment of live birth any infant, normal or handicapped, has the same full and equal right to life as any other person who has been born alive. But I do not believe that the right to life constitutes an obligation on the part of others to maintain life when the maintaining of that life is contrary to the individual's own best interests.

It is generally recognized that adult patients have the right to refuse life-sustaining treatment when they judge rationally and competently that such treatment would be against their own interests. And I believe that where the parents and physicians responsible for the care of a severely handicapped newborn rationally judge that further life-sustaining treatment would be contrary to the infant's interest, that it is morally appropriate for them to either cease or not undertake further life-prolonging treatment.

I would like to clarify that by saying that I do not think Down's syndrome is a case in which treatment is contrary to the infant's interests, quite to the contrary, and I would not put spina bifida in a category for which treatment is counter indicated either.

But there are a great many other conditions, such as anencephaly, where I think you would find very few medical people who would argue that it is in the interests of the infant for its life to be prolonged, even though our technology may well enable it to be prolonged for months or even years. Anencephaly is a condition not in which there is intolerable suffering, but something in which there is no capacity for experience whatever, be it positive or negative, and that being the case I think it is not in the infant's interest to be kept alive.

Other examples would include some of the severe chromosomal abnormalities, such as trisomy 13, which almost inevitably entails death before the end of the first year even with the most aggressive treatment, which will usually include multiple surgeries. And I think you would find very few medical personnel who would argue for the most aggressive type of treatment in cases of that sort.

MR. MANDELMAN. I'd now like to turn to some more specific questions, and in each instance I hope you will feel free to comment on each other's answers.

I'd like to start with Dr. May. Some years ago you wrote an article in *The Thomist* entitled, "What Makes a Human Being to be a Being of Moral Worth." And in that article one of the things you stated—I'm quoting directly from it—"Of all of the beings of our experience, only human beings are beings to whom moral obligations can be meaningfully attributed. By a 'moral being' I mean something different from a being of moral worth. A moral being is an entity that is the bearer of moral duties and obligations."

How do you see a severely handicapped child, a child that is suffering from severe mental retardation, for example, as being able to fulfill moral duties or obligations? Or do those obligations differ depending upon the mental and physical capacities of the individual?

DR. MAY. Well, by "a moral being" there I meant a moral agent. By "a moral agent" I mean a person who has the developed capacity for deliberating and for making free choices, a person such as ourselves and the rest of us in this room.

Now, a newborn infant is not a moral agent and he has no moral responsibilities. The newborn child has no obligations to fulfill to anyone. But I do believe that a newborn child is what I call a being of moral worth. And if you want to use the term "person" as a synonym for that, it would be acceptable.

By "a being of moral worth," I mean an entity that is intrinsically worthwhile and superior to other beings of our experience, such as dogs, cats, rhinoceroses, even chimpanzees and apes; and that as a member of the human species, it is the kind of being that has a radical capacity for deliberation and for free choice. But that capacity has not yet been developed, and it is even possible that it may never be developed because of extrinsic factors. Nevertheless, the child is still a being of this sort and, as such, is entitled to all the respect that other members of the human species are entitled to.

Am I being clear? The distinction was between a being of moral worth and a moral being or agent. The parents of the newborn child are moral agents, and they have obligations toward the child. So does the doctor; so does the society. But the newborn child has no obligations at that time towards its parents or toward society because it is not capable of doing wrong or doing right. In other words, a newborn child cannot do anything right or cannot do anything wrong because it has not yet reached the stage of development where it can make moral choices.

MR. MANDELMAN. Now, what if that child is permanently incapable of ever developing to a point where it can make any choices at all? Would that in any way alter your feeling about whether or not that child should be treated?

DR. MAY. No, it would not because it would still, in my judgment, be a member of the human species and be a person, not a thing. It would have the right to life—in this sense, the right not to be killed—the right not to be killed by others, either actively or by benign neglect.

MR. MANDELMAN. In your view does a person who is an adult who is mentally competent and who knows that they are suffering from an irreversible illness, such as incurable cancer—in your view does such a person have an ethical right to, one, refuse treatment?

DR. MAY. Of course.

MR. MANDELMAN. And does that person have the ethical right to terminate their own life?

DR. MAY. I think there is a difference between refusing treatment and terminating your own life. I believe suicide is wrong and that this is an immoral kind of choice, but there can be nonsuicidal reasons for refusing treatment.

With respect to the care of handicapped newborns or newborns in general, it can be inapproriate to treat them, and they can also be overtreated. I did not mean to imply that every possible treatment must be used. I would agree that there are futile treatments, there are useless treatments, and there are some children who are born and dying or are going to die no matter what is done, and in such instances it would not be advisable or prudent to treat them. But the judgment for not treating them is predicated upon the burdensomeness of the treatments or the futility of the treatments, and is not predicated upon a judgment that their life is a burden, and that you don't want the treatment to succeed in keeping them alive. That's why treatments have been withdrawn, for example, from some children with Down's syndrome or spina bifida. They were afraid the treatment would succeed and the children would keep living.

MR. MANDELMAN. Would you agree that it would be appropriate or would you disagree with the idea that if you had a newborn who was suffering from a lethal genetic defect, such as Tay-Sachs, where as a certainty you know that that child will die by the age of 3 or 4, die, as I understand it, a rather painful and horrid death. If that child was also born with, let's say, esophageal atresia—and I'd like the other members of the panel to comment on that as well—would it be ethical to not treat the esophageal atresia because you know this child will die within a year or 2 and die very painfully.

DR. MAY. I think you're making some assumptions. I don't know that Tay-Sachs children die within a year or so.

MR. MANDELMAN. I think they die by the time they're 4.

DR. MAY. They do die at a young age. But I do think that if a Tay-Sachs child was born with duodenal atresia, that it would be an obligation in my judgment to perform that operation to enable that child to receive nutrients, because I think death by starvation is a very terrible way of dying, and that appropriate care can be extended to the Tay-Sachs child while the child is alive, and that what you are doing here is giving appropriate medical treatment, that the underlying lethal cause is somewhat in the future and many things can happen in the interim.

MR. MANDELMAN. I would like especially Dr. Warren and Dr. Fletcher to comment now. Do you agree or disagree with Dr. May's last response?

DR. WARREN. I believe that the hypothetical case you describe, a Tay-Sachs child who also has a condition which threatens to cause immediate death, is a case which falls within the gray area, and it could be rationally argued that the treatment should be performed or that it should not. And therefore, this is the sort of case in which a decision should be made primarily by the parents with the best medical counsel and with the help of whatever other counselors they may wish to avail themselves of.

MR. MANDELMAN. Dr. Fletcher.

DR. FLETCHER. If I were asked for an opinion in the case, I would recommend that surgery be done because the Tay-Sachs child will have several months of almost normal life, that is, could live a few months before he or she begins to decline and eventually die by 3 or 4 years old. I think you're correct about the age.

The reasoning I would use for that is that there are too many other cases where you could use the same reasoning in order to justify ending the life of a newborn with a similar degree of handicap by avoiding the surgery.

So if you're asking me to comment on that hypothetical case, I could not recommend passivity.

CHAIRMAN PENDLETON. Mr. Mandelman, would you allow Commissioner Berry to ask one or two questions? She has an appointment.

MR. MANDELMAN. Certainly.

CHAIRMAN PENDLETON. Commissioner Berry.

COMMISSIONER BERRY. Father McCormick didn't get to answer that question. Let him answer it first.

FR. MCCORMICK. I'd be happy to let it go by if you want me to, but if you want my opinion on that, I think it agrees more closely with Dr. Warren's statement. I think we have here a gray area case where it could go either way. One could bring up a persuasive reason on either side.

I do incline, however, to Dr. Fletcher's cautions that if you did want to suggest treatment, you might be doing it largely in terms of drawing a line so you wouldn't get into further abuses in other instances. But if you isolate the case on its own, you could make a case either way.

Indeed, the most recent authoritative study on this matter by Robert Weir puts Tay-Sachs in the case of withholding or withdrawing treatment.

COMMISSIONER BERRY. I just have one or two questions, but, first, I'm just fascinated, Dr. May. It says you're an ordinary professor. Are there extraordinary professors?

[Laughter.]

COMMISSIONER BERRY. It is absolutely fascinating.

DR. MAY. It's the terminology at Catholic University.

COMMISSIONER BERRY. Oh, I thought there were extraordinary professors, because I consider you to be quite extraordinary.

COMMISSIONER DESTRO. As a colleague at Catholic University, that's a full professor in Catholic University parlance.

COMMISSIONER BERRY. Okay.

We had a rather lively exchange with some physicians this morning about ethicists and what they do and how they serve on patient review boards and the function they serve.

First of all, I wonder if any of you or anyone could tell me what an ethicist is by definition.

DR. WARREN. An ethicist is anyone who has a special interest in ethical problems. I would like to point out that simply by virtue of being on this particular Commission and at this particular hearing, all of you are ethicists.

COMMISSIONER BERRY. So anyone can be an ethicist.

CHAIRMAN PENDLETON. I thought we were in need of one.

DR. WARREN. Anyone involved in medical treatment is of necessity an ethicist because it is impossible to escape from ethical problems.

COMMISSIONER BERRY. In the sense that we talk about these patient care review boards that are involved in these problems in hospitals, does that definition fit, that anyone could be the ethicist or the ethical consultant on these boards? By definition, what sort of requirements are there? Can anyone tell me?

DR. FLETCHER. I'd like to speak to it. I call myself at the NIH an ethics consultant.

COMMISSIONER BERRY. All right.

DR. FLETCHER. NIH and the University of California at San Francisco are sponsoring together the first national conference for ethics consultants next October. There are 51 people whose chief executive officers have written a letter sponsoring this person, saying that the hospital expects them to provide consultation.

To be able to do this, you have to have a familiarity with the medical setting and familiarity, certainly, with the basic ethical principles and teachings in ethics that the many cultures that make up our culture espouse.

So there needs to be a very thorough educational background and, I think, an ability to provide consultation. Providing consultation is really quite different from providing judgments, although, occasionally, if the people who have the need for the consultation want a recommendation, I will provide a recommendation.

So it is practical help to physicians, parents, patients, research subjects, and medical groups who are in the throes of a problem, or who finished a case and want to look at it and learn something from it.

COMMISSIONER BERRY. To your knowledge, are ethical consultants or ethicists or persons who serve on these boards or serve this function in hospitals generally pretty much the same? That is, if you get one or another it doesn't really make much difference; you are likely to get a grab bag of all the theories about ethics that are available and try to apply them in a particular case? As John Bunzel put it this morning, six of one and half a dozen of the other who you get on this particular committee. Are they different?

DR. FLETCHER. Are you talking about specialists in ethics or the members of the committee?

COMMISSIONER BERRY. Specialists in ethics who are on the committee, people like yourselves who work on these problems. If I ask each one of you, would I get the same answer?

DR. FLETCHER. Probably not. The spectrum of backgrounds and views of the people coming to our conference is quite wide. There are people who are trained in medicine. About 20 of them have Ph.D.s in religion or ethics or philosophy. Probably the largest group of ethicists are people with Ph.D.s in religion or philosophical ethics who teach and also provide consultations over and beyond their teaching responsibilities. There are nurses; there are chaplains.

But what they have in common would be a period of time studying ethics in order to try to master a certain body of material or approaches to problems. But what you would get might be quite different, depending upon their own orientations and their own views and their own persuasions about what was right or wrong.

COMMISSIONER BERRY. Does any member of the panel disagree with that?

DR. WARREN. No. I just think it should be pointed out that the field of ethics is not defined by a certain set of doctrines. It is defined by a certain set of problems to which different ethicists will undoubtedly have widely differing answers.

COMMISSIONER BERRY. Father McCormick.

FR. MCCORMICK. I think, too, that you should advert to the fact that there is a being called a religious ethicist. That simply means that this particular person doing ethics in this context comes from a religious background that may provide quite a difference in the outcome.

For example, a person coming from the Catholic tradition will have a remarkably different attitude toward life preservation than one who comes from the Orthodox Jewish tradition. Specifically, an Orthodox Jew regards every moment of life, no matter what condition it is in, as better than death. Therefore, it is very difficult to get a family to agree to remove a respirator in cases where it would be quite natural for Catholic Christians to do that. So there's a difference in religious orientation, too.

COMMISSIONER BERRY. Then how should one regard a decision, if you're a doctor or people in the hospital or parents, to have one ethical consultant or one ethicist as opposed to another? Do you choose them based on your own orientation about what you think is important, or does it depend on what hospital it is? When you try to make these decisions, how do you pick your ethicist?

FR. MCCORMICK. I don't think it's a matter of you picking an ethicist. If there is someone who is acting in that role in a hospital, it usually will be someone who is congenial with the overall mission of that particular hospital. If it's a religiously oriented hospital, a Catholic one, for example, it would be quite appropriate, not necessary but quite appropriate, to have someone trained in the Catholic tradition.

CHAIRMAN PENDLETON. There was some testimony this morning that a doctor would not pick an ethicist that believes life begins at 3 months. If an ethicist happens to believe that life begins at 3 months, would you pick one like that to settle the ethical problems of the hospital?

FR. MCCORMICK. I'm not sure I understand the question.

COMMISSIONER BERRY. This morning we had this hypothetical that I think Commissioner Bunzel proposed that there was an ethical consultant or ethicist who believed that life really began for a born-alive child at the age of 3 months, if I've stated it accurately. And the question was whether the doctors would think that would be an appropriate ethical consultant to help them make decisions about handicapped newborn infants and what should be done about them.

CHAIRMAN PENDLETON. Thank you Commissioner Berry.

FR. MCCORMICK. Okay, I get the background. My answer to that is that a person who holds a position like that should expect to have it purified and corrected by exposure to his or her peers. And concretely, that particular opinion would not stand up for a minute when exposed to the community of people in ethics and moral theology.

DR. WARREN. I'd like to speak to that. I know of no professional philosophers who believe that life begins at 3 months. There is one well-known philosopher who has argued that the full and equal right to life, which is quite a different matter, begins at some point after birth, possibly 3 months. This is Michael Tooley. He is not dogmatic about it. He makes it contingent upon the state of medical knowledge. We don't at the present time really know just when the infant begins to think, which is his major point. He believes that newborns do not yet have the capacity, to form thoughts, and lacking that capacity, they cannot sensibly be said to have a full and equal right to life.

He would not go on to say that, therefore, it is morally appropriate to let all or even many newborns die. That's a separate question from whether they have the same right to life as an older person. Why? Because there are many other moral factors involved besides the right to life, such as the wishes of the parents, the values of the society, and so forth.

DR. MAY. I would like to comment on that. I think that Michael Tooley whom she mentions does defend infanticide and does so on the grounds, and in fact recommends, that children be given a period of time for checking over after birth, to check on defects, and that there is nothing wrong with infanticide precisely because the newborn child is not a person in the same sense as those who have reached an older age. And I do think that having an ethicist of that type on the committee would be somewhat detrimental to the well-being of the child. I think it would be somewhat similar to appointing someone who believes that black people are three-fourths of human beings on the Civil Rights Commission.

COMMISSIONER BERRY. Three-fifths.

DR. MAY. Three-fifths, whatever it is.

[Laughter.]

DR. MAY. There is a great deal of disagreement, as you can see, among ethicists, but I don't that think this should lead one to the conclusion that it's just a matter of what one personally prefers. I think the truth enters into this matter, and I believe that one can—and this is a debatable point among ethicists but I am one who holds that ethical judgments can be qualified as being true or false.

I think it is true to say that it's wrong to rape a woman. I think it is true to say that it is wrong to disqualify an individual from a job because of that person's race.

And I similarly think that it is possible to develop criteria whereby one can show that it is not right to adopt by choice the proposal to kill someone—have normative propositions—because you judge that person to be better off dead and that the quality of life that that person has is one that you think is a burden to him. I think that's an arrogant assumption, and I'm afraid that is frequently made in these cases regarding handicapped newborns. We have plenty of cases to prove it.

COMMISSIONER BERRY. All I'm trying to do is to understand the role that ethical consultants or ethicists play in the decisionmaking process, and whether it is really true that one is different from another and so on. I'm just trying to understand that.

Do you think that when parents are about to enter a hospital and there is going to be a child born that if there are defects of some sort and some decision has to be made about treatment, that one of the things they ought to think about where an ethical consultant would be involved is, what kind of hospital is it and what kind of ethicist or ethical consultant are they likely to have there, and is that somehow consistent with their own ethics or sense of what's right and wrong, and that these are all factors, as well as some others I hadn't thought of, to be taken into account? And the doctors ought to be sensitive to that, too, rather than simply saying, "Well, we'll get someone who is an ethical consultant to help us solve this problem. And one is about as good as another one. As long as they have some experience in these matters we don't need to worry about it."

That's all I'm really trying to find out. I'd be particularly interested in hearing what Dr. Fletcher or Father McCormick has to say. Dr. Fletcher, please.

DR. FLETCHER. I don't think anyone is as good as anyone else in this kind of work. I think it takes hard work to learn how to do it and hard work to keep your hand in it and do a good job.

But it is a new role in the hospital. I have been working at the NIH in its hospital since 1977. There were only four or five people in the country who were doing something like this in an individual role prior to that time. And I think it is notable that it's the first national meeting of such people coming up in the fall. So it is a new role.

Whether parents should be educated about what kind of ethics services a hospital has, I think, is probably too much to expect. Most parents are not even familiar with the risks of having babies. If parents were really familiar with the risks of having babies in the first place, they might be scared off.

I think they should be familiar generally. I think that physicians, above all else, who are going to call on the help of ethics consultants, ought to be satisfied that the persons that they call on can do a good job in a situation with people who come from very different social and educational backgrounds, and that the people that they invite to perform this service or to render this service need to go through a period of testing and on-the-job training, so to speak, and to pass tests in this area.

It is difficult to talk about because it is a new area that at this point has no criteria with respect to qualifications.

COMMISSIONER BERRY. Thank you very much.

CHAIRMAN PENDLETON. Thank you very much.

Would you go ahead, Mr. Mandelman.

MR. MANDELMAN. I'd like to follow up on some questions Commissioner Berry raised.

Professor Fletcher, in one of his articles, had cited a number of indicia of humanhood which included an IQ of at least 20 and perhaps 40—

DR. FLETCHER. Are you addressing the question to John or Joseph?

MR. MANDELMAN. Well, I have a couple of questions, but I wanted to kind of read this first.

DR. FLETCHER. The author of the statement you are quoting is Joseph Fletcher, not John.

MR. MANDELMAN. A colleague or a relative?

DR. FLETCHER. A colleague, but one with whom I'm in some disagreement.

[Laughter.]

MR. MANDELMAN. Well, this would be a very appropriate question then. He listed as these criteria an IQ of at least 20, possibly 40, ability of self-awareness, self-control, a sense of time, and the capability to relate to others. I guess I'd like to address this to each member of the panel. Do you regard these as valid criteria for determining whether or not to treat a severely handicapped newborn? If you don't, why not? Would you add other criteria in addition to the ones he enumerated, and what might those be?

DR. FLETCHER. I'll begin since I want you to be sure you know that I'm John.

Among the many things that I am in profound disagreement with as someone who has the same name as I and with whom I'm friendly is the use of such criteria to make medical treatment decisions. I think if you look at these criteria, they are really, in my view, desirable qualities in an educated adult, and what you would consider to be desirable qualities to attain if you had a good education and you had the fundamental equipment to get a good education.

I think these are cultural standards much more than ethical standards for making medical choices about treatment and, particularly, nontreatment. I think that the criteria for nontreatment decisions or treatment decisions ought to be as strictly medical as possible. No medical choice is entirely, completely, nakedly a medical or scientific choice. I don't think that quality of life considerations can be ruled out of the universe, but Dr. Joseph Fletcher's considerations are primarily quality of life considerations. I do not think those are the proper set of standards to use for treatment decisions.

MR. MANDELMAN. Dr. Warren.

DR. WARREN. I believe that quality of life considerations cannot be avoided, but the problem with using prognostications about the child's eventual level of intellectual development is that it's very rarely possible to make such reliable predictions, except in extreme cases such as anencephaly or very severe brain hemorrhage. In those cases, I think it's highly relevant that the child will never have any level of human experience possibly beyond the simple capacity to suffer. I would place more emphasis upon the quality of life in terms of whether it is a life of unrelieved pain and suffering or not.

MR. MANDELMAN. I think Professor May is at the other end of the philosophical spectrum. Would you agree or disagree with Professor Warren?

DR. MAY. Where I disagree with Professor Warren would be predicating the judgment to withhold or withdraw treatment, upon the quality of the subject's life. I do think, as I said before, that there are times when it would not be appropriate to treat a newborn, and the quality of life in this sense might relate to it in this way: that a treatment that would be excruciatingly painful for a child with one particular group of anomalies might not be painful for a child who does not have that set of anomalies, or it might not be beneficial, or it may be futile for a child of that type.

So if the burdensomeness of the treatment is related to the condition of the child, then the quality of life goes into consideration. But that is not the same as refusing to treat the child for fear that the treatment will be successful and that the child will continue to live. And I think that is what has been done, and is perhaps being proposed by some, that a child not be treated, not because the treatment itself is painful to the child or burdensome to it, but that the life that the child has is burdensome in your judgment, whereas it may not be to the child itself. It is hard to put ourselves in a position, let us say, of a trisomy 18 child or something like that.

But I see no reason, if the treatment itself is not painful, if the treatment would remove a lethal threat from a trisomy 18 child or a Down's syndrome child, and would be given to someone who didn't have certain anomalies, I don't know why you would withdraw it or withhold it just because you don't think the life of this child is a worthwhile kind of life, even though it might be a short life.

MR. MANDELMAN. I have a last question and then I will turn you over to the Commissioners. I address this more to Father McCormick and it follows up on this question. In 1957 Pope Pius XII is quoted as making a statement in regard to treatment—I assume it meant under these particular kinds of circumstances. After noting that we are normally obliged to use only ordinary means to preserve life, he then stated—this was to a group of physicians—"A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, death, all temporal activities are in fact subordinate to spiritual ends."

Does that statement of the Pope conflict with what Professor May said? Are they compatible with each other? Or is the Pope enunciating a different standard?

FR. MCCORMICK. The Pope in that particular segment is outlining a basic attitudinal approach. He is not applying something. He is simply saying that life has to be viewed as a basic good, but not an absolute one, and that death is an evil, but it's not an unconditioned evil. Therefore, there is a time to die. Not everything must be done to preserve life. It is an attitudinal approach, which then takes the form of a more concrete principle about the use of ordinary—extraordinary measures or whatever you want to call them.

MR. MANDELMAN. Does that conflict with Professor May's view?

FR. McCORMICK. No, because I think Professor May is talking at the level of more concrete applications than Pius XII was.

MR. MANDELMAN. I'm sorry I can't continue, but I'll turn it over to the Chairman and members of the Commission.

CHAIRMAN PENDLETON. Thank you.

Mr. Bunzel.

COMMISSIONER BUNZEL. There are a number of questions that come to mind here. If I understand Mr. May clearly, the right not to be killed is, in your estimation, an absolute.

DR. MAY. Put it this way: I would hold that life itself is not an absolute good. There are other goods. But I do think we have some absolute obligations and some absolute rights.

For example, I think you have a right not to be lied to by me today, and I have an obligation to tell you the truth and not to utter falsehoods to you. And I believe that as human persons we have the right to secure enjoyment of our lives against hostile attacks by others. Some of us do believe that some kinds of killings can be justified, such as killings in self-defense. I think there are some kinds of killings in war that can be justified.

But I do think that individuals who are not engaging in any kind of hostile behavior toward others, who are minding their own business, that such individuals ought to be secure in the possession of their life, and that the right to life in this sense is absolute; and it is part of our constitutional guarantees as I would consider it. In other words, the purpose of the government, I think, is to secure and to protect the rights of its citizens. And among the rights that we have would be the right to the secure possession of our lives against hostile attacks by others or from judgments that are discriminatory toward us that would have as their effect our own death.

Did I answer your question?

COMMISSIONER BUNZEL. Did you say that one of the absolutes you would consider is the right not to be lied to?

DR. MAY. Certainly, the right not to be lied to in situations such as this. In situations where truth is expected in a discourse, yes.

COMMISSIONER BUNZEL. If we had the time, I think perhaps we could engage in quite a discussion on that point alone, because I can conceive of some situations in which there might be some competing values in which the outright absolute of not lying to a person might want to be tempered and weighed against the other value, let us say, of something called kindness in certain situations.

DR. MAY. I did specify the situation with respect to lying here. And that would be in courts of law, for example, and in hearings of this type.

My other consideration regarding the right to life, in my judgment, is innocent human beings or persons who are technically innocent who are not themselves engaging in any kind of activity that poses a threat to the life and security of other human beings have a right not to be killed. There is a difference, too, between killing and letting die.

COMMISSIONER BUNZEL. Yes, I understand that, and I wanted to come back to that in a moment.

What I am basically trying to get at is whether or not you, or any of you on the panel, as I tend to do in my own thinking on these kinds of subjects, by the way, operate with a kind of conflictual model. That is to say, I see a competition of values, a conflict of principles very often. Therefore, it is difficult for me to start with rigid or even soft absolutes and to cling to them.

I tend to see many of the issues that we have been discussing in the last 24 hours as ones in which there is a legitimate conflict of values. And I would think that those who are ethics consultants would be among those who would see this absolutely clearly. And I suspect that you all do, but I want to be sure that I'm stating that properly, that, in fact, there is a legitimate conflict of values among ethicists and among the issues they deal with.

DR. MAY. I would say this. I don't think I would start off with an absolute of this kind. I would say that one ought not adopt by choice a proposal to kill innocent human persons. I think that might be a conclusion of certain principles and premises—just as I think one should not rape women.

COMMISSIONER BUNZEL. But I want to be sure. It seems to me, if I understand that correctly—perhaps that's an inapt analogy because I can't conceive of any time, no matter how you start from certain premises, that you might conclude that it would be justified to rape someone.

DR. MAY. You'd be surprised at the creative imagination of ethicists. I think there are some who will justify rape under certain circumstances and conditions, but that would take us perhaps too far afield.

In my judgment, there can be a conflict of positive duties, in other words, and you can't always be carrying out positive duties, but you can forbear simultaneously the doing of many different things; and all that this requires is the forbearance of taking legal action against innocent human persons. I think that would be compatible with many other kinds of duties.

COMMISSIONER BUNZEL. I want to follow this up with another kind of question, but before I do is there anyone else on the panel who would like to address this particular set of concerns?

DR. FLETCHER. Yes. I often enter situations very much aware of the conflicts in the case, different views about the priorities in a case. I also hear many physicians say sort of apologetically when they call me up, "Well, John, I know there are not any answers." I don't know how many meetings I've been to where they start off on this note.

I think that's to give up. In other words, you can be so impressed with the conflicts that you stop thinking or you stop looking for the best thinking about the problem. And our society and other societies are very rich in good thinking. This good thinking has to be sought out. It's not self-evident in the case. Often you don't have time when the case is breaking to consult the best thinking about it. That's why it is important not to make judgments too hastily.

So there are conflicts, to be sure, but I try not to rest in the conflict, but to look for and seek out the best thinking about the problem and to try to come to a satisfactory resolution of the problem, which generally means that one principle has to trump another one. And you have to be willing to take the risk to trump with another one in order to resolve the moral conflict.

COMMISSIONER BUNZEL. Ms. Warren.

DR. WARREN. There has been a good deal of discussion in the last day about the concept of discrimination, which I hope we will get back to.

It seems to me that it is a kind of wrongful discrimination against infants to hold that there is no moral objection to keeping them alive when there is no prospect in their future but dismal, unrelieved suffering. Most people would readily agree that it is wrong to keep adults alive against their will when their prospects are nothing but unrelieved suffering. I think it's equally wrong to do that in the case of helpless infants who are unable to tell you to stop doing it. Just because they can't tell you to stop doesn't mean there's no objection to inflicting suffering on them.

COMMISSIONER BUNZEL. That interests me, and I assume that it interests all of you. And I assume that that particular point of view would be perfectly acceptable to the convention of ethicists in San Francisco; that is, the position that Ms. Warren has taken is perfectly acceptable. Because what I am really trying to get at is a different kind of question but related to this. I think you said there were 51 or so who had been invited to the convention

DR. FLETCHER. —to a meeting in Bethesda, Maryland.

COMMISSIONER BUNZEL. I'm sorry, in Maryland. That's a big change.

Let me ask you this question: In order to attend the meeting or convention, would all the ethicists have to agree on when infants become persons?

DR. FLETCHER. No. All they needed was a letter from their chief executive officer saying that they provided ethics consultation in their hospitals.

COMMISSIONER BUNZEL. What I'm trying to get at is whether there is in any sense, either explicit or implicit, a hierarchy of values which suggests that there is a boundary beyond which a legitimate ethicist can no longer be considered legitimate.

I raised this question in another way this morning with a hypothetical example. Let me put it still another way. Do neonates have a right to life, and must all ethicists who are legitimate entertain the same answer?

FR. MCCORMICK. I think the introduction of the word "legitimate" is a little confusing. People in ethics can be sometimes dead wrong, as all of us can. And a person who would hold some outrageous view of human personhood that was shared by virtually no one else, that person would be judged to be wrong. But you wouldn't say he becomes illegitimate or something like that. It's a term that we are unfamiliar with.

I think perhaps what you may be getting at, though, is how much can we expect in terms of consensus by people in this field. That is a major legitimate concern, and I think that the proper answer is that studying the three commissions, the Federal commissions that have been in existence—the National Commission for the Protection of Human Subjects, the Ethics Advisory Board, and the President's Commission for Bioethical Problems—they found, contrary to some people's expectations, a broad area of consensus quite achievable, not on all minor points at all.

And I think when you're dealing with, say, the personality of the newborn, you are going to have disagreements and so forth. That is to be expected. But there comes a point at which you will find—I think most all of us agreeing, for example, that a newborn per se has a right to life. I don't think you'll find many people denying that statement.

DR. WARREN. On the contrary, I think most people in our culture would tend to believe that it is worse to wrongfully kill an infant than to wrongfully kill an older person because of their innocence and helplessness.

But I think it's very interesting to note that, in terms of the full sweep of human history, this is an unusual position. The vast majority of human cultures throughout the world, throughout history, have practiced infanticide not because they saw nothing wrong with it, but because they had absolutely no choice. In the absence of readily available effective contraception they simply could not raise all the infants that were born. Therefore, they accepted infanticide as the lesser evil. And this is still very much the case in some parts of the world today.

In other words, I think we should recognize that we are in a position of unique privilege, that we are wealthy enough that we are able, and I think obligated, to attempt to save the life of almost every infant that is born.

COMMISSIONER BUNZEL. Before the Chairman cuts me off completely, as he is about to do, let me just ask one other question for the sake of clarification—

CHAIRMAN PENDLETON. Only for ethical reasons.

COMMISSIONER BUNZEL. Don't touch the body, please, unless you're a registered nurse.

[Laughter.]

CHAIRMAN PENDLETON. Certified ethicist.

[Laughter.]

COMMISSIONER BUNZEL. From the wine country in California.

[Laughter.]

COMMISSIONER BUNZEL. Is ethics—and I'm talking about it now in the sense that we are talking about ethics consultants, the ethical considerations which we have been discussing from the point of view of what these people would do in these committees in hospitals with physicians, parents and so on—am I right in assuming that ethics is more than a body of material simply to master, like the alphabet, or engineering?

DR. FLETCHER. Of course, society is guided by a number of central traditions or systems of morality that we all are supposed to learn if we are well brought up in society. Every human being, if he or she is well brought up, learns moral rules and principles to help save society from chaos every day.

But there are people who are set aside or chosen to be specialists in helping us. And all of us know what to do when we get into a moral conflict of great importance—whether a President should lie to the country about a U-2 incident, or something of that magnitude, or whether a handicapped newborn deserves selective nontreatment.

These are moral choices of very great moment. And people specialize and have a vocation in helping those in those kinds of difficulties, and those who think about these things worry their way through such a problem, and there's a literature about it that accumulates. It helps to understand the literature. But the realities of the problem and having some preparation and rehearsals for when you're in a situation like this, if you're teaching ethics, is where the payoff really is. People who find themselves in these difficulties say, "Your teaching or your help has really helped. It has helped eliminate the problem with the alternatives available," and related the best thinking of these traditions to the problem they had.

COMMISSIONER BUNZEL. It raises a question, interestingly enough, as to whether or not there ought to be an ethicist, let us say, in the White House, as well as in the hospital and a variety of other situations.

Professor Warren has said earlier in answer to a question, perhaps facetiously, that anybody is an ethicist who is interested in these kinds of questions, as are members of this Commission. I don't know whether she meant that literally or whether she was being generous in the notion that the members behind this table here would be sufficiently trained and just as capable of aiding physicians in these situations.

What I'm trying to get at, frankly, as I'm sure you see, is whether or not ethicists are trained—I mean there isn't a cookbook in which there are rules of ethics. There are books that have been written about ethics, and they go back as far as we can remember.

But if I am an ethicist because I'm interested in these problems or because as an undergraduate I took some courses that happened to interest me at the time, if that makes me an ethicist, then perhaps I have some moonlighting possibilities with the hospitals. And if I'm not, I would like to know what disqualifies me. And I'm not really being flippant here. I'm really quite interested in the degree to which a person becomes qualified as an ethicist and if there are criteria about these matters around which there is a consensus.

DR. WARREN. May I speak to that? I have always been very resistant to the notion that there is a certain group of people who possess the entire truth about morality, and that's why I suggested that the members of this Commission, by virtue of their interest in these ethical problems, are at the very least amateur ethicists.

One can distinguish between amateur ethicists and professional ethicists; one can distinguish between sophisticated ethicists and unsophisticated ones, but I think there is no human being alive who doesn't at times turn their attention to moral issues. And that's all ethics is about, turning one's attention to moral issues.

As for where ethical authority comes from, it comes from nowhere but the validity of one's arguments. The most well-educated ethicist in the world has no moral authority other than what comes from the force of the arguments she or he is able to put forward.

CHAIRMAN PENDLETON. Excuse me. I just don't know how you can certify to be an ethicist and do the things you have to do in the kind of setting in a very serious and sensitive area. But if you say that validity is the certifier, then I still need some more help. Who validates?

DR. WARREN. I don't think anyone should validate ethicists. But if you're looking for an additional member of a hospital committee, I think there are a number of specific qualities one would look for, such as the ability to explain the moral options to people who haven't really been exposed to the problem before, the ability to draw out their feelings and help them to discuss the issue and come to grips with it. That is not strictly an ethical task; it's partly a counseling task.

CHAIRMAN PENDLETON. It's almost like saying to someone that 60 degrees is twice as high as 30 degrees when there is no absolute zero.

DR. FLETCHER. If I could add: If you were a hospital administrator and considering employing someone to be a clinical ethicist or to function as the identified consultant in your hospital, you would surely look for someone who is very familiar with the clinical setting, someone who is no novice at that, because you are not paying him to learn about it. Number two, you're looking for someone who already has a good track record in the literature and who is not dumb about the traditions of ethics that they are going to be interpreting.

CHAIRMAN PENDLETON. Mr. Fletcher, I can certify to you that there are immoral situations where there is morality—in terms of there being honor among thieves. There is a certain kind of morality there that people practice, you might say—I heard you say that people who are brought up the right way, who have moral underpinnings and so forth are the kind of people who understand. But I think that people who deal in immoral situations who also understand are those that a certain group of us would consider to be in immoral situations. I'm just uncomfortable with how you get to be who you are and what a strong role that plays in the process of determining the care of newborns.

FR. MCCORMICK. Why, may I ask, are you uncomfortable with that, that certain people by training, experience, exposure, etc., can actually open the eyes of other people to dimensions of situations which they might have overlooked? That's what ethics is about. It's really corrective vision.

CHAIRMAN PENDLETON. I think I heard earlier something about the fact—I think Mr. May talked about something about determining medical treatment in his opening remarks—determining something else. What did you say about it in the beginning of your statement today, in answer to Mr. Mandelman's question, his first question?

DR. MAY. I think I said the crucial issue was a matter of justice and equity to the newborn and in selecting certain groups to be treated and not treated, not to unjustly discriminate against some by refusing the treatment because we judge their lives not to be of value to them. There are other criteria for determining that. I think that's what I said.

CHAIRMAN PENDLETON. I guess why I'm uncomfortable is that we have all this training and all the advances in neonatology and pediatric treatment and so forth, and people become certified and board certified and what have you. Then we have people who have a primary role to play in this process, and as a certification, it does not exist—maybe it should not exist—but I think that that's what makes me uncomfortable about how you get to be the way you are. I heard earlier that your arguments can be validated, that this is how you draw these conclusions, and people validate that. But it just seems there's something missing that I can't quite identify.

DR. WARREN. Another word you might use is lucidity. Can you present the problems in a lucid way that helps other people to understand them and to come to their own resolution?

CHAIRMAN PENDLETON. Is that to assume that parents are not lucid when they make decisions to treat or not to treat?

DR. WARREN. I think it is important that they be given some counseling about what the options are, because very often they are simply not aware that there are options.

CHAIRMAN PENDLETON. If the doctor is the protector of the patient, as we heard earlier, then why do we need ethicists?

DR. WARREN. I'm not sure that in every case you do, but there are many types of problem situations that can arise, such as disagreements between the doctor and the parents, disagreements between the parents, or simple uncertainty on the part of the parents. They may just not know what in the world to do, and they may be searching for any kind of help they can get.

And an ethicist may be one of a variety of people they may turn to for some kind of help in dealing with this tragic situation.

COMMISSIONER BUNZEL. You wouldn't want more than one ethicist on a committee, then, because there might be disagreement among the ethicists.

DR. WARREN. Oh, on the contrary, I think it would be very healthy for there to be disagreement, so that the parents become aware that there isn't a single monolithic Truth, with a capital T.

COMMISSIONER BUNZEL. I agree with you about that.

CHAIRMAN PENDLETON. Would you say somehow there is an intervenor role between society and the patient and doctor, that that's a role to be played, in a decisionmaking process about what the options are?

DR. WARREN. Personally, I would like to see the decision kept as much as possible in the hands of parents and physicians, but sometimes it is helpful for them to discuss it with other people, particularly those who have spent a lot of time thinking about cases of that sort, and who may be able to tell them about additional options that just haven't occurred to them, or may be able to give them arguments which they hadn't thought of.

CHAIRMAN PENDLETON. Mr. Destro, we are late, but this is an important topic to us, and we want to try to get as much on the record as we possibly can.

COMMISSIONER DESTRO. Let me follow up on this line of questioning and then turn to another one.

Let me start with Father McCormick. I guess the question I take out of Commissioner Berry's, Commissioner Bunzel's, and Chairman Pendleton's question is not so much a question of certification of ethicists, but you used the idea of somebody—and this is my term now—what you may call a mainline ethicist, and then somebody—your term was "outrageous."

Let's say you had a hospital administrator who had to pick an ethicist, who thought that Michael Tooley was the greatest ethicist since the beginning. How likely is it going to be that he is going to choose someone who agrees more with his view or with someone who would be more along the lines, for example, of Paul Ramsey?

FR. MCCORMICK. Well, if I understand what you're driving at, I think that any hospital CEO or someone like that who is thinking of taking on an ethical consultant should consult with the peers of that person and find out: Is the person published? Is the person a reasoned, disciplined thinker? Is the person clinically sensitive? What do you people think of him, his peers? Wash him out in public a little bit and find out whether he's going to fit.

COMMISSIONER DESTRO. My question is a little bit more blunt than that. How likely is it going to be that a hospital administrator is going to choose someone who is a little bit more in their own school of thought than it is for someone who would really challenge their starting points?

FR. McCORMICK. Well, I think that's probably true: It's probably buried in human frailty, that we tend to praise, reinforce, to hire, etc., those who are minor reflections of ourselves to some extent, and our own thinking patterns, and so on.

COMMISSIONER DESTRO. The reason I asked the question—and this is something that has been a criticism in listening to many of the disability groups—is that their vision of the process has been that it's been a rather closed process, largely in the control of the medical profession and the ethical consultant that it hires. And the problem from their perspective has been: How do you break open this process to some other points of view, to the points of view that other people don't hear?

And if you have the mainline ethicists, the ones the people who do the hiring consider to be the legitimate ones, how likely is it that you are really going to have a real advocacy argument going on in the treatment decisions, rather than people kind of agreeing with each other because they all generally have the same starting point?

FR. McCORMICK. I won't speak for the panel, but I don't accept the assumption upon which that is made, that is to say, that there is a closed process. I think a good, sensitive person in the field of ethics is going to include all points of view to the extent that that is possible. And to argue that it's closed, I think you'd have to have a lot more evidence than I've ever seen. I believe that good discussion between family, patient, physicians, ethicists, has a built-in advocacy component to it. I have seen it time and time again.

COMMISSIONER DESTRO. Dr. Warren, would you explain to me why you would consider the Tay-Sachs example to be a gray area?

DR. WARREN. I think that the way in which Tay-Sachs progresses is particularly horrible, that it involves intense, prolonged suffering, and it is not something that I would willingly inflict upon another human being. But on the other hand, I would not be so presumptious as to say to a parent of a Tay-Sachs child, "You ought not do everything possible to keep that child alive." I think it's their choice. They are the ones who know how much of themselves they can put into it, and I really do think that it's their choice.

COMMISSIONER DESTRO. I guess the question that I have had all along in terms of looking at this as a question of discrimination—I don't mean this as a negative commentary on any of you because I respect you greatly—but if I see, as a member of the Commission, that section 504 of the Rehabilitation Act says that you don't discriminate on the basis of handicap—and let's for purposes of this discussion assume that Tay-Sachs is one of those conditions—then it would seem to me that you are making an argument for an ethical exception to the rule because Congress has already made the judgment that you will not discriminate on the basis of handicap.

DR. WARREN. Yes, I'd like to say something about the concept of discrimination as it is used in the moral context. "Discrimination" means making a distinction between cases on the basis of some factor which is morally irrelevant. For example, if I refuse to hire you because I don't like men, even though the job is one that a man could do perfectly well, that is wrongful discrimination. But if I need a sperm donor, it is not irrational for me to demand that the sperm donor, be male because their sex is obviously relevant.

I think the same is true in the case of many of these decisions about handicapped infants, if one assumes that to allow the condition of handicap to influence the medical treatment is in each and every case wrongful discrimination. One overlooks the very real possibility that the condition of handicap in itself may be a highly morally relevant factor with respect to the type of medical treatment that is appropriate.

COMMISSIONER DESTRO. We had some doctors yesterday who said if you had a "normal" child who had a duodenal atresia, and we have used the example of Tay-Sachs or some other kind of handicap, there would be no question that if the handicap existed by itself you wouldn't be able to withdraw food and water, for example, and if the kid were normal, you would go ahead and have the surgery. But it is in the mixed case, where one is present with the other, that we get into difficulty. And it seems to me, from a lawyer's understanding of discrimination, that you are using the handicap as the reason to justify not doing something that you would do for somebody who is, quote, "normal," that is, defining that as the absence of the handicap.

DR. WARREN. I think that the original Bloomington Baby Doe case is one in which, if the facts reported by the media are correct, the concept of discrimination may very well be relevant. It may very well have been the case that the child was wrongfully allowed to die simply because it had Down's syndrome. But I put a great deal of emphasis on that word "if" because I personally have many doubts about whether the picture presented to us by the media is correct. I have seen alternate and more detailed accounts in which the claim was made that the child was not simply afflicted with Down's syndrome and esophageal atresia, but also was thought to have very severe brain damage because it was asphyxiated at birth and had a very difficult resuscitation, and the X-rays apparently showed a very greatly enlarged heart.

Now, if those things are true, then it is not clear to me that the decision not to treat was based primarily on the Down's syndrome. The point is we don't have all the facts in that case, and I am leery about making assumptions about what those facts are. The courts which held in favor of the parents were in possession of far more medical facts than we are.

COMMISSIONER DESTRO. So in other words, you would put yourself in the school that considers quality of life to be a critical factor, then?

**Dr. Warren.** Yes, with certain very careful caveats. I do not think that low IQ by itself constitutes an abysmally low quality of life. I would place the emphasis on pain and suffering, not on quality of intelligence.

**Commissioner Destro.** Dr. Fletcher.

**Dr. Fletcher.** I said earlier that you can't rule quality of life considerations out of the universe. Anyone who feels, imagines, thinks does speculate on pain and suffering and on morbidity and these matters. I admire very much an article by Richard McCormick about what I think is the best thinking about what quality of life considerations mean, so I think I'll pass it to him.

**Fr. McCormick.** I find at some point that the quality of life component in our judgment is simply unavoidable. I feel comforted in that because that is the conclusion of the President's Commission, as well as the final rule of HHS, published April 15, where it said that when a child is born and will never recover consciousness, therefore permanently vegetative, if you want to put it that way, that is clearly a quality of life judgment even though it's a very narrowly based one.

May I say a word about the handicapped for a moment, since you were asking about that? I think that language, "Don't discriminate on the basis of handicap," is very loose language. One can argue conversely that handicap is precisely the basis on which you withhold treatment from certain infants. If the handicap is indeed terminal cancer or if it's something like that, these are all handicaps. So it's very, very misleading language to face into these problems in terms of nondiscrimination on the basis of handicap.

**Commissioner Destro.** So in other words, quality then would determine what is extraordinary or ordinary?

**Fr. McCormick.** Very often at that level you try to disguise it. The question is not whether quality of life ingredients play a part, but where we draw the line.

**Dr. May.** Reference was made to Father McCormick's article. I was looking it over the other day. It's called "To Save or Let Die." I presume that's the article. There is one passage in it—and I'll quote it—that I think illuminates the problem. In it he says, "The kind of life thus saved, burdened, painful" etc., etc., "is what makes the means extraordinary, and that kind of life is a burden."

I have problems with that. I do not believe that the child must be treated under all circumstances, and that one can legitimately withhold and withdraw treatment from handicapped children for reasons that are analogous to those that are used by competent adults for refusing treatments for themselves—because of the pain of the treatment, the futility of the treatment, the burdens that the treatment imposes.

But I do believe that life itself is something good, however burdened it might be, and that many of our handicapped persons themselves—this, I think, is brought out by Dr. Koop's work—no child on whom he operated over many, many times ever regretted that he was operated upon and that his life was preserved.

We sometimes make judgments about what is meaningful based on our subjective preferences, and when we get to the quality of life, this is something that gets into degrees of difference. I think it's very difficult, then, to find a nonarbitrary quality of life that will be a criterion for withholding treatment. And then we're going to get borderline cases, baby X, baby Y, baby F, and it will be very difficult to discriminate among them, and therefore if you are going to use quality of life as your criterion I think you are ultimately rooted in some kind of a subjective swamp, whereas you can avoid that by using reasons analogous to those that adults use for withholding or withdrawing treatment for nonsuicidal reasons.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. I don't know if we may have gone too far out on this one to get back.

If a parent adopts a child, he has a right to raise that child in whatever culture, traditions, language, religion that he belongs to or what he knows. But if the parent makes a decision as to treatment or nontreatment based on his experiential knowledge and/or listening to all these ethicists and review committees and everything else, at what point is it wrong to follow a parent's decision? And how can you justify following or not following the parent's opinion or decision not to treat and not have Title IV or the Child Abuse Amendments become a threat that really would be against the better interests of the child? Can you give me some idea on that?

DR. MAY. I do think, first of all, parents have certain rights with respect to their children, but they also have to exercise those rights responsibly. For example, if a parent were a member of some kid porn group and thought it was perfectly all right to have his child of the age of 2 or 3 participate in pornographic films, I believe, quite legitimately to protect the child, the State should intervene.

Similarly, parents can unfortunately make mistakes in treatment decisions about their children. And that if the child is unjustly denied a treatment—and this is a possibility, I presume—on the presumption that the parents are seeking to take the best care of their children, then that presumption would have to be overridden by certain kinds of facts or evidence. But it is a possibility that a parent could discriminate against the child and want the child to be dead because they think that it's better off dead than alive, and they may be influenced in that judgment by others. So there is a need for protection of the rights of a child in the event that the parents cannot properly exercise their responsibilities toward it.

COMMISSIONER BUCKLEY. Would you answer that?

FR. McCORMICK. I think you are concerned about the proper check on parental discretion, and it seems to me that there would have to be a certain flexibility granted parents within the concept of the reasonable.

When parents get outside of that, then I think there will be public outrage, as there has been. And I think that is the probable check on some parental judgments that are way out of line, and the courts, of course. I have known cases where decisions were about to be made where all of us concerned were ready to go to court to protect the child. We thought the parents had made the wrong judgment.

So there are two possibilities.

CHAIRMAN PENDLETON. I want to thank you very much, and it is interesting. If you have other things to submit to us, please do that. The record will be open for 30 more days; there may be more questions someone might want to ask of you in writing, which will be put into the record.

We'll take a break and have the next panel, the Patient Care Review Committees.

[Recess.]

CHAIRMAN PENDLETON. Are all the witnesses here so I can swear them in?

[The witnesses were sworn.]

## Patient Care Review Committees

### TESTIMONY OF RONALD E. CRANFORD, M.D., CHAIRPERSON, INSTITUTIONAL ETHICS COMMITTEES ADVISORY BOARD, AMERICAN SOCIETY OF LAW AND MEDICINE; JOHN FLETCHER, ASSISTANT FOR BIOETHICS, NATIONAL INSTITUTES OF HEALTH; JEFFREY POMERANCE, M.D., DIRECTOR OF NEONATOLOGY, CEDARS-SINAI MEDICAL CENTER, LOS ANGELES, CALIFORNIA; AND LEONARD A. WISNESKI, M.D., CHAIRMAN, ETHICS COMMITTEE, HOLY CROSS HOSPITAL, SILVER SPRING, MARYLAND.

MS. MASSEY. My name is Peggy Massey, and I'm a staff attorney with the U.S. Commission on Civil Rights.

The first question, beginning with Dr. Cranford, is: Will you each please state your name and position for the record.

DR. CRANFORD. Dr. Ronald E. Cranford, associate physician in neurology, Hennepin County Medical Center, Minneapolis, Minnesota.

DR. WISNESKI. Leonard A. Wisneski, M.D., clinical professor of medicine at George Washington University Medical Center, and Chairman for the Ethical Advisory Committee at Holy Cross Hospital in Silver Spring.

DR. POMERANCE. Dr. Jeffrey Pomerance, director of neonatology, Cedars-Sinai Medical Center in Los Angeles.

DR. FLETCHER. John C. Fletcher, assistant for bioethics at the Warren G. Magnuson Clinical Center of the National Institutes of Health.

MS. MASSEY. Dr. Cranford, will you briefly explain how you became involved in the movement to create ethics committees or patient care review committees in hospitals?

DR. CRANFORD. When I finished my residency in 1971, I formed an intensive care unit in neurology. We had many ethical dilemmas at that time. Also, in 1971 because of a concern about overtreatment of patients and other ethical dilemmas that were raised, we formed a thanatology committee. Our thanatology committee developed over the years. In 1980 we recognized that we were dealing with problems more than just death and dying. We then formed a full-fledged biomedical ethics committee in the Twin Cities of Minneapolis-St. Paul. We had four committees at that time that went from a death and dying committee to a biomedical ethics committee.

In 1982, because we recognized the need for a network of these committees, we formed an informal network of bioethics committees in the Twin Cities of Minneapolis and St. Paul. In 1984 we formalized that network, called the Minnesota Network Institutional Ethics Committees. In the next year or two there will be 26 of the 34 hospitals in the Twin Cities area that will have an ethics committee in place.

In addition, all three level III neonatology units in the Twin Cities formed together in over a 2-year period the principles of treatment for disabled infants and formed a neonatology intensive care unit network at the same time.

MS. MASSEY. Dr. Cranford, would you explain on a national level what activities you have been involved in that would help to facilitate the development of ethics committees in hospitals across the country.

DR. CRANFORD. Well, prior to 1982, there was a grassroots movement among many hospitals nationwide to form institutional ethics committees, IECs—this was prior to the Baby Doe case. In 1982, when the Baby Doe case arose, there was a movement to form infant bioethics committees. So in terms of institutionalizing, this still is a grassroots movement nationwide.

At the same time, there have been numerous organizations which have accepted a leadership role in terms of advocating these committees, both in terms of infant bioethics committees and institutional ethics committees, and have tried to form networks, as I said, the Minnesota Network for Institutional Ethics Committee.

And around the country now, what is happening on a voluntary basis is that numerous areas and health care systems are forming networks of ethics committees. In California, for example, the California Association of Catholic Hospitals, 39 of the 44 hospitals in that system have ethics committees. We have formed a network throughout the country, like New

Hampshire and Vermont for one, Colorado for another, Minnesota for another. Networks of ethics committees are forming in various areas.

In 1982 and 1983, because of the interest in ethics committees, the American Society of Law and Medicine, which is an interdisciplinary group of lawyers, doctors, and others, felt there was a need to encourage this mechanism, and so we had the first national conference on ethics committees in 1983 in Washington, D.C. Last year we had four regional conferences on ethics committees in Houston, Detroit, Los Angeles, and Boston; and this year we will have one in New York.

And we have set up a National Center for Institutional Ethics Committees through the American Society of Law and Medicine, and we tried to set up an advisory board of prominent people around the country to lead this center. We have also tried to find resources around the country to develop these committees on a voluntary basis, and many of us have been traveling to various States working with individual committees and working with networks to develop these committees.

Several of us have worked with the American Academy of Pediatrics in the development of infant bioethics committee guidelines; and many of us, including pediatricians and others, have worked with the American Academy of Pediatrics to encourage development of these infant bioethics committees and institutional ethics committees nationwide.

MR. MANN. When do you find time to practice?

DR. CRANFORD. It's very difficult to do.

MS. MASSEY. Briefly describe the basic structure and role of review committees in hospitals. At the same time, will you briefly describe what, in your efforts to create these committees, you are telling medical professionals across the country in regard to how to report cases of alleged neglect of handicapped newborns in hospitals.

DR. CRANFORD. We have to distinguish between institutional ethics committees, which I have been involved with a great deal, versus infant ethics committees. The movement for institutional bioethics committees started prior to the Baby Doe case in Bloomington, Indiana, in April 1982. The functions of the ethics committees are articulated in books and articles that are now being published in this area.

The basic functions of these committees are, number one, educational, to educate health care providers concerning ethical dilemmas, by having conferences, having outside speakers in, ethics rounds, and so forth; and primarily since there aren't very many physicians and others within institutions who are very experienced in this area, to self-educate the members of the committee.

Secondly, we are in the process of developing policies and guidelines, locally, State, and nationwide, on various areas. The most successful or the most prominent in terms of developing guidelines are the "do not resuscitate" and "no code" guidelines, we have also developed brain death guidelines. The network in Minnesota developed principles of treatment of disabled infants in that area. And we are in the process of developing guidelines in other areas, as articulated by the President's Commission report, concerning institutional ethics committees, developing publicly available explicit policies and guidelines.

Thirdly, these committees function in a consultative or prospective review. That is, we are consulted on individual cases as they occur to give advice, assistance to physicians and others who request our expertise. This advice is advisory, and the vast majority of work that has been done with institutional committees on a nationwide basis has been advisory rather than mandatory.

The fourth major area is the retrospective review where we go back and review individual cases and see how well they were handled or to review certain types of practices over a period of 6 months or a year, such as decisions not to resuscitate a patient, and make sure that good ethical decisionmaking practice was performed in these areas.

So these are the four major functions of the institutional ethics committees, as we envisioned them.

The ethics committee per se is a multidisciplinary group of individuals convened by an institution to broadly deal with ethical dilemmas. So the key to an ethics committee, as we see it, on a voluntary basis, on this grassroots basis, is multidisciplinary. The composition of these committees often starts with 5 to 10 people and increases to 10, 20, or 30 people; and the actual composition varies. But it has to be multidisciplinary. It is composed of physicians and nurses, and then other allied health professionals such as clergy, social workers, respiratory technologists, and others, and increasing view toward having community representatives on these committees, and the committees are becoming larger and larger.

The most common breakdown of the composition is one-third physicians, one-third nurses, one-third others. Only a small percentage out of the more active communities have community representatives, but this is one of the major movements on these particular committees.

I'd separate that from the infant bioethics committees, and there has been a rapid acceleration of these committees, somewhat related to but not totally related to the Baby Doe case in Bloomington and the resulting laws and regulations.

Ms. Massey. Under the recently enacted child abuse legislation, how will instances of nontreatment be reported to the local welfare departments?

Dr. Cranford. I can't give you a precise answer, but I can tell you what we're doing in Minnesota. What we have done in Minnesota with our network of infant bioethics committees, as well as our network of institutional ethics committees, is we have incurred a great deal of cooperation between the child protection service agencies and our network of committees so that there is a lot of interaction between the two.

We feel that part of these committees, both the IECs and the infant bioethics committees—we have to be more upfront about these ethical dilemmas and work together, and that is exactly the cooperative relationship that we have established in Minnesota. We have not developed the reporting mechanism per se in these situations. It is our feeling that the majority of ethical dilemmas can be resolved by working with the family and the physician and the institutional ethics committees in these situations so we have a collaborative atmosphere that is developing. But the actual reporting mechanism has not been worked out in detail yet.

Ms. MASSEY. Will the other members of the panel respond to the same question: How will these cases be reported to the child protective services, if necessary? Dr. Wisneski.

DR. WISNESKI. When I explain the structure of our committee, it might be more clear. But the way we will respond to it will be by having the Obstetrical-Neonatal Issue Concerns Subcommittee evaluate such cases, report to the Executive Council, which is basically the supervisory governing body of our Ethical Advisory Committee, and from there we would report in as necessary.

DR. POMERANCE. At our hospital, a person from the Department of Social Service would be part of our Life Support Advisory Committee, and any time it was felt that there was a child abuse or possibly about-to-occur child abuse, it would be reported through the social service agencies.

DR. FLETCHER. NIH doesn't have any obstetrics, since we are altogether a research institution; but I have been identified as the point of contact in the institution in case a problem did arise with an infant who would be brought to the hospital. Where a case developed, I would contact the child protection services in Maryland.

Ms. MASSEY. Dr. Wisneski, briefly describe how the ethics committee was created and how it operates at your hospital.

DR. WISNESKI. I will try to be as brief as possible.

In medical school we were taught that the real enemy was death. And during the late sixties and early seventies, due to technological advances, especially in regard to cardiopulmonary resuscitation and the use of respirators in intensive care units, we found out that, by being excellent physicians by practicing medicine to the best of our abilities, in many situations we were actually creating and fostering human suffering.

We became very upset with this and tried to look into the whole issue and come up with guidelines, if you will, a construct for changing some of this. In the Quality Evaluation Committee of the Board of Trustees of Holy Cross Hospital, we decided to address some of these issues.

The major issue which started us in thinking about an ethical advisory committee was the issue of the "no code" blue. We felt that in a hospital there were many codes being performed on terminally ill patients who really should not be receiving such treatment, that the CPR [cardiopulmonary resuscitation] was truly for extraordinary means and should not be used in every case.

Therefore, in early 1980 we formed a task force, and the first job we tackled was in naming the committee. We decided to name the committee the Ethical Advisory Committee—advisory, I would like to stress, because we advise the remainder of the hospital and the hospital community in ethical considerations.

We developed a purpose statement. That purpose statement is that the Ethical Advisory Committee exists in order to assure the preservation of fundamental attitudes, values, and patterns of human response, consistent with the congregation's philosophy for health care, "congregation" meaning the Sisters of Holy Cross.

The goals of the committee were formulated, and those are as follows: education of the total hospital community in ethical issues to promote interdisciplinary exchange of dialogue, to provide a basis for unity through assembling various disciplines, preservation of patients' rights, to serve as an advisory committee for hospital policy, and to advise the Holy Cross health care system about ethical issues that have applicability systemwide.

We decided the composition of the committee should be composed of diverse elements of the hospital community, including the hospital president or CEO, six physicians, the director of the human resources administration, an ethicist, two pastoral care representatives, one social worker, seven registered nurses, the vice president of nursing, a patient representative, and we decided to have legal and other consultants on an ad hoc basis as well as nonmember subcommittee volunteers.

We have bimonthly meetings, and we initiated standing subcommittees in the beginning to address various issues. The initial subcommittees were those of "no code" and living wills; termination of life support and quality of life; obstetrical concerns, which was expanded to neonatal issues; patients' rights and hospital philosophy; and employee relations, which we are now evolving into the area of organizational ethics.

Issues that we have and are planning to address include the "no code" issue; the living will, in which we formulated a medical power of attorney; patients' rights and responsibilities; termination of life support; hydration versus feeding of the terminally ill patient; treatment of handicapped newborns; quality of life issues; medical staff involvement with relatives; transplantation issues; premature termination of pregnancy for medical reasons; and last but not least sterilization procedures at a Catholic institution.

And in the future we are planning on formulating an education subcommittee. Again, as I indicated, we are looking into the field of organizational ethics as it involves the hospital community and the employees, as well as social justice issues, that of the new movement of wellness or preventive medicine, and maintaining the mission of the Sisters of the Holy Cross while assuring financial viability in a changing health care environment.

Ms. MASSEY. I have one question to ask Dr. Pomerance, and then I will turn it over to the Commissioners. Dr. Pomerance, I'd like to ask you a question about your patient care review committee regarding cases. Do you have any cases that are mandatorily reviewed? And, secondly, is the attending physician required to follow the advice of the committee in cases which are reviewed by the committee?

DR. POMERANCE. We have a Life Support Advisory Committee for the newborn area, and it has been in existence for about 4½ years. What brings this group into session is parents requesting some downgrading of care, the care that would ordinarily have been provided. If parents wish all care to be given, this committee does not meet; but if parents want some downgrading of care, this committee must meet. Therefore, the first portion of it is mandatory. If there is going to be a downgrading of care, the committee meets.

The committee is multidisciplinary and takes notes on the meetings, which are then written into the chart, and these are read to the parents.

If the decision of this committee or the recommendation of this committee is for a continuing of care if the parents have requested it be withheld, the parents are allowed to address this committee, and the committee will reconsider the matter.

The committee's recommendations are just that. They are recommendations. In theory—I emphasize in theory—they are not a decisionmaking body. However, I think it would be very difficult in reality, if the committee recommended continuation of life support that the parents requested to be withheld, for an individual physician to withdraw that care when the committee had recommended it be continued. So even though its recommendations are, in theory, only recommendations, I believe, in fact, they become much more than that.

CHAIRMAN PENDLETON. I just have a couple of questions. Dr. Pomerance, who makes the decision to convene the committee and under what circumstances do you convene, other than these you mentioned? Would one reason be the issue of the parent wanting a downgrading of treatment of the newborn? Are there other reasons that the hospital might convene the committee just on its own?

Hearing Dr. Wisneski talk, it looks like the board of the hospital doesn't have much to do, that a lot of what is happening in the hospital, from education to treatment, there is a committee convening—or maybe I got the wrong impression. But who decides to convene? Anyone can answer the question.

DR. WISNESKI. In our institution the committee might convene depending on the patient's request, the family's request, the physician's request, nursing personnel, etc. There are many mechanisms for initiating this process.

CHAIRMAN PENDLETON. What are some of the reasons for convening recently, except in the newborn—in anyone's situation? Dr. Pomerance.

DR. POMERANCE. We recently, within the past 2 weeks, had a meeting involving a newborn infant who had a syndrome, a well-known constellation which involves severe mental retardation. Frequently, as it did in our child, anomalies of both upper limbs are present so the hands are quite malformed. Usually these infants die within the first year to several years, although there are records of children that have grown to adulthood that attained the age of 30 or a little bit more.

This child had a diaphragmatic hernia, and the parents, considering what the future was for this child, requested that surgery not be performed. Our committee met on that basis. I brought with me the parent's statement, and if you have an interest I'd be happy to read that to you.

CHAIRMAN PENDLETON. It can be a part of the record if you'd like. I just want to ask one other question. Have you ever convened a committee because of a discrimination allegation against a hospital on the care of the newborn?

DR. POMERANCE. Our committee meets whenever there is going to be downgrading of care, so it is not up to a physician to call the committee. It automatically happens. Our committee has been in existence long enough so there are some full-time personnel who know very well when this committee needs to meet. By and large, the case you have alluded to doesn't slip by and have care withheld without it having gone by the committee.

CHAIRMAN PENDLETON. Are you saying that downgrading is a case of discrimination or an allegation of discrimination?

DR. POMERANCE. It is potentially so.

CHAIRMAN PENDLETON. Have any other panel members had experience of a committee convening because of discrimination under 504?

DR. WISNESKI. No.

CHAIRMAN PENDLETON. What do you think the Federal role should be in this case? We asked some of the physicians yesterday, as well as some of the organizational representatives—Commissioner Bunzel's question was: "Did you really go to bat to have this law passed? Did you really want it? Did you not want it?"

Some of the parents said yesterday that they didn't advocate for the Child Abuse and Neglect Act. There is a responsible State role to play in this. I am trying to figure out why we have it and what good does it do?

And if that's the Federal role, do you like that Federal role? If not, what should the Federal role be?

DR. WISNESKI. If I might approach that initially, I feel that the Federal role should be to supervise hospitals in general to provide general guidelines. I think it is, quite bluntly, somewhat dangerous to legislate individual ethics, and I would hope that the Federal Government would give us the freedom to act with discretion in some of these cases.

However, I would think that it is very important to supervise on a broad base and to quality control and make sure that there is no abuse, and if there is such abuse, then perhaps further investigation would be needed.

That is basically my personal point of view.

CHAIRMAN PENDLETON. Would the posting of signs in the nursery like they had in Baby Doe be appropriate supervision?

DR. WISNESKI. I think that is close to ethical legislation, and that bothers me.

CHAIRMAN PENDLETON. How do you define supervision, then? What should the Federal supervisory role be?

DR. WISNESKI. I think perhaps to monitor the State hospital associations, and the State hospital associations monitor the county societies, and there is quality control at all levels, leading to the Federal Government, but not directed at intervention from the Federal Government to an individual hospital.

CHAIRMAN PENDLETON. Dr. Pomerance, do you want to respond?

DR. POMERANCE. The Baby Doe regulations as they exist now have greatly changed our ethics committee's deliberations over the last couple of years. As they are now, our committee, I believe, is reduced to being a prognosis committee. That is, if the prognosis is that this child is likely to die reasonably soon, despite our medical efforts, and the parents want to discontinue some portion of care, that will be permitted. But if by our technology we are able to keep this child alive for at least a prolonged period of time, it does not fit into the Baby Doe regulations, and therefore, we are pushed to continue the treatment.

I believe this is not good. The quality of life is an issue for all adults who are permitted a say-so because they are called competent, whereas now the quality of life is totally removed from consideration for the newborn baby.

Part of the fear is that these committees will make mistakes, and undoubtedly these committees, just as any human being or combination of human beings, will make mistakes. But to go to the opposite extreme and say that one must give care just because one is capable of keeping an infant alive I think guarantees a much greater number of mistakes.

CHAIRMAN PENDLETON. Dr. Cranford.

DR. CRANFORD. I think in the aftermath of the Baby Doe case in Bloomington, Indiana, in 1982, there was a justifiable concern about how health care institutions handled these types of problems, both substantively in terms of the Down's syndrome and the myelomeningocele and procedural, in terms of how they handled these decisions. I think in the aftermath of that that one good side of the Federal law and the Federal regulations has been to increase our sensitivity and increase our awareness that hospitals should develop good decisionmaking practices, related to all these questions in both infants and adults, and I think that's been one of the major thrusts of our committees, both the general committees and the infant bioethics committees.

I think, too, that because of the Federal legislation—and there has been a great deal of publicity and awareness concerning, as I said before, treatment of Down's syndrome children and myelomeningocele—I think it's been a more beneficial way because I think we have shifted more to a standard of being concerned with what is in the best interests of the infant with Down's syndrome and myelomeningocele than rather parental autonomy. But insofar as that overall thrust, I think that's been very good.

The problem is—and I think we are going to find out in the next few years—that the situation is much more complex than we thought, and that the Federal law introduces some simple elements which are not going to be that simple in the future. I think in the long run, in a way, the law may be counterproductive because it may raise more questions than it answers, and that will be where I think the Federal Government should come in. I think at this point, given the complexity of these situations and given the lack of consensus and given the rapid evolution of these problems, the role of the Federal Government at this time should be to encourage dialogue, to encourage cooperation, but not come down in a mandatory fashion in a heavy-handed way to try to present a simple solution to a really complex problem.

I think it would be counterproductive in the long run for the Federal Government to come down in a heavy-handed or mandatory fashion at this time by, for example, mandating committees, which I think would be very, very bad. The President's Commission report said an ethics committee may be a good thing, but there's no track record. There's no experience with these committees. I think we have to keep in mind that, prior to 1982, it was estimated that only 1 percent of hospitals nationwide had these committees in place, and apparently it's about 20 to 25 percent, although we don't have accurate statistics on that. I think there has been enough voluntary effort and enough coercion or persuasion from the Federal Government to start us on the right track.

What I would plead for and ask for is a chance for the medical profession working with these disabled infants groups, and working with these other disability groups, to try to develop a spirit of cooperation at the State level between the child protection service agencies and the State government to try to work out some of these complex issues that are facing us and to make these committees broadly representation of not only the hospital, but the community.

That's what we're trying to do with the networks. That's what we're trying to do with the individual committees in terms of having, for example, community representatives on the committee. On our committee, we do have an ethicist, both on our adult committee and our infant committee. We also have on the infant committee a representative of the National Down's Syndrome Congress. And we have worked throughout the country with our informal network and with various disabled groups, like the National Down's Syndrome Congress, to make these more representative of society in these situations.

So I would hope that the Federal Government would not continue to mandate in this area, but would continue on the track of encouraging a dialogue in these areas. They could increase funding perhaps, but I don't think that any further heavy-handed approach is the right route to go. That's what I would recommend in general terms.

CHAIRMAN PENDLETON. Dr. Wisneski.

DR. WISNESKI. When we organized the committee, we found that it was extremely helpful to look at the work that the Carter Commission on Bioethics had performed and to read some of the publications. I would urge the Federal Government, especially at this point in time, to reinstitute a bioethics commission for the purpose of acting as a resource center, dialoguing and having conferences where we can come to some firm consensus of opinions in the field of medical and bioethics.

CHAIRMAN PENDLETON. I have just one more question. What are the criteria for selecting the ethicists in your hospital?

DR. CRANFORD. I think you have to distinguish between an ethicist and a moralist. I think you have to distinguish between a clinical ethicist—and that's what we are really talking about. This is the new thing in this area, clinical or practical applied ethics. An ethics committee is one form of practical or clinical ethics. John Fletcher is another form of an ethics committee or clinical ethicist. And what we need today and what we are getting is someone that can relate ethical principles, legal principles, societal values, with clinical application at the bedside.

So clinical ethicists could come from the area of ethics or could come from the area of medicine, but the common denominator is to bring ethical principles and societal standards to the bedside and be able to apply them. And that's what an ethics committee is. That is the hallmark of clinical ethics versus moral views.

So our criteria for a good ethicist is one that would know ethical theories of all the different types, would know how to approach a problem from an ethical standpoint, as opposed to his moral views. We would be much more concerned with an ethicist who is concerned about broad ethics in terms of ethical approaches to problems than his moral views. In my opinion, if somebody had a way-out moral view, I think he'd lose credibility in terms of his clinical ethics.

But that's our criteria. We selected someone who we thought was dynamic, we thought was energetic, we thought was broad-minded in his ethical approach, and was good at ethically analyzing these cases because they had been presented certain times at the University of Minnesota Medical School, and we thought he was able to work in an ethical framework in these situations. I think that's what we need in these situations. It's not the moral views. It's the clinical ethics that is really important here.

CHAIRMAN PENDLETON. I think we have been trying for almost 24 hours to find out how you get to be one, how you get to be part of the club, and what are the criteria by which you become part of the club. And since this seems to be such, if you will, an omnipotent part of how we treat the handicapped newborn among other kinds of medical conditions. I don't think this Commission has any handle, if you will, at this present time on what an ethicist really is, how you pick them, and what do they do once you pick them. And it seemed to run the same through all the panels we've had, and I guess we're not clear.

The point I raised earlier that pediatricians and obstetricians and neonatologists—people look for you to be board certified and what school you went to, and you have a whole bunch of things up on the wall, and you've written and published, but I don't see such requirements for an ethicist. And if this person is central to the care, then how does that happen and how do you pick them?

DR. WISNESKI. I think you're absolutely right. I think 10 years ago it would have been just as difficult to pick an endocrinologist because certification boards were not initiated until about 8 years ago. Five or 6 years ago how would you pick a good emergency room physician? Their boards just came out recently.

The point is, because of what is happening today, we do have many educated individuals who know the field of biomedical ethics. Yet, there hasn't been set curricula to my knowledge; there hasn't been certification boards. But I totally agree with you that that probably should be coming in the near future. But at this point in time, we pick people on their credentials and their experience, like you do in every other area.

CHAIRMAN PENDLETON. We heard a long time ago that dentists used to be horse doctors, and then something happened and they got certified. But at least we know that the endocrinologists went to medical school and so did the emergency room physician. But there seems to be some area in here that you don't get a handle on.

When I speak to students at universities, especially black and minority students, I'd like to tell them there is a new field for them to go into, that there is a situation here where we can expand your horizons. What can we say to them?

DR. CRANFORD. The problem that is the ones you're selecting are from one discipline, so you have credentials and training and education in one discipline. We're talking about clinical ethics. We're talking about two or more separate disciplines. And the reason you don't have criteria and standards is because this is a new area, as I think Dr. Fletcher can attest to. We're talking of combining ethics and ethicists with the clinical work at the bedside, and that's what an ethics committee is, combining those two.

An even more important question is how do we decide whether ethics committees are of value? That's a question that's going to arise more and more.

COMMISSIONER BERRY. The simple question, I guess, is: How do you get to grow up to be an ethicist, if you want to tell somebody how to grow up to be one?

DR. FLETCHER. I get calls all the time.

COMMISSIONER BERRY. How do you get to be one?

CHAIRMAN PENDLETON. What do you say, sir, when they call you about how you get to be one?

DR. FLETCHER. Well, you get at it through first pursuing a vocation that gives you experience in a clinical setting. That is, you can either come to it from a philosophy or religion background or from a medical background. If you come to it from a philosophy and religion background, studying those disciplines helps train you to think about ethical problems. If you come at it that way, you've got to get an apprenticeship in a clinical setting. You've got to get a hospital to hire you to learn a lot about the clinical setting.

I spent 2 years at NIH—I was working on my Ph.D.—doing a project of ideas that gave me some clinical experience.

COMMISSIONER BERRY. Could we stop right there. Is there a program? We're trying to get somebody through this. They go to school and learn philosophy or whatever. Now, is there something called an apprenticeship in ethics at hospitals, at NIH, that you could apply for and get admitted to?

DR. FLETCHER. Yes, that's right. There are three programs in the country.

CHAIRMAN PENDLETON. Did you say free or three?

DR. FLETCHER. Three.

[Laughter.]

DR. FLETCHER. There's one right here in Washington at Georgetown University through the Kennedy Institute of Ethics, their Center for Bioethics, and they have a Ph.D. program. There are two other universities in the country with Ph.D. programs in bioethics. And once you get your degree, institutions employ you to help them in the ways that we have been talking about.

COMMISSIONER BERRY. Mr. Fletcher, the people who serve on these committees we have been talking about, we can assume that they are people who have come through one of these programs?

DR. FLETCHER. No, you can't assume that.

CHAIRMAN PENDLETON. There are three parts to it—the physicians, the nurses—

COMMISSIONER BERRY. But I mean the ethicists.

DR. FLETCHER. No, you can't assume that. Mr. Pendleton was assuming that there are a lot of such people.

CHAIRMAN PENDLETON. No, I was not assuming that. I heard somebody say that we could be ethicists. I said we might need one, but I don't know if we could be one.

DR. FLETCHER. When you said that ethicists are omnipotent in terms of the decisions that are made and in treatment decisions for handicapped children, in my opinion, Mr. Chairman, you are according to the people who do what I do far more clout than we actually have.

However, people who serve in the role on the ethics committee that is sometimes called the ethicist role may or may not have such an academic background. Many of these persons are clergymen or women; they may be lawyers with special interests in ethics. You would find them on the ethics committees in terms of the outside members; right?

DR. POMERANCE. Yes.

DR. FLETCHER. Dr. Wisneski, don't you have outside members on your committee?

DR. WISNESKI. Yes. I have a little concern here. Because if we do identify, if in 5 years we have a board-certification process for an ethicist, does that mean that that ethicist is the one who makes all ethical judgments because that's the authority?

CHAIRMAN PENDLETON. I don't know.

DR. WISNESKI. Well, I don't think it should be at all, because many times I have found a 75-year-old woman lying in the bed who happens to be the best ethicist at the moment.

CHAIRMAN PENDLETON. I was coming to the point that when I was at school—and Mary Berry and I went to the same institution—I was taking philosophy and talking about all things being relative. I used to hang out on the street corners in Washington, and the guys on the corner say, "Everything is everything"—[laughter]—and it all amounts to the same thing. And they certainly have not been to the schools where I went, but they understood what was going on in their surroundings.

Now, I guess I'm trying to get to the point—I guess Commissioner Berry has hit on it—is there an apprenticeship that you go through? We heard something about the apprenticeship or the process. But I guess we are saying, from what we can see, that the ethicist is central to a lot of what is happening. The legislation has ethics in it. All we're doing here has ethics in it. And it does seem that that's a rather omnipotent position with respect to the newborn. And if you don't have the power, who does have the power to make decisions? Dr. Pomerance.

DR. POMERANCE. We have not had an ethicist on our committee, not that we would not welcome having one, but there are not a plethora of ethicists around. I would argue that not all ethicists are ethical, just as not all physicians are ethical, and having a committee made up entirely of ethicists wouldn't necessarily make better decisions than a committee that had no ethicists on it.

I think it brings certain experience with them, and everybody's experience is a little bit different. That doesn't mean one person's experience is better than another. It just allows the ethics committee to perhaps get off the ground a little bit more rapidly having an ethicist on board than one that did not have such a person.

DR. WISNESKI. If I might elaborate on the position of my power as chairman of the Ethical Advisory Committee, there are many individual instances when we would bring together the involved parties who were having difficulty, and my power would enable me to be absolutely silent while the involved parties dialogued and came to a mutually agreeable decision, and everyone was very happy from an ethical viewpoint.

So the statement about power concerns me a little bit. I would look at an ethicist as a recognized authority in the field of medical ethics, such that that individual could give advice and such that anyone could identify that individual as being a medical ethicist, sort of an offshoot of a philosopher, practical philosophy if you will. And I think that will be developing. Right now it's in the early stage, but we are evolving in that direction very quickly.

DR. FLETCHER. Your alma mater, Mr. Chairman, has such a person, Dr. Marian Secundi. She teaches medical ethics in the School of Medicine, and she is also part of a postdoctoral program in this community that is looking for interested young people to go into this line of work. So by all means, encourage young people thinking about careers in law, in the ministry, in medicine, in philosophy, to specialize in questions of scientific or medical ethics.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. In education courses dealing with counseling, one of the exercises we get is that when we look at a situation, we list what is there and separate it into observations judgments, and then from there arrive at a study of that situation.

In your ethics committees, at what point does making the statement, "This child has severe mental retardation" change from being a statement of fact—say that he is anencephalic and you can tell because he has no neurological reflexes or none of the reflexes that should be there—at what point does that change from being a statement of fact to a statement of prejudice?

DR. FLETCHER. A statement of prejudice?

COMMISSIONER BUCKLEY. Yes. We hear when you say, "This child has Down's syndrome," that you are discriminating. When do you make the difference? Because what they're saying is you're discriminating against them, against treatment of these children—Down's syndrome is used a lot—more than other conditions. When do you change from being a statement of fact to a statement of discrimination?

DR. WISNESKI. I'm having difficulty with the words "discrimination" and "prejudice" in this light, because as a physician you're giving it diagnostic terms. We're making a diagnosis. We try to always be as objective as we can be. And where does discrimination and prejudice come into play there? Where?

COMMISSIONER BUCKLEY. It seems that I have heard that from some of the other individuals that have come on other panels, where they say, "Because I'm handicapped, you discriminate against me. Because I'm handicapped, you don't give me everything that I should have as far as treatment or any other conditions."

Do you see that as being there in the medical profession or in the ethics committees that are there now to help make sure that the proper decision is being made as far as how to help these children?

DR. CRANFORD. One role of an ethics committee is to think in terms of an ethical approach, and one has to separate the facts from the values. When a child is mentally retarded, mildly, moderately, severely, that is a fact. When you say in this situation because a child is severely retarded, therefore, the parents have the right to stop treatment, that is a value judgment that you make, because you're balancing what is in the best interests of the infant, or preservation of life, versus parental autonomy. The issue we are getting into in these areas is the balancing of the preservation of life or what is in the infant's best interest versus parental autonomy.

Those are value questions. So the value of an ethicist or an ethics committee is to separate those, look at the facts, look at the values, look at what the patient wants, which we don't know, and look at what the family wants, and separate those out.

I think the word "discrimination" is entirely inappropriate in this context. First of all, when you stop treating a child who is severely handicapped, I don't think that is discrimination. I think there has to be another word for that, because we are stopping treatment on the very basis that it is severely handicapped. I don't think it was ever meant it's discrimination per se.

You may think it's wrong to do that morally, to stop treatment on the basis of severe retardation or anencephaly. That's a separate matter. But to use the word "discrimination" is just confusing the issue here. So we put moral values on those two cases. To stop treatment to a Down's syndrome child who can be minimally retarded to severely retarded is not discrimination. It's wrong. It's morally wrong because that infant has a potential. And as long as we continue with the words "discrimination of the handicapped," we're not going to get anywhere. Discrimination was never meant to apply to these circumstances.

Is an anencephalic child handicapped? An anencephalic child has no cognitive function. If that isn't handicapped, I don't know what is.

So we're using the wrong word here.

COMMISSIONER BUCKLEY. Thank you.

DR. POMERANCE. The Baby Doe regulations made it clear that the reason it was all right to stop care in an anencephalic infant was because the care was futile, not because the child was handicapped.

I would argue that that is inappropriate thinking. Anencephalic children die very quickly, partly as a self-fulfilling prophecy of the medical profession together with parents and anyone else involved. They don't receive intensive care. And I would bet that if I were to do my worst and try to keep an anencephalic child alive, many of them I could keep alive many months and some of them possibly years, but I think it would be a travesty to do that, not because the care is futile, but because the result of it is terrible.

And there are other cases that aren't any better off than anencephalics, but don't die quite as easily because they have a closed skull, but no more brain. The name of that is hydronencephaly. The amount of brain is about the same as an anencephalic, but they have the good fortune, if you will, of having a closed skull so they don't get infections, which is the main thing that kills them. I think it needs to be reviewed for different reasoning rather than just the futility of the case.

COMMISSIONER BUCKLEY. Do you have something to add, Dr. Wisneski?

DR. WISNESKI. Yes, I do have one comment, and I don't mean this comment to be in a facetious manner.

A lot of my impressions are not just abstract thoughts. They come from seeing, from the emotionalism, from being involved.

It is easy sometimes to logically try to figure out various constructs, especially when it comes to human suffering. But I think seeing, being there, watching, and feeling—most of all feeling—and knowing in your heart that that infant is not going to live long, and that because of our technology we can preserve that infant's life to a point where we can keep it going in an unnatural fashion—I would like to know what truly is ethical discrimination in that regard.

COMMISSIONER BUCKLEY. Thank you, because those three responses have helped me more than a lot of things.

CHAIRMAN PENDLETON. Commissioner Destro.

COMMISSIONER DESTRO. I'd like to pursue that just for a minute.

What I am hearing is that certain cases are not worth pursuing. And I guess it's the criterion on which you judge "not worth pursuing." And I've heard the term used "futile," "salvageable"—and it goes up from "minimal," will the treatment succeed in the sense of producing someone who has some ability to lead their life, to what Dr. Pomerance discussed which was basically a situation where you could keep someone on a machine, but what you would be doing basically is keeping bodily functions alive.

I see that as being very different from the example we used in the previous panel, which was the Tay-Sachs child with duodenal atresia. Would you put that on your sliding scale and tell me where that fits, Dr. Pomerance?

DR. POMERANCE. I would like to comment on that and point out that that is a very artificial construct, because it never happens that you know a child has Tay-Sachs disease as a newborn and has some other life-threatening anomaly. The way it really happens is you either know before they are born, and by and large, although there are exceptions to this, those infants are aborted, or they are born as normal-appearing infants and maybe have duodenal atresia and get operated on because no one knows they have Tay-Sachs.

If, in theory, you were to know the thing you just mentioned, at the time that child is born that child is a normal newborn, as best you can tell by your examination. If that child had duodenal atresia, I think it would be appropriate to operate and correct that defect. If later on this child is starting to suffer the ravages of Tay-Sachs syndrome, this child was to have some other life-threatening event, it would be the release from the mortal suffering that is going on, and it would be a great kindness to allow that child to die at that time as painlessly as we could arrange.

COMMISSIONER DESTRO. That would be, for example, a situation where if they got an infection instead of having a life-threatening physical condition, you wouldn't provide antibiotics but just let the infection run its course?

DR. POMERANCE. That's certainly what I would wish to do.

COMMISSIONER DESTRO. Let me just ask you in terms of the ethics committees—Dr. Wisneski, you indicated on page 2 of the form we had for your interview that the committee considered what the hospital's philosophy is, more or less. It was charged in part with determining the hospital's way of looking at things. Is that a fair way of reading that? Let me just refer to the specific thing.

DR. WISNESKI. If you are referring to the purpose statement in which we say "consistent with."

COMMISSIONER DESTRO. But does the committee make a determination of what the hospital's philosophy is and does it explore—if it is not clearly stated, does it go through the process of trying to figure out what it is?

DR. WISNESKI. We certainly do. And I would say that the reference point for our functioning is essentially the philosophy of the Judeo-Christian ethic, and that happens to be unanimously the background of everyone on our committee.

COMMISSIONER DESTRO. In other words, is it a fair statement, in the other panel members' view, that if you are going to have a patient care review committee, or an ethics committee, that it ought to consider the hospital's basic philosophy on patient treatment?

DR. CRANFORD. I think, in general, it does because that's one of the key issues. For example, in Catholic hospitals if you had an ethics committee that advocated abortion in a Catholic hospital, I think there'd have to be some concordance between those two philosophies. An acute care hospital, on the other hand, is mandated by law to take any type of patient so you have a more pluralistic position.

One aspect of the committee is that it reflects to a large extent the views of the hospital at large, including the overall mission. So you have to look at the overall mission and decide what type of hospital it is and to make that congruent with the decisions that are made. And it is essential that hospitals are going to handle these somewhat differently.

One of the critical areas here is looking at mandating certain philosophies for hospitals which is different from one hospital to the other.

COMMISSIONER DESTRO. What I'd like to ask, if that is the general feeling, is: How much outside involvement on the ethics committee do you feel is either necessary or warranted—like an outside ethicist or members from outside disability advocacy groups? How many members, or should you have members from outside people to open up that committee? Because we have heard from people that they are predominantly composed of people from inside the hospital. How much input should you have from outside the hospital?

DR. POMERANCE. I think we should evolve to having a lot of input from outside the hospital. Our attorney on our committee, for example, is not the hospital attorney. I was anxious that that be so, because the hospital attorney tends to represent the hospital, and we wanted someone representing the infants, just as we are all supposed to do.

Somehow most physicians seem to have come to the conclusion that it is their special purview whether or not they should continue medical care. And I would argue that is not a medical decision; it's a social decision. At our hospital our Life Support Advisory Committee is very heavily into medicine and inhouse people. I hope over the years it will evolve to one being much more involved with people from outside the hospital. I believe that they are quite as capable and maybe in some ways more capable of coming to appropriate decisions.

**Commissioner Destro.** Does anyone disagree with that?

**Dr. Cranford.** No, I think the more these committees evolve, that is, if these committees don't inspire trust and confidence from the community and from society, they are not going to work. These are going to have to withstand the scrutiny from the community.

So I think there are certain strategies that these committees have to use to inspire trust and confidence, such as being multidisciplinary, such as putting notes in the chart, advisory or whatever, to having community representatives who are truly representative, National Down's Syndrome Congress, disabled groups, judges, lawyers, community representatives.

We also need to make policies which are publicly available, explicit. We also need to have brochures available for people coming to our hospitals telling them about our ethics committees, which we are beginning to do.

We also need to have community education to make them aware of what our policies are. We need to work with public agencies, like the CPS [children's protective services] agencies, and we need to develop the networks so that they know what we are doing on a broad community scale, and those community networks also need to work on the national level.

The more up front we are, the more open the system is, the more trust and confidence people will have in these committees. The more closed we are, the less trust and confidence people have in these committees.

**Chairman Pendleton.** Thank you, gentlemen.

We will try once again about these ethicists. I know some guys that want to talk to you.

We'll take a break.

[Recess.]

**Chairman Pendleton.** I would like now to swear in the witnesses.

[The witnesses were sworn.]

## Administrative Handling of Treatment Decisions

### TESTIMONY OF GORDON AVERY, M.D., DIRECTOR OF NEONATOLOGY, CHILDREN'S HOSPITAL, WASHINGTON, D.C., AND THOMAS YOUNG, ADMINISTRATOR, FAIRFAX HOSPITAL, VIRGINIA

**Mr. Mann.** I'd like to thank you both for coming.

To begin with, will each of you please state your name and present position for the record.

**Mr. Young.** I'm Thomas Young. I'm the administrator of Fairfax Hospital in Falls Church, Virginia.

**Dr. Avery.** I'm Dr. Gordon Avery. I'm director of the Division of Newborns, Neonatology, at Children's Hospital, National Medical Center.

MR. MANN. To begin with, Dr. Avery, what did you think of the efforts of the Federal Government under section 504, the Baby Doe cases, and the regulations?

DR. AVERY. Well, that's a very broad question. That dialogue has gone through multiple phases. I guess the first phase was when the initial regulations came out, and I thought at that point they were hasty, poorly thought out, a very blunt instrument for doing the intended protection of infants. And I felt that the way that the actual investigations were carried out were cumbersome and destructive. And you might infer that because my hospital, and indeed myself, was part of the suit that led to the hearing before Judge Gesell and the overthrow of the original regulations.

I was also part of the negotiating that went on on revised regulations, and I very much supported the idea of institutional ethics panels because of my experience over the years with research institutional review boards, which for 20 years now have been protecting human subjects in hospitals, I think rather well, and extrapolate rather well to the need in the current situation.

I also was concerned and interested in the very carefully negotiated compromise that came out with the child abuse legislation amendment, and I felt that, as articulated, it represented a rather remarkable concordance among rather diverse groups. I think some of the language was very carefully chosen as to what it should specify and what it should leave loose or unspecified because of the need to individualize and because of the balance between limits which have to be set and individualization around cases and circumstances.

I felt when the so-called clarifying rules from HHS came out that they confounded the compromise that had been so carefully worked. They wrote in a lot of language that was not the same in spirit and in effect as what the legislation was. It was as though HHS had another agenda they were trying to pile onto the law. And 11,000 letters later, or whatever it was, I think what finally came out was a great deal better, and perhaps not exactly to my liking, but something that could be lived with.

So I guess I'm sitting here before you as somebody who has been a party to these discussions, who, like everyone else in the matter, is very concerned about the welfare of infants, that they should be protected, that things should be done which are in the best interests of children, but also in the way that does the least violence to families, institutions, and to ordinary due process.

MR. MANN. Thank you.

Mr. Young, could you address the same issue, please?

MR. YOUNG. I don't have Dr. Avery's personal experience in dealing with the controversy. Certainly, as the administrator of a hospital which delivers nearly 7,500 babies a year and has a substantial neonatology program, I'm certainly very interested in the direction of the legislation and the regulation.

We were subject to an anonymous telephone call over the hotline during the early phases of the first efforts. I would agree with Dr. Avery's assessment that that whole procedure was very hastily put together, was very cumbersome, and very poorly designed to meet the desired objectives and, essentially, was both pointless and disruptive.

And I would say that following the subsequent legislation, regulations, and amendments, that I am very satisfied with the regulations that have come forth. I think that there is adequate acknowledgement and sensitization to the rights and the issues of the infants involved. I think there is a sensitivity to the complexity of the decisionmaking. And I think that, most of all, it relies on the historic and very successful relationships between individual hospitals and practitioners of medicine and the child protection agencies as a means to implement the regulation.

MR. MANN. Thank you.

Dr. Avery, could you describe the ethics panel at your hospital, please, what it does and who is on it?

DR. AVERY. Yes. We have a panel that has between 16 and 18 members. Ten of them are physicians, one is a lawyer, one is a priest-ethicist, one is a social worker, two are nurses, one is a member of the lay board of directors, one is a patient representative, and one is an administrator. We have, at one or two of our individual case reviews, had a parent, and in one case, a lawyer for a parent present.

I feel that the representation of the group is various enough that a wrong tack or a blind spot that a medical group bringing a problem to the ethics panel might have would be surely challenged by someone on the panel. And I think that consensus building is the way panels like that work, not by split votes of six votes against five or something of that sort. It just isn't the way life plays out in the trenches. It turns out that issues are always complex, that there are elements of truth on both sides of the issue, and what is being struggled for is the best decision in the interests of the family and of the child.

There are plenary sessions of our ethics panel that take place on a regular basis, whether or not a particular case has been placed before it. And at those sessions they are undertaking to work out a style of operation, a general philosophy, and so forth. In addition, I believe about eight cases have been reviewed, about half of which are from the nursery and include children up to 14 years in age.

Our current policy is to review cases by request, not to have some sort of requirement that all cases be reviewed of a particular type. And the intent is to be advisory to the medical care team caring for the child in question. However, it is well-known within the institution that our board exists. It is there for the protection of the rights of children. And anybody feeling that there was a grievance in a particular case would have access to ask that case be reviewed.

Maybe I can let you ask further questions if you want to draw out more.

Mr. Mann. I'm just curious, do you think there is a role for adult handicapped persons on these panels? Do you have any such persons on your particular ethics panel?

Dr. Avery. We don't at this moment have someone specifically to speak for the handicapped or who is handicapped, but that is as much as anything because we consider that all 18 members of the panel are advocates of the handicapped in the sense that every child who is sick has a handicap or he would be home with his family.

We, therefore, are looking for the different disciplines that can best bring to bear on the issues in a given case. If one of our members were handicapped, we would hardly notice one way or the other.

Mr. Mann. I'm sure you wouldn't hold it against him.

How did you choose the ethicist on your panel?

Dr. Avery. Well, the chairman of our panel, in fact, is a hematologist-oncologist who chose to take his academic sabbatical to study ethics at the Kennedy Institute and, therefore, has qualification as an ethicist in addition to as an oncologist dealing with death and dying on a regular basis for more than 20 years. But we also felt that it was useful to have an ethicist who is not a member of the hospital staff as a further resource. And I wasn't party to the choice of that particular individual, and I honestly don't know just how he was chosen.

Mr. Mann. So do you think it's important to get people from outside your hospital on this panel?

Dr. Avery. I think it's desirable to have part of the makeup of the panel be from outside the hospital. But I don't have a tremendous fear that this is going to be an inside job that will whitewash things if you don't have a majority or something of that sort from outside, because of my many, many years of sitting on institutional research boards for research where the issues are very similar. The problem is the protection of the human subject who is a child. There are some people in the environment who have a conflict of interest in that they want to do the research, and there are others who are being extra careful to make sure that the rights of the child are carefully looked at.

And I have sat in literally hundreds of research committee meetings and I am satisfied that the child is very, very thoughtfully protected in that mechanism, better so than one could by writing a whole list of dos and don'ts in code form, and better than could be done by people swooping in from a distant city to investigate complaints.

I think the ongoing review by people who know the situation and who have chosen careers in caring for the sick, by and large, is a very effective protection mechanism. And then if there is a sprinkling of people with other points of view—parents, clergy, ethicists, lawyers, someone from outside the hospital—that simply helps to give the breadth of view needed.

MR. MANN. Mr. Young, does your hospital have such a panel?

MR. YOUNG. Yes, we do. We have what is called an ethics forum. I'm sorry I don't have the exact membership or data that Dr. Avery was able to give to you, but there are some half a dozen to eight physicians on the panel. It's chaired by a physician. There are two attorneys, neither of whom represent the hospital, who are members of the panel. There is an ethicist, a couple of social workers, I think three nurses involved, and an administrative representative. There may be one or two more than that.

MR. MANN. Mr. Young, are you concerned about liability to your hospital arising from treatment choices made in these cases?

MR. YOUNG. Certainly I am.

MR. MANN. How do you go about protecting the hospital?

MR. YOUNG. I think that the protection of the hospital resides in policies and procedures that ensure that competent judgment that is consistent with the standard of care is being applied. I think, additionally, it is essential that there be an open flow of communication and every individual who has anything to do with patient care having the confidence and the knowledge that is not only their right but their obligation to bring issues that those individuals feel are either inappropriate or unethical to the attention of the appropriate authority of the hospital. That is certainly the approach I think is the most effective.

MR. MANN. Could you address the same issue, Dr. Avery?

DR. AVERY. Yes. There isn't any way to practice medicine in 1985 and be safe from—

MR. MANN. Lawyers.

DR. AVERY. —lawyers. The best way, even though there isn't any way, is to be as right as you can in your dedication to the welfare of the patient and the family. And if you are doing your level best and the family knows it and the rest of the care team around you knows it, and you stub your toe, it is amazing how often you are forgiven.

I've been at this 22 years. I'm an intensive care specialist. We have three or four deaths every month in my unit. And there has never been a suit—and I have turned off my share of respirators—or even a complaint related to one of those.

We have 100 nurses that work in our unit. We have respiratory therapists, we have lab technicians, we have people traipsing in and out. We have unlimited visiting 24 hours a day, 7 days a week. There is no way we could keep, quote, "awful secrets" secret. And yet, our protection is doing our level best to do what's right.

MR. MANN. Let me ask one more question before I turn it over to the Chairman. Dr. Avery, where do you get the resources for the treatment of these cases? Do you take cases and not take into account the ability to pay? They cost lots of money. Where does the money come from?

Dr. Avery. It comes from the Telethon. It comes from the door-to-door campaign. It comes from the gifts at Christmas. We have had an open door policy at Children's Hospital for more than 110 years, and we have lost money, in excess of $2 million, every year that I have been at Children's since 1963. They made some changes in the Medicaid rules, and suddenly we had $8 million more in deficit last year, and we had to lay off 103 employees and still try to give the quality of care. And we still accept patients that we know can't pay and we still lose.

We can't print money in the cellar, and we may have to, in some time and place, curtail our policies.

We certainly lose a lot of money in the intensive care nursery giving care that can't be collected from anyone.

Mr. Mann. Mr. Young, could you answer the same question, please?

Mr. Young. We have, certainly, a similar experience. We have been in operation for 25 years and have continuously had the policy of delivery of care to any individual regardless of their ability to pay. Certainly in the area of maternity care, and even more so in the area of specialized care to the newborn, you have a very distinctly disproportionate share of those patients who are unable to pay for their care by virtue of the risk factors that lead to the problems we are treating in the nursery.

Essentially, where the monies come from—again, we can't print it in the cellar; we can't invent it—it comes from whatever governmental sources that are available to partially subsidize the care, but that is minimal. Essentially, it comes from the other patients, as well as we don't have as well-endowed a voluntary giving program that Children's has, and that certainly is important, but the largest share comes from other patients who are able to pay for their bills.

Dr. Avery. I'd like to make an additional comment. I wrote what I thought was a very nice editorial that at this time the *Washington Post* decided not to print, and it dealt with the ambiguity of the requirement in effect of a full court press in every case, totally regardless of the consequences, and at the same time an injunction to look at cost-benefit ratios and to make hospitalization less expensive and to let, in effect, the public off from paying so much for medical care. And in an intensive care nursery setting, it looks like nonlogic from the community.

If the community, in fact, said, "Caring for a premature infant of less than 750 grams is not something we support because we don't have the money," and then kept logically to it and said, "Fine, you don't have to resuscitate such a child," and so on and so on, I might not agree with it, but it would at least be logical.

If they said, "Full court press in every case. It doesn't make any difference what you think the quality of outcome is or the length of the illness or any other consideration. We are dealing in absolutes. There is no flinching; do it all," then the community should say, "And we will pay it all. And if the family doesn't have it, we will ante up, and when the handicapped child goes home, we will pay for his aftercare."

But what I see is something different. I see 20-day caps on how long Medicaid will pay. I see cutting the resource for nurses in the community for aftercare. I see families left with impossible debts and no support. And if this is a social debate, I think society better have it one way or the other, but not ask for it both ways.

MR. YOUNG. Could I say one thing, too, if I may? One thing I want to make clear is that in our hospital—and I don't believe that this is unusual—it is unusual for the people treating the patients, and particularly the children, to know whether these patients are paying or not. There is no way of knowing what the insurance coverage is or what the financial circumstances are unless there is some sort of a relationship struck up with the parents. So I'd like to make it clear that the ability to pay for the care has nothing to do with the treatment decision.

MR. MANN. That's all the questions I have, Mr. Chairman.

CHAIRMAN PENDLETON. Dr. Avery, we know that in the case of Baby Doe we first dealt with a couple of conditions with respect to handicapped newborns. Could either one of you give us some indication as to the numerical universe of conditions that one might see with respect to handicapped newborns? Not the combinations. In your experience much has been focused on spina bifida and Down's syndrome and other kinds of problems. What is the range we are looking at now? What is the universe in terms of the number of conditions that we should be concerned about in this issue?

DR. AVERY. That is a very thoughtful question, and I wish people would ask it more, because I have been through a hundred debates and discussions in which there appear to be only two conditions, spina bifida and Down's syndrome. We haven't had an argument about what to do related to a Down's syndrome or a spina bifida in the last 15 years in my hospital. We have operated on literally hundreds of infants with both problems. So this constant reference, "Well, what we mean is Down's syndrome and duodenal atresia"—folks, it is not where the action is.

If you really want to look at numbers, the most common dilemma that we have is the tiny premature at the lower limit of viability. And we know what the numbers are.

We have records going back for years, and we are getting better and better, but the fact of the matter is if you're talking about a baby of 650 grams birth weight, they have about an 85 percent chance of dying no matter what we do, even in doing everything, and a 25 percent chance of being brain damaged if they survive.

You may like those odds; you may not like those odds; but we've got some pretty good numbers. They are not rare.

Seven percent of all children in this country are born premature. About 1 percent nationally are born under 3½ pounds. In this city almost 3 percent, 2.8 percent, are born under 3½ pounds. There are some high-risk populations that have more than their share of the tiniest, most fragile babies. And certainly, in every 1,000 live births, there are perhaps several dozen that are in this range of are they viable or not. Is this something that we, the society is going to go on with, regardless of outcome, regardless of cost, regardless of anything else, and regardless of how the care goes?

When you start out with the kind of odds I told you, a little bit later you may have a child who's hung up on a ventilator, who has had a massive hemorrhage in their brain, who has shown other signs of deterioration, and may have one failing organ after another. And yet, with the powerful life support systems we have, if the game is, "Can you play a game? Can we keep this baby alive another month?"

"Well, maybe."

"Do you think the child has a reasonable chance to survive?"

"Well, no."

"Do you think the child has a reasonable chance to survive and participate even minimally in human experience?"

"Well, no."

Do you go on?

That's where we are day after day. And I don't think that the law or the social debate or all this Baby Doe stuff really tells us what to do in those circumstances. We wind up having to use commonsense. And our caring, our affection for this little person lying there, is part of the equation. There is a time for affirming his dignity and not beating him to death.

CHAIRMAN PENDLETON. Let me try to ask something. I hope it doesn't prejudice the rest of this hearing.

COMMISSIONER BERRY. Carefully.

CHAIRMAN PENDLETON. I'm just wondering whether or not what I have heard in the past 24 hours or so—how would you define discrimination in treatment? What I'm hearing now and what I heard in the early part of the day is that people are trying to make every attempt they can, under the set of Federal rules and a set of moral obligations, if you will, with the help of ethicists and other people, to say, "Here is what we want to do for this handicapped newborn."

There is a cost for death. I mean there's the cost of treatment. We talk about the ones that live and the ones we keep alive through various means. But there is also obviously a cost if you carry that baby for a certain period of time beyond birth, if you carry it on through and the baby dies—whether that's 2 hours or 20 hours or 20 weeks, there's a cost somewhere associated with that, which is also a social cost.

How would you define discriminatory treatment with respect to handicapped newborns? What would it be?

We have this big rule out here, 504, and we have other things that are the Federal presence. And there's been a lot of talk about discrimination against the handicapped newborn. The thing we are trying to find out, not only do the rules apply, but I think what we'd like to be able to say as a Commission is what constitutes the kind of discrimination that needs to be remedied. And is 504 the remedy? Is the Child Abuse and Neglect Act the remedy? What is the remedy for the condition that we see?

DR. AVERY. All I can give you is a personal answer to that kind of question.

I came in at the end of the previous testimony, and I heard someone say that discrimination is the wrong word. And because we are trying to apply it, make it fit, beat it, bend it, twist it, we wind up having a terrible time. We're talking about these as disabled infants.

Well, that means that the other infant can work at his job normally and pull down a paycheck. Every infant is disabled. There is no infant that can speak or walk or do anything profitable. They are all helpless little beings that we care for.

So we are bending words that come from another context and arbitrarily applying them to fit them in under a law that was written 10 years ago, and to me we have tripped over our own feet in the process.

We started over. We did better. We are concerned that wisdom be applied in very complex and difficult circumstances where we are trying to compromise various values. And we really aren't involved in trying to prevent discrimination to handicapped, which is where that 504 law comes from. That had to do with access to public buildings, people who were not hardly newborns—adequate training to take into account the special needs related to a handicapping condition in an individual who is otherwise able to participate in social intercourse and be a member of society.

That was the intent of the law. That is what was being thought about when it was written. And except as a springboard to accomplish someone's agenda, it really doesn't apply to the intensive care nursery.

So part of my answer to your question is I think that 504 has nothing to do with the subject. It has been bent all out of shape in the process, and if we need new legislation in this area, let's just take a blank piece of paper and write what we mean in language that applies to the circumstances and do it straight. It's going to be like the income tax law if we don't watch out.

As far as the child abuse approach, that, at least, is not quite so oblique, because I think it is possible to do wrong by a child, to put some other interest ahead of the child's interest. And I think that it is not an absurd extrapolation to think that there could be neglect in a medical circumstance as well as there could be in a home circumstance.

So if you very thoughtfully write some additional legislation around the protection of a child against abuse or against neglect, since children are dependent and they need to be protected and cared for, I think you're closer to the mark there. And I already said I think that what came out of that effort is a more thoughtful, sensible, appropriate instrument to apply in this setting.

I'll say one more thing and risk being the regular professor who talks too much.

My feeling is that the law has a role in defining a perimeter within which the action takes place. It doesn't give the answer for each individual transaction. It says doctors, nurses, families, hospitals, communities have to do their business around each individual case, but they are not totally free, because if they get beyond certain limits, they can't do that; it's against the law.

So I think what the law should aim at is to define a perimeter and give a backup mechanism in case the system doesn't work. But I think the system will work most of the time, so it is the exceptional case that is being provided for, not the usual case.

And I think, just as you drop a pebble into still water and you get concentric ripples, each one a little farther from the impact site, I think this is the way decisionmaking should be around these very, very difficult issues.

The most usual thing and the closest thing is the transaction that takes place in the individual nursery, with the individual family and the individual medical-care team. But in case there are problems, in case there are questions raised, there should be in the institution a way of looking at those and backing up the wisdom of the individual practitioners, and that is the institutional review board.

In case that mechanism occasionally breaks down or doesn't resolve the issue or there are complaints that need to be looked into, there needs to be a local mechanism beyond the hospital for looking into the case that goes awry. That is whatever the local child abuse setup is for protecting children in other circumstances. And if that whole schmear breaks down, there may be a role backing up behind it all of the State and Federal Government, but those are the outermost circles, and they shouldn't be where the whole process begins, in my view.

CHAIRMAN PENDLETON. Mr. Young, do you have a comment about that at all?

MR. YOUNG. I certainly would agree on the basic point that the issue of discrimination is a contrivance, in my opinion.

CHAIRMAN PENDLETON. A contrivance, you say?

MR. YOUNG. Yes, it's contrived to find a way of dealing with the perceived problem, and certainly, the issue of discrimination as it might apply to the handicapped individuals in a medical setting certainly would need to assume that an individual can effectively make use of treatment and is denied because of a handicapping condition, such as, for example, the rules surrounding the supply of sign interpreters for the people who are hard of hearing, that without that the care wouldn't effectively be available. But in the case of the newborn, it really isn't an issue like that at all, and I think it's being forced into the 504 situation.

CHAIRMAN PENDLETON. Thank you.

Mr. Destro.

COMMISSIONER DESTRO. I have only one question, and that is: From a perspective of hospital administrators, would you address the degree to which currently the cost factors are taken into account in deciding to go ahead with the care of, not necessarily the low birth weight infants, but the one who is more likely to be, say, severely physically or mentally disabled, and the degree to which you might think that that would either increase or decrease as time goes on. Does that become a bigger factor?

Am I making myself clear? If not, I'll try to rephrase the question.

DR. AVERY. You said "administrator," and I picked up the microphone. Isn't that something?

[Laughter.]

MR. YOUNG. I'm an administrator, too.

DR. AVERY. That's true.

By my experience, the way it comes up in our place is not around should we operate or should we not operate, should we turn the respirator off or should we go on with it. It comes up more around: At what point do we transfer to a convalescent facility? Can we set up home care with nursing help at home?

When the action has rolled back from, "Will the child survive acutely?" to, "How in the world are we going to take care of this child who has a tracheostomy, who needs six medications, who needs this, and who needs that," and we notice, "My gosh, the kid has been here 8 weeks already and the bill is passing the $150,000, and we don't see any way out of it."

Yes, the administrator would like to know what our planning is and how we are going to move things forward and how are we going to get the child to less expensive care, meaning care that is coming out of the pocket of the hospital right now. Yes, we do look for: Will someone cover it? Is there a convalescent hospital that can give this care more cheaply?

But I don't ever remember essentially being poised on a "go, no go" decision and saying, "Well, we could do it, but think how expensive it would be." It just doesn't play that way.

MR. YOUNG. I go off just a little on a tangent from that in saying that I would maintain that the ability or inability to pay does not affect the kind of decisionmaking that Dr. Avery is talking about. What does enter into it is the scarcity of resources that typically we and Children's Hospital, and certainly in this area most of the special care nurseries operate to full capacity. There's a scarcity of physicians in the nursery, there's a scarcity of nursing care and the equipment, etc. There's a continual urge to make the most effective utilization of those scarce resources as possible.

I would be just as interested in pushing the neonatologist to place a patient who is well-insured and paying for every penny's worth of charges that I can think of a way to charge in a convalescent facility as I would someone from whom I expect no payment at all.

So I think it's really more of an issue of the effective use of resources than it is in terms of the ability to pay.

I would say, however, where the subject of payment and the ability to afford the care will come in is sort of a survival kind of issue: Do you offer this service for which we have no way of providing the economic base? If it is a new service that is being proposed, you are less likely to enter into a service, though a case may be made for its need, if you can't find the resources to afford it.

As hospitals come under increasing financial pressure, they may well be forced to make some hard decisions: Do I start screening people on the basis of their financial need? An easier thing to do would be to shed some of the services that don't pay for themselves. I think that is where the issue is going to arise.

COMMISSIONER DESTRO. This is my last question. Is it possible that some of those decisions might be made on the basis, say, you have a full facility and one bed left. That is the typical kind of triage situation that ethicists like to debate about. Is it possible that you might opt to say, "Well, let's give it to the one that has a better chance down the road?" than it is—

MR. YOUNG. Ironically, it works the other way. We have been faced on a number of occasions with precisely that issue, and the issue that we have been faced with most frequently has been the issue of no resources left in the special care nursery. We may have the ability to take one more baby in the special care nursery, and two or more women in labor that have high-risk pregnancies.

In our situation what we normally do is pick up the phone and find out whether Dr. Avery has space for that situation, or we go to George Washington University.

The fact of the matter is that it is very difficult, very cumbersome for Virginia Medicaid to pay for anything that is outside the State of Virginia. GW finds it just as easy as we do to collect from the private insurance carriers. So we are faced with the decision: Do we divert the paying patient to a facility in the community, or do we have to try to ship a patient who is unable to pay to Charlottesville or Richmond?

And in each of the three cases in which I was actively involved—there have been more cases than that, but the ones that I have been actively involved in we have opted to take care of the Medicaid patient for which we get a gesture of payment, and nothing near cost, in lieu of the paying patient.

CHAIRMAN PENDLETON. Gentlemen, thank you very much.

We are recessed until tomorrow morning at 8:30.

[Recess.]

CHAIRMAN PENDLETON. We will now reconvene after the one-night recess.

I am going to swear the witnesses.

[The witnesses were sworn.]

## Support Personnel

### TESTIMONY OF CLAUDETTE ANTUNA, M.S.W., DIRECTOR OF SOCIAL WORK, MIAMI CHILDREN'S HOSPITAL, MIAMI, FLORIDA; SALLY MACK, M.S.W., CHAIRPERSON, SOCIAL ACTION COMMITTEE, ASSOCIATION OF PERINATAL SOCIAL WORKERS; JOY PENTICUFF, Ph.D., ASSOCIATE PROFESSOR, SCHOOL OF NURSING, UNIVERSITY OF TEXAS; AND JEANE STILWELL, R.N., COORDINATOR, SPINA BIFIDA CLINIC, ORLANDO REGIONAL HOSPITAL, ORLANDO, FLORIDA

MR. SCHULTZ. I am Robert Schultz, staff attorney for the Commission, and I'd like to begin by asking each of you, beginning with Ms. Mack, to give your name and your present positions, please.

MS. MACK. My name is Sally Mack. I'm a social worker at Children's Hospital in Boston, working in a clinical research program. I am also in private practice, seeing families who have had problems around the birth of their child. I am also the social action chairperson of the National Association of Perinatal Social Workers.

MR. SCHULTZ. Dr. Penticuff.

DR. PENTICUFF. I am Joy Penticuff. I'm associate professor for the School of Nursing at the University of Texas at Austin. I also coordinate the high-risk perinatal clinical specialist program there, and I'm a member of the Committee on Ethics and Care of the Newborn of the Hastings Center in New York.

MR. SCHULTZ. Ms. Antuna.

MS. ANTUNA. I'm Claudette Antuna, director of social work at Miami Children's Hospital. I am also past president of the Association of Perinatal Social Workers.

MS. STILWELL. I'm Jeane Stilwell, a certified nurse practitioner, and I'm coordinator of the Spina Bifida Center in Orlando, Florida.

MR. SCHULTZ. Beginning with you, Ms. Mack, what is the function of the perinatal social worker and, specifically, what is the relationship to parents, family, physicians, other hospital staff, and the infant?

MS. MACK. The function of the perinatal social worker—and by the way, I forgot to mention I did work in a neonatal intensive care unit for 4 years—is to enable families to cope as effectively as possible with the situation they are in when their baby is in a neonatal intensive care unit. That is the function of the social worker in the intensive care unit.

Perinatal social workers, in general, work in any aspect of the childbearing field. It may be in prenatal care; it may be in a community clinic. But specifically around decisionmaking procedures, the neonatal intensive care unit social worker is involved in helping families adjust to the reality of having a very sick newborn. And we may do anything from helping develop the family's strengths, their capacity to gather information, help them ask the questions that they need to ask, give them time to think through their reactions, help them develop the resources they need, whether it's just to get transportation to come to the hospital to see their baby or provide for food or lodging if they can't afford that themselves, and to look for resources in the community to which they take their baby home. And also we do a great deal of bereavement work with families whose babies do not survive.

MR. SCHULTZ. Specifically with regard to the treatment-nontreatment situation, at what point do you enter that process and how extensive is your involvement?

MS. MACK. Well, depending on the unit and how many social workers are available, many families are just seen automatically. By virtue of the fact that a parent has not been able to take care of their own newborn, they are already in stress. So immediately, if we have time, we introduce ourselves and let them know we are available to assist them in any way.

Very often it just starts out with practical problems until they get to know us. The fact that we are not a hands-on person, but are really neutral in the situation, and we're specifically an advocate for the family, they often start talking to us about anything.

So we have already done an assessment of the family, and very often it's our assessment and our feedback of where the family is in their own thinking and coping and ability to understand, or reservations about, "Are they really telling me everything? Did I understand this right? Did I ask the question I really wanted to ask?" But the assessment is one thing that all social workers are involved in.

In terms of decisions about continuing treatment or not, that really varies from hospital to hospital—I have been asking people about that—depending on how long the staff has worked together, on how available the social worker is. A lot of the decisions are made in the middle of the night, of course, when someone from the social service may not be there.

MR. SCHULTZ. In counseling the parents of handicapped newborns, what options are presented to them for the infant's subsequent discharge from the hospital, specifically, adoptions, institutionalization, foster care, and so forth?

MS. MACK. Once again, I should reinforce the fact that we do a lot of listening. We really try to help people fully express all their questions and doubts. One of the first things we do is try to acquaint them with other families who have gone home with a baby with similar problems so they can see how other people in the community are managing, or connect them with resources in the community that may be able to help them.

If the family is really expressing doubts about being able to take their baby home, we do talk to them about foster care or adoption or institutionalization. One of the problems, of course, is that there are very, very few resources available—very few.

MR. SCHULTZ. Dr. Penticuff, are nurses ever involved in treatment decisions affecting handicapped newborns? If not, should they be involved?

DR. PENTICUFF. Nurses are involved in these decisions, but I would have to say that, typically, their involvement is not a direct, overt communication or collegial kind of discussion between the nurse and the physician.

Usually the communication is more of an indirect, rather tentative kind of questioning about whether the course of action is, in the nurse's view, the right thing to do. Again, it depends very much on the institution, as Ms. Mack pointed out. In some institutions, nurses have more encouragement to speak up and to voice their opinions about this type of decision. In other institutions, nurses may really be sort of a target of sanctions if they were to question the decision of the physician in the case. I would say that in the better institutions there is this atmosphere of discussion and encouragement of questioning.

I think that the nurses, because of the fact that they are at the bedside 24 hours a day, 7 days a week, are often in very close interaction with the families, and they also are in very close interaction with the infant. And I believe the nurse's perspective in having that kind of close interaction sometimes results in the nurses being very concerned about, for example, the amount of pain an infant might be in, or the amount of discomfort that an infant might be in, and also the pain and discomfort of the family. So sometimes the nurse's view may be more closely aligned with the views of the family than they are possibly with the views of the physician who is typically, in most hospital NICUs, the one who makes the decision in my experience.

MR. SCHULTZ. Let's direct our attention to the nurses now, the impact on them. Let's start with the nontreatment situation. How stressful is that kind of situation and how do nurses cope with that?

DR. PENTICUFF. It is extremely stressful, as you might imagine, and in a way it depends on the reason for the nontreatment. If it is a situation where a baby—and I know you've heard a lot of medical terminology the last couple of days—but if it is a situation where a baby has a totally incurable kind of problem, like the heart is not properly structured and there is no way the baby will be able to survive, and this is quite clear, the nurses, I think, are more easily able to take care of this baby than if it is a situation where the nurse might feel that the baby needs to be given more of a chance, although I have to say I think that's quite rare. I think the typical problem is more that heroics are being performed, and this is a baby that, in the nurse's judgment, suffering is just being prolonged.

When the nurse makes her mind up that she believes this baby is not going to survive, and then she has to participate in heroics, it's just as stressful as when the nurse believes this baby ought to be treated. So it can be either situation.

But if the nurse disagrees with the physician, the nurse must still follow orders, and it can be quite stressful. Some nurses leave nursing over such situations. They may transfer out of the unit. It's almost a clue as to how bad the situation is as to how much turnover you have in the NICU. So the ultimate thing is to get out of the unit and maybe never come back.

Mr. Schultz. Do you feel in your experience that physicians are aware of this stress? If so, how do they help the nurses to cope with it?

Dr. Penticuff. Again, I would have to say it depends on the institution. It depends on how long these people have been working with each other.

If the unit is such where nurses are encouraged to discuss the way they feel about a case and the physician-nurse communication is open and direct, the physicians in that case obviously are sympathetic and do have a good understanding of what the nurses are going through. In fact, the nurses in those situations have a good understanding of what the physicians are going through because they're going through a hard time as well.

But there are some places, I think, where the physicians have not reached that level of personal growth in this type of situation that would allow them to really not be so defensive or authoritarian and so forth, but it is almost a process of growth. And all of these professional people have to be helped along in this process of growth.

In some institutions, this has happened. In other institutions, it becomes almost a battle-lines-drawn type of situation and very destructive.

Mr. Schultz. Are there any programs in place, Doctor, to help nurses to cope with this kind of situation? If not, can you suggest any?

Dr. Penticuff. Well, I have not seen very many. In the literature you will find some passing mention of, "Wouldn't it be nice." In many cases it is the social worker who tries to encourage communication among the various people involved, not just with the families but also the physician-nurse relationship, and so forth. But really aside from that, I have not heard of any type of real stress reduction program.

It is also true that at some institutions they have bioethics rounds, and nurses are invited to participate and many nurses do. That is an educational program to help the entire staff understand the nature of the problem and reasonable decisionmaking approaches. And that does help reduce stress. Once you can understand something, you can participate.

But I think in terms of just programs that are focused on resolving stress, reducing stress, etc., I am not personally aware of such.

MR. SCHULTZ. Ms. Antuna, what is the role of the Department of Social Work Services at Miami Children's Hospital?

MS. ANTUNA. The role of the social work program, whether it's Miami or any other, is usually to try to help families adjust to the hospitalization of a loved one. We become involved in crisis intervention. We offer support to families. We coordinate resources for families.

There are many different kinds of activities that a social work department covers in the hospital. We are involved in many systems. We help families with the financial arrangements, the bureaucratic system, the legal system, through a multitude of activities and roles that we fulfill in the hospital.

MR. SCHULTZ. There are some hospitals that don't have such a department. How do they handle the situation? How do they provide this kind of social support?

MS. ANTUNA. They don't. The Joint Commission on Accreditation of Hospitals does not mandate that there be a social work department. It mandates that someone take the responsibility for providing some kind of consultation. That's the minimum standard that hospitals can get away with. Recently, there was an attempt to reduce skyrocketing hospital costs by eliminating the criteria and standards for provision of social work in hospitals. The attempt was not completed, and there was a lot of discussion that perhaps this was not the best way to go.

But for the most part we are not a revenue-producing department, and I don't necessarily agree with that standard because I think we help hospitals, in fact, retain revenue, therefore, helping them because we don't actually bill for our services in many places. But because of this, we are not considered a very valuable part of the institution as far as money making machinery is concerned.

MR. SCHULTZ. Turning your attention now to some of the specific instances and experiences that you have had with families facing a treatment-nontreatment decision situation in the handicapped newborn, would you describe the handicapped child with mental and physical development and how the family is doing in instances where you have maintained contact?

MS. ANTUNA. I have been at Miami Children's Hospital 12 years, and in the last 10 years we have seen approximately 10 cases in which parents did not give consent to a surgical procedure to be performed on their child, based on the fact that they were going to be retarded or significantly impaired. Therefore, their choice was not to give permission for surgery. In all cases we took the family to court and won the decision to perform the surgery.

Interestingly enough, the protective service agencies that we tried to involve did not want to become involved and felt that there were too many ethical decisions for them to participate in the process and, therefore, were not helpful in any of the instances. And it was the hospital's counsel, along with expert testimony, that mandated that the State take responsibility for becoming involved in the decisionmaking process.

The cases that we have been involved in are the ones you have been hearing about all week, children with Down's syndrome or spina bifida.

What is interesting is that we become involved from the very beginning when the decision is being considered, and it is usually the social worker who maintains contact with the family throughout this process of stress, and is often the one that the family can relate to after the child has gone home. We may be that one constant person in the institution that they can relate to.

I'm not sure that covers all the questions.

MR. SCHULTZ. Did the parents of these handicapped children face any unusual difficulties in securing appropriate services?

MS. ANTUNA. Yes, they do, particularly in the State of Florida. We are certainly ashamed to mention it, but we are the 48th of all the States in this Union in terms of provision of human services for people, so that is not a very high priority in our State.

Therefore, with our knowledge that infant stimulation programs for children are of utmost importance for children in order to help them achieve their maximum potential, it becomes very frustrating when we know that there are approximately 120 infants at this moment waiting to go into an infant stimulation program which will benefit them greatly and which they probably won't be able to participate in for a few years. So we have lost a lot of ground.

There are financial resources that are very—well, that produce a lot of problems for the families. We do not have accessible medical care for all these children, and these families go through a tremendous strain trying to secure any type of resources that will benefit their children.

MR. SCHULTZ. Ms. Stilwell, this is my last question before I turn the panel over, but it's a long one so take your time.

We've heard in the last couple of days about the costs in these kinds of situations. What is the average first-year cost for the treatment of, let's say, a spina bifida child, and who pays for this treatment, and comment on the role of how the State fits in with payment and insurance in your experience.

MS. STILWELL. In our facility, we came up with an estimated cost of care a couple of years ago, and that was around $50,000 for the first year. That includes perhaps one shunt revision, which many of these children have to go through in the first year, one orthopedic surgery, and a set of braces. It also includes their well child care as far as what is recommended by the American Academy of Pediatrics in immunizations.

In our State the Children's Medical Services, which is a division of HRS—their criteria for a family of four is $9,700 gross income. If that family makes even $10 more, that family may be turned down by Children's Medical Services. Even if Children's Medical Services picks this family up, the costs they don't cover are just the routine well child problems. They do not cover catheters; they don't cover maintenance antibiotics or prophylactic antibiotics. Many times they do not cover physical therapy, occupational therapy, or developmental programs. They do not cover any kind of psychological evaluations for the family or psychological counseling for the family. That's probably most of the major things they don't cover.

One other thing that usually becomes a problem, maybe not in the first year but later on, is architectural barriers in the home for the family, and there is no way to cover those costs.

If the family has insurance, and about 48 percent of the families we deal with in our clinics have insurance, sometimes that insurance may cover 80 percent, leaving the family responsible for the other 20 percent. And many times a problem with the family is that if they decide that they want to change jobs, in order to better their income or something to that effect, a lot of times insurance companies will not pick up their child because of a preexisting condition, and they may have to wait a year, or they may never be picked up by that insurance company to cover their child's medical expenses.

MR. SCHULTZ. In order to avoid that income cap that you described, have you seen happily married families contemplate separation or divorce?

MS. STILWELL. I certainly have. We have several families who have actually debated whether to have a divorce or not just so they could get some kind of financial help from the State.

MR. SCHULTZ. I thank all of you, and I yield, Mr. Chairman.

CHAIRMAN PENDLETON. Thank you.

Ms. Stilwell, I'm interested in one of the comments in the report of the interview with you. I want to share it with you, and maybe some of the other panelists have something they want to say about it also.

In counseling parents, the statement here attributed to you is that they usually can be swayed in any direction depending upon who talks to them and how the problem is presented.

We have heard a lot of ethical talk in the last day or so. Is it your experience that ethicists have a position on conditions that the neonate has and can make some judgment prior to whether or not the doctors have made their judgments about what might happen and can sway the parents one way or the other?

I guess one thing that comes to mind is how did Gross come up with his formula, and if that becomes a way to sway people's decision to come up with some numbers. I notice you take into consideration some of the same kinds of things that go into the formula—not the formula, certainly. But it seems to me that somehow factors come together and you can decide what to tell the parents about the way to go. And I'm interested in that process.

MS. STILWELL. In my institution, when we have a baby that is born or transferred to our hospital, I am the one who sits down with the family and goes over with them all of the problems that spina bifida entails, and I try to give them a very realistic view of what their child's potential might be related to their lesion. I usually give them the very most negative and the very most positive, but try to stay kind of in the middle of the road.

At that point the family usually has never heard of spina bifida when their baby is born, and they need to have trust in someone. And I spend hours with these families. I sit down and I get to know them as people, who's in their family and what they do, and those sorts of things.

I feel like we don't offer those families a choice as far as treatment or nontreatment. We just kind of say, "These are the things that need to be done for your child now. We need to do the surgery within the next 24 hours. We need maybe to do a shunt in 3 to 5 days."

I offer them the option that if they feel like they can't handle that, there is either temporary placement available or permanent placement available with other families.

The biggest thing that I try to do is to point out to that family the normalcy of their child and to let them know that it is a child, and maybe this is not the child that they dreamed of and hoped for, but that it is a child. And I take them to that baby and point out all of the normal things about that child and really try to get them to see those things.

We have not had a nontreatment case, so to say, in our hospital. I have been there 4 years now. We have had other babies transferred in; the Miller family is one of those, and I worked very closely with them, and their opinion changed a lot after we worked with them and showed them all of the things that Shermika would probably be able to do.

CHAIRMAN PENDLETON. Do any of the other panelists want to comment on that?

MS. ANTUNA. I would. I like that one a lot, because we are a tertiary care facility for children—

CHAIRMAN PENDLETON. Tertiary care means what?

MS. ANTUNA. It's very sophisticated, very high intensity services for children, very specialized. We get our children from the entire community, and for the most part, some information has been given to the family prior to the time the child arrives at our hospital. And there are many, many different and diverse types of opinions that have been given about these children. For the most part, we get these chidren because the hospitals they are coming from really don't want to take care of them. If there is any question about them not wanting surgery or further treatment, they don't want to have anything more to do with it, so they ask that the child be transferred to our facility. That is probably why we see more of the nontreatment issues coming up.

But we have been put in positions by physicians who have said, "The child is not worth saving," and that impression has been given to the family. Therefore, they come to us prepared to battle us and say we are inhumane, and to try to do everything to save this child—they have begun to formulate their opinion that the child is not worth saving. Then we have to start a process of trying to educate them and put them in the position where they have the most information to really give an adequate consent.

The first case I became involved with, the mother could not move from the hospital where she had delivered, and I went to that hospital and I explained to her what we were going to do if she did not give consent to the surgery. I asked her if she had seen the child and she hadn't. It is now the policy of our hospital that when we transfer the child to our facility, either the mother or father will see that infant, because what they imagine is usually a lot worse than their baby is. We even give them a picture of the baby as it is at that time so that the mother staying in the hospital doesn't form all kinds of ideas as to the condition of her child.

Sometimes, even with as much information as we try to provide, if that child needs surgery and the family still does not want to give consent, we have no choice but to proceed through the court. And we have done that on several occasions.

CHAIRMAN PENDLETON. So you feel as though the judgment that you might reach in this case is that the child should be treated whether the parents want to or not. So that's the time of intervention.

MS. ANTUNA. We don't really have that much time. When we are talking about a child who has Down's syndrome with duodenal atresia that needs to be fed or it will starve, we really don't have the luxury of time in terms of waiting for the family to go through a period of crisis and try to get as much information. Maybe we have as many as 4 or 5 days to work with this family, but they may still choose not to have the surgery. We try to give them as much time as possible to come to grips with what they are doing, but we don't always have the luxury of time.

CHAIRMAN PENDLETON. I guess I'm trying to pinpoint something here. Do most of you or all of you believe that your role is treatment irrespective of what the parents might feel?

I think what Mr. Abram was getting to yesterday was the question of: Can we, and should we, in the light of the conditions that surround the neonate, low birth weight and the like—though we can save them, should we save them?

It seems to me that if the parents want nontreatment and you want treatment and you go to court and prevail, that interests me.

MS. ANTUNA. If we prevail and the family still does not want the child or does not want any contact, then there are other alternatives and we have places. You heard Mr. Daniels say on Wednesday that they did put the child up for adoption. So there are other options, so that if the family still feels they cannot handle the situation, we give them the opportunity to explore other avenues.

As a blanket statement, I do not agree that all children should have to be saved.

CHAIRMAN PENDLETON. Do you think nontreatment is not an alternative?

MS. ANTUNA. That depends on the case.

CHAIRMAN PENDLETON. Dr. Penticuff, do you want to make a comment?

DR. PENTICUFF. This is just my own personal view, of course, but I am much more sympathetic with the family's view of whether they believe that their baby ought to have the type of sophisticated life-saving treatment that we are capable of providing in the NICU.

I guess my view of this and my reason for having this—and let me say also that there are some cases where you absolutely have to treat. I mean it's not even controversial anymore. I'm talking now about a very, very small, almost statistically rare situation. But in my mind, if the family says that they can't deal with this situation, if they believe that their baby's life is going to be a life full of pain and suffering and so forth, then in so many ways as a nurse I have to believe that who loves this baby more than its family? And how can we, almost in a bureaucracy, say to every family, "You have to treat or we are going to treat this child. We are going to take this kid away from you."

I just find it goes against my grain as a nurse to see families struggling with this. I'm talking about a process where they get good information and where there is actually a difference of opinion as to whether this baby will benefit from treatment. I think we need to have the families have the primary role in making decisions. If they are reasonable people and have gotten good information and are going through this process in as much of a rational way as you can in such an emotionally filled situation, then I feel, at some level in my mind, it is wrong for us to say, "We are going to take your baby." Because who is going to see after that baby in 15 years? Where will all of us be in 15 years? Where will that baby be in 15 years? I guess that's one of the reasons I feel so strongly about that.

CHAIRMAN PENDLETON. Ms. Mack.

MS. MACK. I'd like to elaborate on that. My philosophy is very similar to Dr. Penticuff's. I think my role as a social worker at Children's Hospital in Boston was primarily the advocate for the family, to really help them think through and express and come to terms with their own feelings about this. Not only does the family have the long term responsibility for this baby, but sometimes these children do not survive even after all the procedures have been done.

So I have stayed with families whose baby was kept alive, for instance, for an entire year, during which time a baby who had been very premature but perfectly formed by the end of the year was blind and deaf, had seizures all the time, had been asphyxiated, and finally had to have a tracheostomy. That baby continued to live for a year while an older child had to be sent out of the State to another family to be taken care of so the mother could get back and forth. The parents had separated for a while.

That is not such a rare story. I have been with many families where the families broke up around the stress of just not being able to help each other through the torture of watching their child being kept alive for 6 months or a year or whatever.

So the main job is to help these human beings continue to function through and beyond this crisis situation. And even if the baby does survive, the family has been through so much that there are years and years of healing. And we do try to give them a long term followup or get them in touch with other agencies who can help them continue to resolve this situation.

CHAIRMAN PENDLETON. I have some other questions, but I want to yield to my colleagues who might want to ask the same questions. Mr. Destro.

COMMISSIONER DESTRO. I'd like to ask Ms. Antuna first and then Ms. Mack: You both deal a lot with the families. Do you feel in your experience that there is any sense among the families where they can distinguish between, basically, a situation where they have a child who may or may not benefit from treatment where there is a real question about whether or not the treatment is beneficial? One of the pediatricians or neonatologists earlier used the term "a salvageable baby," and one that might be considered in common parlance one that if you treat it, it might just grow up to be handicapped in some way. Do you understand my question?

MS. ANTUNA. I'm not sure I do. Would you rephrase it?

COMMISSIONER DESTRO. The thrust of this hearing is to determine to what extent there might be discrimination in treatment against handicapped newborns. What I am looking for, and something that I really don't have a handle on, I think, after all of this, is the distinction between when you're talking about treatment that is really questionable from a medical standpoint and treatment which is questionable from a mixed medical and social viewpoint. We had some of the ethicists yesterday saying, "Really what you have here is you're making a social decision not to treat," as opposed to keeping a baby on a respirator for a year and no one has any real idea whether it will be helpful or really hurt the baby. Does that make it a little clearer for you?

Ms. ANTUNA. Yes. I think there are two different issues. I see those children that come in need of a surgical repair which is very different from that child who is in the neonatal intensive care unit who everyone has worked on trying to save the child, and perhaps the child is just not going to make it, and maybe 6 or 8 months down the road you finally realize everything you're trying doesn't help.

Having been involved with parents who have fought not to give consent based on the fact that their child is going to live to be impaired mentally and physically, because the information they received was that the child was going to die if no repair was done and that was probably the most merciful thing one could do for that child—I see that as being a different issue from the one in the neonatal intensive unit.

I think it goes back to what Jeane was saying before, and that is the information that these parents receive. It is not uncommon to see pediatricians say that if you have a Down's syndrome child, just forget about it, put it in an institution, just forget you had the infant. I have had that conversation with many pediatricians in our community.

First of all, we no longer institutionalize infants. Even in our backward State of Florida that does not occur. We put them in group homes or in foster homes, and we hope they are adopted if they cannot stay with their natural family. But we do not have institutions for just Down's syndrome children.

There are many, many neurosurgeons and pediatricians in this country who still believe that a spina bifida child doesn't have much potential in school, will never grow up to be of any help to anyone, will be severely retarded and impaired and will only be a burden to the family, and will, therefore, tell this to the family upon the birth of their child.

So I see it as a separate issue from the one I heard described by the neonatologists. Because in those situations, hopefully, if the family has been brought along and communication has been established with that family, that family also recognizes the amount of time and effort that everyone has put into that child. And the fact that we have really tried to save these infants, and hopefully, with the family we can come to a decision that there is no more that can be done. We often call those a "do not resuscitate" order, where if a child deteriorates, the family signs a kind of waiver to the institution saying that they are not going to hold us liable if we decide not to treat any longer. But it's a different issue altogether and I don't think the regulation that has been established for the so-called Baby Does necessarily addresses the neonatal patients. I see them addressing the other group of patients primarily.

COMMISSIONER DESTRO. That has been my impression, too, but it's hard to separate the two during the course of all of this. Do you see that as being a reasonable distinction, Ms. Mack?

Ms. MACK. I really had a different experience actually than Ms. Antuna. I have never seen a doctor who did not want to save a Down's syndrome baby in my experience, and if anything, I have seen them save much, much, much more compromised infants than that.

My concern, I guess, is not so much with the doctor's advocacy for the right of the infant to survive. I have been very impressed in quite the opposite direction, in their hope and belief that they can do something even for the most severely handicapped infant, unless it's just going to prolong dying indefinitely or whatever.

What I am struck by—I think your question was whether families really can understand the issues, given the uncertainty about the future, how do they make a decision knowing that no one can give them 100 percent assurance as to how things are going to turn out in the long run.

COMMISSIONER DESTRO. That's part of it, but I guess what I'm trying to get a handle on, since you deal so closely with the families, is how much of the decision to treat or not to treat—in my own mind I've always drawn a distinction between the extremely young neonate and the one that may grow up to be impaired, and that's what they're talking about. In your experience do you get any sense of a difference in the way parents approach those two cases? Do you know what I'm getting at?

Ms. MACK. Between a child who will be compromised and a child who will just be saved and then will be normal? Is that what you're asking?

COMMISSIONER DESTRO. My own reading on this shows that sometimes in the neonate situation they don't know how the baby is going to turn out.

Ms. MACK. Right.

COMMISSIONER DESTRO. That's why I draw somewhat of a distinction. We have been using Down's syndrome and spina bifida, but I suppose you could use other examples. Say a baby is born with some kind of a defect and may develop some kind of an infection, and then the question becomes, "Do you want to go ahead and treat the infection?" Do you see what I'm getting at?

Ms. MACK. I see this in the context of how parents get to know their own child. In my own situation, I had normal children, but if something had gone wrong during delivery, I would always be looking to see if it was really okay.

Parents have to deal with a lot of uncertainty. But when you already know that there is something wrong—you get to know your baby over a period of time, and the baby's defect or handicap is only one aspect of your relationship. You get to love that person as a person, even if you know your baby isn't going to survive.

One of the things that is so important that I have seen done just so amazingly well is that doctors and nurses really love that baby also, and together with the parents they really have an alliance in which they all bond with that baby. And they are really pulling for that kid as a person. You learn to take it a day at a time and to see how your child is doing.

Very few parents really hang on to just the concern of, "How normal is my baby going to be?" The baby is a total person to them after a while, and our job is to help the parents be total persons, too, as they are relating to this child.

And the working alliance and communication and understanding over a period of time, between the doctors and nurses who can really interpret and help make the baby a less frightening responsibility to the parent, and the parents' freedom to ask their questions and to say things like, "Boy, I'm really getting to resent this child" or something like that. And you say, "Sure, of course you do, and that's okay. Anyone would, running back and forth for 3 months and still not knowing whether he's going to make it."

I think that's one of the points I want to make today—it's not directly your question—but the ability to face so much pain and the roller coaster up and down—is he or isn't he going to make it? He's had another bleed into his brain, and what is that going to mean? Now his heart is starting to have a problem. Now he's starting to have seizures.

You really need to have someone who has more mastery over the situation than you do to hang in there. And one of the things I'm concerned about is that that relationship not be jeopardized, both for the parent-infant bonding relationship as well as for the mental health of the family who has a long, long road ahead of them.

COMMISSIONER DESTRO. Would any of the other witnesses like to comment on that question? Is that distinction a reasonable one in your mind? I'd like to get the whole panel's opinion on that distinction because in my own view that is one of the core distinctions here.

MS. STILWELL. I think that that is definitely true. I definitely see a difference between a neonate and a baby that is born with a birth defect. When I speak of the children that I see with spina bifida, most of the time, other than the initial surgery that they need and the surgeries that they will need later on, as far as being seriously ill, I don't consider them ill. And I don't consider them to be going to be hanging on to life, say, for 6 months down the road.

If we have a baby that is born with numerous other birth anomalies besides the spina bifida who we don't think is strong enough to even go through the initial surgery of having their back closed, usually we will sit down with that family and discuss the problems. What we will usually do with those babies is just kind of wait. We give them supportive treatment. We feed the baby; we give them antibiotics to prevent infections, and those sorts of things. But it's kind of a wait-and-see game with those babies to see if they are strong enough, say, 2 weeks down the road, to go through with the surgery then.

We don't see that happening often, fortunately, with the babies with spina bifida. Usually it's the back lesion and hydrocephalus, and most of the time there's not a lot of other anomalies with that.

CHAIRMAN PENDLETON. Mrs. Buckley.

COMMISSIONER BUCKLEY. Let me see if I can go back. Dr. Penticuff, in some of what we have here so far as the interviews that were done with you, you made some statements that I wish you would explain a little bit more for us.

We have the statement that you feel that what should be done in the cases of these severely handicapped children or these children we're talking about is that there needs to be an assessment of the lives we are prolonging to ensure. And there's another part where you feel that the legislators may not be aware of the implications for guidelines for treatment, and the result of these might be that there might be overtreatment.

What I am interested in trying to consider is that if because of these Child Abuse Amendments and because of the fact that we hear discrimination being brought up when they talk about how you are looking at these infants when they are born, and we have heard about some cases where we are culturally taught abhorrence of these children—can you give us some idea of how you feel or what you feel might be some of the problems that might happen as a result of this fear, that there might be suits, court action, or publicity. In some cases, the press has come into this to the point where it has produced serious scars on the family, the nurses, the doctors, and in some cases, produced economic problems for doctors and hospitals and so forth. Can you talk some more about this part of it?

DR. PENTICUFF. I'm sure that you probably have been getting the last couple of days some kind of an idea of how varied all the opinions are about these things. My opinion is based on the experiences that I have had as a staff nurse and as coordinator of our high risk perinatal clinical specialist training program for nurses who do this type of work.

So just sort of prefacing my opinions with that comment, I am concerned that if hospitals and if medical directors of neonatal intensive care units and counsels for hospitals, say the attorney for the hospital, read the regulations in sort of the light of, "This hospital might be sued," or, "We might get bad publicity in the community," and so forth, then what my concern is is that you will get a baby who, say, is born very prematurely, maybe not a baby with spina bifida or a Down's syndrome baby, but just an extremely premature infant who possibly even in that hospital its chances for survival are maybe either unprecedented, and the odds are just really against it in this institution for this baby to survive.

But because the physicians and the hospital administration are concerned about legal sanctions and so forth, or press or whatever, they might feel that where a few years ago they would have been comfortable withholding treatment or withdrawing treatment that had been initiated, possibly nowadays they might feel a pressure to treat a baby that even in their own minds they really don't believe is going to make it, and in fact, statistically they have no evidence to say that they are going to be successful.

I think the situation is so complex because typically what happens, especially with these premature infants, is that it's true that you don't know, and it is true that there are some survivors in weight categories that were unprecented 2 years ago. To sort of summarize it, then, my concern gets to be that we in the NICU are much less comfortable at stopping treatment that has been initiated, possibly in some ways out of a concern that it might be misinterpreted as withholding of treatment from a handicapped newborn.

Now, once a baby has a bleed into its brain, you can immediately say that this baby is at risk for developmental delay and so forth, and you can say this is a handicapped newborn.

But I agree that the distinction between a baby with a spina bifida lesion that is present at birth and is a full-term baby and so forth is quite different. We are down in the weight categories now to between 500 and 750 grams. And the World Health Organization has a definition of live birth which is that if you're less than 500 grams you're not even a live birth. But any baby born with a heartbeat will be resuscitated in every institution that I know of.

You can look at it from several viewpoints. You can look at it from the cost viewpoint. It surely is extremely costly. The thing I look at it from is not so much cost, although I think we are all concerned about that, but what the parents are put through and even what the baby is put through. Sometimes you think of it as medical experimentation. The physicians are very proud of those statistics, and I've even heard residents brag at being able to intubate a 620-gram baby. It's almost like taking the most dangerous slope on a ski slope or something like that. So I guess I have a certain amount of cynicism in that situation.

And unfortunately, the problem in my mind is that the parents are not really told that, "In this institution we really believe that this baby doesn't have very much of a chance. Here we have high tech and we're going to use it, and maybe this baby will make it and won't that be great."

COMMISSIONER BUCKLEY. Ms. Mack, do you have a comment on that?

MS. MACK. Well, I guess what I was thinking about is the need to help families get beyond that concern about experimentation and the physician's excitement at his or her own heroics, and so on. I just see that as a terribly important role of the social worker, who isn't involved in the medical care, to help parents express those questions out loud. It is not for us to say, "Are you worried about experimentation?" I wouldn't put that thought in someone's head. But if they want to ask a question—I just feel that they go on for the rest of their lives second-guessing themselves, and they need to feel that they were as totally there as they could possibly be.

You know, so many people tell me that they really felt almost psychotic during the time their baby was in the hospital; that they really had trouble thinking. I don't know if any of you have ever taken a child in just for an ordinary operation, but it's very hard to remember everything that was told you even though it's pretty much matter of fact. And in trying to think that through when there are so many fast-changing situations for your baby—also different doctors have different opinions, some of them treat more aggressively and some of them more cautiously, and you don't remember which doctor told you which thing.

So that so much work needs to go into just helping parents think through what their questions are. And I think there really are variations from hospital to hospital. I think there's more excitement about being on the cutting edge of technology and so on in different places.

COMMISSIONER BUCKLEY. I'd like to ask Ms. Antuna and Ms. Stilwell: In your institutions after the Baby Doe regulations came out and all the furor over the Baby Doe cases, and then the Child Abuse Amendments came out, did you feel that your institution was under more pressure to treat these children, and did you see then more children treated against the consent of the parents, and then placed in foster homes or institutions because the parents could not handle the pain of taking this baby home? Did you see a difference then in your staff work or in your doctors' care?

MS. ANTUNA. Maybe I could give you a little history. The first case that we became involved in which we took a family to court because they didn't give consent was in 1975. And as I said the State wanted no part of it. We had to sue the State to make them become guardians of the child.

I don't see that there has been any additional pressure. If anything our facility looks at these regulations as saving them money, because now, instead of having to hire our own attorneys to go to court for this, the State will, in fact, put forth the petition and take action, which is something that previously they were reluctant to do.

So I don't see that our facility has felt any pressure. We had an ethics committee before the regulations came out. And because it's on a voluntary basis, I see many hospitals that will not have ethics committees and will try to skirt around the issue.

So in terms of my particular facility, it has not had any impact on us. We were doing it before the regulations came out, and we are continuing to do it a little better now because the regulations are there.

My concern is that the children's protection agencies in our State which have been poorly staffed and who will now be mandated to take on additional responsibility will be in a lot of trouble. They weren't doing a very good job of protecting children from physical and mental abuse before, and now they have the added responsibility of trying to figure out what medical neglect is all about.

So in terms of the regulations, we have passed the buck to them to do something, and I don't know that we have given them the tools or money needed to train these people to do what is being asked of them to do.

MS. STILWELL. I feel it has made no change in our facility either. And I can speak just a little bit to our neonatal intensive care unit, that they have established more of a team where if there is a problem with nontreatment of the neonate, then that team meets and works with the family to try to work something out, or else we'll call the HRS child abuse committee.

COMMISSIONER BUCKLEY. One thing that I found very interesting in Ms. Stilwell's account was that you try to show them all the normal things their baby can do. I find that very interesting because yesterday we heard some statements about how we learn by culture to discriminate against a deformity and against someone that is, quote, "not normal."

I am interested in how you feel this positive way of looking at these babies would help us get away from the idea of discriminating against them. Some of the doctors we talked to yesterday got very upset when we said that if you think about the fact that this is a mentally retarded child who has multiple—and I'm not talking about Down's syndrome or spina bifida; we already know we can work with them—but the ones who have severe problems. How can you take this concept of doing it in the nursery and expand that to society? What can we do to expand it to the point where we can be more tolerant of these children and be able to consider helping them more?

MS. STILWELL. That's a big question.

Well, first of all, one of the reasons I do that is because I think that your initial impression of anyone, it doesn't matter who, if you meet someone out on the street, your initial impression is very hard to change. And I think that too many times babies that are born with any kind of birth defect or illness—we really focus on what's wrong with the baby, telling them, "This is wrong, this is wrong, this is wrong. Your baby probably won't do this or any of these things."

I think it is very important that we give them a positive initial impression of that baby, that if they have another child, take it to this baby and try to point out similarities between that child and the baby that has just been born so that they can see in their mind that, yes, this is a child first, but it may have some problems.

As far as society goes, we need to do a lot of education. One of our problems is, just as I think Dr. Hahn said yesterday, there are lots of barriers for adults with disabilities. There are architectural barriers; there are barriers as far as employment goes; there are lots of prejudices. I don't know how you can change that other than do a lot of education of the public and try to make them more aware that, yes, a person with a disability can do just about anything they want to do. Their ability to do is dependent upon what we allow them to do.

COMMISSIONER BUCKLEY. When you do this and the child eventually dies, or if you do this and the child in 1 or 2 years really turns out to be like the one child that you pick up and you almost go through the brain mass, have you really helped the parents or have you just increased their pain?

MS. STILWELL. I think you have helped them. I think the parent needs to bond with the child, no matter what that problem is that that baby has, because if they don't bond with that baby, they will never be able to get over or get through the death and dying process, even if that child lives 2 years, 6 years. There are no guarantees even with a baby with no problems whatsoever that that child will live 2 years down the road.

But I think it's very important that you allow the parent to bond with the child and to love that child. It's going to be painful for them, but at least if that baby dies, it is ended and they can say goodby to that child. If you don't do that, I've seen many times that parents are never really able to let go. They are usually very bitter. That is not to say they might not be bitter if the baby does die and they have bonded with it, but chances are they are not going to be as bitter or have bad feelings towards the medical profession or towards anyone if they have been allowed to love that baby and care for it.

COMMISSIONER BUCKLEY. Ms. Antuna. In your institution it seems that if the parents opt for nontreatment, then you remove them from this bonding process that Ms. Stilwell has been talking about because you're taking it away from them.

MS. ANTUNA. No, in the cases that we went to court on it was only on the decision not to have surgery; the children remained in temporary custody of the State while the children were hospitalized, and we helped the families bond with these children, and then went back to the court with them. And I became an expert witness in each of these cases, saying that this family was now ready to take care of that child and take it home. And in each one of these situations, except in Mr. Daniels' case, the children were, in fact, discharged with the parents. And they felt very grateful that the decision had been taken out of their hands and that something had been done for their children. And the children were discharged with them, and we helped them through the whole process.

CHAIRMAN PENDLETON. Mr. Guess.

COMMISSIONER GUESS. Thank you, Mr. Chairman.

Let me preface my questions by once again pointing out that the staff should be commended for assembling such articulate and knowledgeable panels on the subject we have had over the past few days.

And in looking at this panel, it struck me that, given the process, you are probably in the most unique position to view each component along the way from the totality of the situation, if you will. And I might ask each of you: Given that perspective, and using as an underpinning our charge to look at the civil rights of the newborn as pertains to treatment or nontreatment, if you could design a system, taking all the variables into consideration, without taking resources into consideration, you have a free hand to write the system, what would an outline of your system look like? Ms. Mack.

Ms. Mack. You say if all the resources were available, which we know they are not and probably never will be?

Commissioner Guess. I'm giving you a blank check.

Ms. Mack. I guess I feel that every family who gives birth to a child who they cannot take care of as they had expected is automatically in shock, and they feel guilty and angry and their self-esteem and sense of control are all deeply affected. The ideal situation would be one where all the possible support could be given to this family, where their care-givers would be free to communicate with them fully, where no one was threatened by outside allegations, where they could ask every question they wanted to ask, where they could feel as totally present and informed and in control as possible; that the standards of the hospital would be not just those of the medical care-givers per se, but that there was input from the community in terms of community standards. I think we have heard from all the physicians—they know they don't live and act in a vacuum—there are standards in our community.

I was interested in the discussion about Tay-Sachs families. There are community attitudes about suffering and about how you prolong life and so on.

Those families who do choose to use every possible resource they can to keep their child alive would be able to bring their baby home if they want to. My deep concern about the situation that exists now are families who fight and fight and sacrifice in order to treat their child and are never able to take care of the child in their own home. It is a tragic compromise. They may take them home for a while, but they can't keep up the 24-hour vigil of watching a respirator and whatever. And those families who do choose to keep their child should have all the support in their home so they can have that child be a member of the family and not a human being who they produced, but is now 400 miles away in another part of the State or even in another State. I think that is really one of the toughest aspects of this problem.

Commissioner Guess. Dr. Penticuff.

Dr. Penticuff. This is sort of like Christmas. What I think we really need to do—and I'm going to talk sort of in broad sweeps rather than in terms of individual cases. I really believe that we have a system of perinatal care in this country that is balanced on the wrong end. We are really heavily invested in what we think of as rescue care, high-tech care. I think there are some good reasons why we are. We started out wanting to save premature babies about 15 years ago or so, and now we are going far beyond what anybody ever managed that care would be like.

But the consequence of it is that I don't believe that we are preventing the kinds of births that require neonatal intensive care. What I mean by that is that I think we need much more adequate prenatal care. In my ideal world, every pregnant woman would have extremely good prenatal care. Now, I truly believe that this would decrease the number of babies that have to have neonatal intensive care, and all of this pain and suffering the families go through, the children go through, the handicaps associated with complications of premature delivery, which I'm talking about primarily here. I'm not going to touch on some of the other aspects of prenatal care, but I definitely think that we have to be much more serious about prevention rather than this wonderful—some people use the term "sexy"—high-tech care that we find ourselves in today.

The other thing is that I believe that parents need to have more of a prerogative in decisionmaking in the NICU. I believe that it's a fallacy to think that parents have that prerogative. And I think even our panel today pointed that out. Parents are, basically, not given a choice. They are told, "This is a list of things your child needs." Regardless of how gently they are informed this, in my own mind I don't see in the NICU that families are being told, "You have a choice." They are simply being told, "Here's a consent form. Sign it." If they don't sign it, they are taken to court immediately. And I'm not saying that's wrong in every case, but I'm saying, in my mind, there's something the matter with that.

I believe parents need to be more educated. We need in this country in our junior high schools and high schools for teenagers to know more about birth defects and the need for adequate prenatal care if they're pregnant, and just a general kind of education focus that I think could help us very, very much in the future.

Then I really believe that nurses need to be more involved in collegial interchange with the rest of the professionals, and we do need more encouragement in hospitals that have NICUs where staff do have support programs, where they do have educational programs, where there is more of a development of communication among all of the people that work in the NICU and the families within the NICU.

I believe that with the sort of recommendation for the infant care review committees that it is quite important that there be a mechanism for the education of the people who will serve on those committees, and at the moment in looking through the regulation, I don't see that as really having been addressed. I think that is an important aspect.

Of course, I definitely support nurses' participation in these, and I also believe that, in that sort of grassroots around the bedside, that the nurses' views in the case need to be encouraged and brought out.

Another problem I think we have and that we need in an ideal system is resources for the families. I won't reiterate what Ms. Mack has said, but I support it 100 percent. And I really hope that we are not going to think we have done the job simply by ensuring the civil rights of babies in the NICU. The Chinese believe that if you save a life you're responsible for it. Nurses believe that, too. And nurses see these children all the way down the line—in pediatric surgery units in hospitals, in back wards of institutions. Nurses are employed in all of those settings. And I truly believe we are not being just or humane if we save a life today and ignore it tomorrow or 10 or 20 years down the line. So I think that as a society, if we are going to take this stand, it is necessary for us to recognize the implications of it.

We need respite care for families. They need to have a place where their child can be cared for so the family can take a vacation. We need help for the siblings in this situation. We need financial support so families don't consider getting a divorce just as a way of getting a check from the State. And we need to look very carefully at long term rehabilitation costs for these children and just to make sure that we are going to continue our commitment to them beyond the doors of the neonatal intensive care unit.

COMMISSIONER GUESS. Ms. Antuna.

MS. ANTUNA. Since you have given me a blank check, I am going to write all the things that I would like to see. There are some things that probably couldn't come about, but some things could easily come about, and I think there is a responsibility to ensure that that occurs.

Many hospitals, as I mentioned, have social departments, and we need more social workers working in the perinatal area, in the obstetrical clinics, in school systems, anyplace where we can be of assistance in helping people come to grips with the decisions that they have to make in life. That would certainly be one area where I would strongly encourage that to occur.

Education of all people would be paramount. And we have been granted some money through HHS to provide for a psychosocial faculty coordinator in our facility. That person has the responsibility to teach physicians who are going to be the primary caretakers in the future, and try to educate them on all the different psychosocial issues that come about in hospital settings, try to teach them how to deal with hostile families, how to deal with different decisionmaking items that they have to come to grips with.

I would like to see education of the people that take control of the kind of medical neglect cases that are going to be surfacing. I'd like to see them be qualified individuals. We have stipulated qualifications for people on renal dialysis. I think that's the least we can do for the people taking care of the welfare of these children.

We do need to expand our allocation of monies for the States to develop better programs, to develop quality programs, so we can help families who choose to take these children home with all the facilities they are entitled to. If a family chooses to keep a child, they will usually have less resources available to them than if they put their child in foster care.

Things like the Kay Beckett [phonetic] waiver that medicaid is now providing where they will give 50 families all the resources they can use for children who use ventilators in these States—50 children in each State is not adequate. There are a lot more children that need services, and I think right there we are discriminating, and how they come to find these 50 children is going to be quite a task.

So there are some things we can do and some things we cannot do, but I think in terms of the qualifications of individuals who are working with these people and making decisions would be my priority.

COMMISSIONER GUESS. I know I made a mistake in giving somebody a blank check, but can we also have Ms. Stilwell's response.

MS. STILWELL. I think I agree with everything everyone has said so far.

One of the things I'd like to see is a change in society. If we are going to be committed to allowing a person with a disability to live and to treat them, then we also need to be committed to allow that person to develop to their full potential and to provide a society where that can happen.

I think a financial system is a definite must. We should not have any kind of criteria for a family. If the family chose to institute their child and the State had to take over, the cost of that child would be much more than if the family takes care of the child.

Another thing I would like to see is teaching of physicians in medical school—maybe not just in medical school, but in all health care professions—to teach more wellness. I think that too many times you see health care professionals who feel that they have to treat things and cure them. And if you're treating a child with a disability, that doesn't happen. And just because they have a disability doesn't mean they are not well.

CHAIRMAN PENDLETON. I might just ask a question about financial resources.

Is it discrimination to treat a child that is born with, say, just a birth defect, carry that child through and spend hundreds of thousands of dollars on that child, and not on a well child who might have a fantastic IQ? How do you draw the line or where do you draw the line? I'm just trying to figure out: If you've got a child born bright with a 200 IQ, at some point, what do you do for that child? Just let that child make his or her own way through the social order and say that society should order payments for treatment of the child that has a disability?

I do believe that people should be judged by their abilities and not by their disabilities. There is no question in my mind about that. But where do you resolve the conflict?

MS. STILWELL. I think in our current society, for a gifted child, there are many more resources for that child than a child who is born with disabilities.

CHAIRMAN PENDLETON. You're talking about State resources and the like. I'm not so sure the States or the Federal Government provides as much for a gifted child as for one with a disability.

MS. STILWELL. I don't know. I can't speak to that.

CHAIRMAN PENDLETON. Ms. Mack.

MS. MACK. I do want to say something about the resources in that way, and especially in regard to the question of discrimination. The thing I am most concerned about these days is that, at least in the State of Massachusetts where I come from, black children die at twice the rate of white children, just because of the lack of normal services, both prenatal care for their families and well child care. So that if we are really looking to see where discrimination shows up in the health care system, as far as I'm concerned, it's in the preventive services—in terms of economics, in terms of race, in terms of minority groups. These people don't have beginning health care.

CHAIRMAN PENDLETON. I'm not prepared to put it on a racial plane. I'm prepared to put it on the plane—I don't look upon race as the only discriminating factor in this country. There is no doubt in my mind we could discuss many reasons why that is the case, and I think I alluded to some earlier on.

But I'm just wondering: How do we balance these competing interests?

DR. PENTICUFF. Yes, I think this is a problem that is probably the most important question. We don't have a blank check. We do have a limit to the amount of money that we can spend in this country for everything in health care. So I don't believe that we as a society have grappled with that at all.

CHAIRMAN PENDLETON. Should we?

DR. PENTICUFF. I'm afraid that we must. I truly believe that we have to. I'm afraid that, right now, in a lot of ways, I think we're taking the easy way out, because the easy thing to do is to treat everyone; okay? And without really stopping to think about the consequences of ensuring the life of every baby that is admitted to the NICU to the best of our ability—you know, I'm concerned that we have such a momentum to provide care today that we are not really willing to face the consequences of what that is going to mean in real dollars in the next 15 years.

You talk about the discrepancy between services for a child who is extremely bright, who might solve, you know, all kinds of problems in the future if this child could just be challenged appropriately and have the potential developed in that child. And I guess that I really believe that if you could find a group of people who were prepared, you could really get a group of people together, you could have a panel or whatever, and I think that they could come up with some probably rather revolutionary notions of where we ought to quit spending our money in neonatal intensive care. The money that you save in that way doesn't necessarily mean it's going to go to the education of that very bright child.

CHAIRMAN PENDLETON. Yes, I understand. I guess we are being caught up in our own momentum. The advances in science allow the very bright physicians, the research types of physicians, to make decisions about how we can begin to save low birth weight, multiproblem newborns, and when you continue into that arena it's almost a Catch-22. You do something and you hope it comes out right, and if it doesn't come out right, you keep trying because that's what you were trained to do.

It seems there is no resolution to that kind of dilemma. I think I've heard people say in this hearing that at one time if a child had spina bifida, that was the end-all. Now, because of research and treatment and work by very bright physicians, if you will, or disciplined or determined persons, it has allowed that kind of newborn to be saved.

So I don't know where all this comes out. But we do have, I guess, competing successes that compete for resources and attention and space in the social order.

COMMISSIONER GUESS. Mr. Chairman, following your same line, since this Commission often talks about the theory of limits, and since in our country we talk about values that dictate acceptable risks and we allow certain risks to remain—if we don't want an auto accident, we could bring it to zero by not having an automobile. If we don't want plane crashes, we could bring it to zero by not having planes. But we allow certain acceptable risks.

Is it reasonable that we are doing a pretty good job now with what we have in terms of this whole question? I mean are we doing a decent job?

CHAIRMAN PENDLETON. Ms. Mack, you are sort of chomping there.

MS. MACK. Do I look eager? Well, actually it does pertain to the question. No, I don't think we are really where we can be. I was thinking that this is where our medical ethicists could be really helpful to us, that in medical schools and in training programs, they really do help people stop being quite so literal about where the technology can go, the exciting outer edges they can go to, and think about their total responsibility to society.

I think we are way out of balance right now, just as we are in a lot of other technological aspects of our life. And we really all have a responsibility to think about what our goals are for ourselves as a society, because in the direction we are going we are really not giving everybody an equal chance for a healthy life, and we are doing amazing things. And if I had a very high-risk child, I would be so happy with these technological services that are available. You know, this baby I was telling you about who was kept alive for a year, our chief of neonatology estimated that we probably spent about a million dollars on that child who, even had she survived, could never have lived in her parents' home. Think of the number of children who could have been helped with that amount of money by a WIC [women, infants, and children] program or their mothers who could have had prenatal care. We really do need to rethink our priorities, and we need a lot of help. And I think medicine is ready to ask for ethicists and then some to help them think it through.

CHAIRMAN PENDLETON. Thank you very much. It was a very interesting panel and we appreciate your coming and sharing your experiences and knowledge with us.

We will recess briefly and then have the next panel.

[Recess was taken.]

CHAIRMAN PENDLETON. I would like to swear the witnesses.

[The witnesses were sworn.]

## The Federal Role in Treatment Decisions

### TESTIMONY OF GARY J. CARUSO, FORMER LEGISLATIVE DIRECTOR, HOUSE SUBCOMMITTEE ON SELECT EDUCATION OF THE COMMITTEE ON EDUCATION AND LABOR, U.S. CONGRESS; CHARLES COOPER, DEPUTY ASSISTANT ATTORNEY GENERAL, CIVIL RIGHTS DIVISION, U.S. DEPARTMENT OF JUSTICE; ROBERT D'AGOSTINO, FORMER DEPUTY ASSISTANT ATTORNEY GENERAL, CIVIL RIGHTS DIVISION, U. S. DEPARTMENT OF JUSTICE; AND DAVID RUST, EXECUTIVE SECRETARY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

CHAIRMAN PENDLETON. Counsel.

MR. MANN. Thank you. I'd like to thank all of you for coming.

To begin with, could each of you, starting with Mr. Rust, state your name and position for the record.

MR. RUST. I'm David Rust. I'm the Executive Secretary of the Department of Health and Human Services.

MR. COOPER. I am Charles Cooper, Deputy Assistant Attorney General, Civil Rights Division of the Justice Department.

MR. D'AGOSTINO. Bob D'Agostino, presently in private practice, formerly the Deputy Assistant Attorney General for Civil Rights.

MR. CARUSO. I'm Gary Caruso. I'm currently with Congressman Solomon Ortiz, and formerly of the House Subcommittee on Select Education.

MR. MANN. Thank you.

Mr. Cooper, can you describe the current status of the Baby Doe court cases?

**Mr. Cooper.** Certainly. The only case that the Justice Department is currently involved in is the case called *AMA* v. *Heckler.* It's a case involving the validity of regulations promulgated by the HHS in the area of medical treatment of handicapped newborns.

The case came up out of New York district court, relying on the Baby Jane Doe case, that is, the *United States* v. *University Hospital,* invalidating the regulations in that case. It was affirmed in the Second Circuit also on the basis of the Baby Jane Doe case.

We have petitioned for *certiorari,* and we understand that the case will be on the conference list. Actually, it was supposed to be on the conference list for the Supreme Court yesterday, so we should have an answer in the not too distant future as to whether the Supreme Court will grant a petition for *certiorari.*

**Mr. Mann.** Assuming for a minute that *certiorari* is granted, and assuming also for a minute that you finally win, and that the regulations under section 504 are upheld, how do you think that would affect the administration of the Child Abuse Act of 1984?

**Mr. Cooper.** I don't think it would affect the Child Abuse Act amendments in any substantial way. Certainly, there are some overlapping requirements in the Child Abuse Act regulations and the 504 regulations that are at issue in the AMA case. But the 504 regulations focus directly on the hospitals, the programs in the funded hospitals that deal with handicapped newborns, whereas the Child Abuse Amendments focus principally upon the State and local child abuse authorities. So the two sets of regulations have entirely different principal focuses, and I would not anticipate that a decision validating the 504 regulations would have any adverse impact on the child abuse regulations or their enforcement.

**Mr. Mann.** What do you think, Mr. Rust?

**Mr. Rust.** The Department has looked at that issue, Mr. Mann, and we believe that the two authorities are very different, that they are compatible, that we would probably go back and redo some pieces of the 504 regulations if the Court sustains our authority to do so. But we do not see it having any detrimental impact on the matter of enforcement of the Child Abuse Amendments.

**Mr. Mann.** Mr. Cooper, should the government lose the Baby Doe case, do you see any continued role for section 504 in this area?

**Mr. Cooper.** Well, I assume that you mean if the petition for *certiorari* is granted and the Supreme Court affirms the court of appeals, then, no, 504 will not have any application at all in this area.

The Court of Appeals for the Second Circuit, in the Baby Jane Doe case, held that section 504 was not intended by Congress to reach at all the health care services decisions as they relate to handicapped newborn infants. So if that is affirmed, then 504 will have no application at all in this very important area.

**Mr. Mann.** I'd like all of you to answer this next question, starting with Mr. Rust. We have heard from a number of witnesses the last few days who described the application of section 504 by the government as unduly intrusive, unwieldy, leading to many problems on a local level. What do you think? Do you think that the application of section 504 was as flawed as many of our witnesses have described?

**Mr. Rust.** No, Mr. Mann, we don't. The Department issued two sets of regulations in final form under that authority. We believed then and we believe now that that authority does, in fact, give the Department a role in these cases. We think it's extremely important. It has been stated by the President on a number of occasions and reiterated by the Secretary and a number of others that this is an area where we are concerned that these children receive nondiscriminatory care, and we think the Department which funds these hospitals at very high levels has an appropriate role to play in seeing that they provide the kind of health care that these children deserve.

**Mr. Cooper.** Clearly, the Justice Department does not agree with those who argue that the regulations or any enforcement of section 504 in this area is unduly intrusive on local or individual decisionmaking.

It is our view that that question was answered by Congress when it passed 504 protecting handicapped individuals—and in our view that includes individuals of all ages—from discrimination based on their handicap. They mandated a Federal role for HHS and for the Justice Department when litigation is necessary under 504 as surely as they did mandate a similar role under Title VI where the question of race is involved, and Title IX in educational programs, when sex discrimination is alleged.

I think it is important to keep in mind that what the Federal Government is intruding upon in this area are decisions that are discriminatory, decisions that are based on a person's handicap. And we believe that is an entirely proper Federal role. We think that Congress has mandated it.

**Mr. D'Agostino.** Well, obviously 504 regulations would be intrusive. All the civil rights regulations have been intrusive. Under the civil rights regulations, they have taken over prisons and schools and put the State of Alabama in virtual receivership. Those certainly were intrusive actions. Yet, we don't have the same critique in the same quarters about that. Certainly, in that respect, the 504 regulations are less intrusive. And again, I second what Mr. Cooper just said. What we are intruding about is someone's life. There are no rights if you don't have the right to life.

**Mr. Caruso.** I have to also agree with Mr. Cooper. Being on the Hill when some of these things were written, I know what the intent of the members of the committee was, and in fact, it was to cover everyone under Title VI, under Title IX, and under section 504.

MR. MANN. Do you think that the Child Abuse Act of 1984 is a sufficient answer to the problem, Mr. Caruso?

MR. CARUSO. I believe it is. One of the problems the committee had was that it seemed this new phenomenon, known as Baby Doe, was not being addressed by the courts in a consistent manner across the country. And what the committee wanted to find out was if, in fact, while an infant is under the care of a doctor and in the hospital prior to being released to the parents, what was the magic age where all of a sudden this child's rights began?

It seemed that if the child had gone home and some accident or something had happened and the parents were liable, then the State, under all the other regulations and the law that Congress passed, could intrude, if you want to call it that, or take custody of the child if that child's life was in danger. But the courts would not uphold that while the child was under the doctor's care.

And I think the Congress said, "There is no magic age when a child's rights become active. It's when, in fact, that child is born."

MR. MANN. Would any of the rest of you care to comment?

MR. D'AGOSTINO. I would like to. I think Mr. Caruso really hit the nail on the head. Where the problem lies, of course, is what the courts will or will not enforce. The Child Abuse Act, I think, is a sufficient response if the courts will indeed protect handicapped newborns, something I'm very skeptical about. Let me say I think it's the most practical accommodation of the problem at this time.

MR. RUST. I would agree that it's an adequate response, and I think part of it was that that bill happened to be pending at the time. It was an appropriate vehicle. There is a State, local, and Federal mechanism to carry out this child protective service. We have been funding them for a decade or more. So there was an existing mechanism that we could add additional responsibilities to for protecting these children.

As to the long-range adequacy, we're going to have to see as it's implemented. It takes full effect in October. The regulations are out now. Many of the provisions of the statute become fully effective on October 9 of this year, and we're going to have to see how it's implemented.

One of the things I think has been very encouraging in getting this legislation passed has been the degree of cooperation up until now that has existed between disability groups, prolife groups, medical groups, the Hill staff, and the Department in coming up with a system that will work. And we are hoping that what we have done, at least to some degree, is to sensitize the medical community and families and child protection agencies. So the public awareness impact of this, the broadening knowledge and concern, may be another benefit of this whole process.

MR. COOPER. I think it is important to keep in mind that the Child Abuse Act is limited to requiring State child protective agencies to have in place procedures for receiving and investigating complaints of child abuse. And that would include withholding treatment from newborns. But it does not in any way place any independent Federal duty on hospitals or health care services programs. And that is the role and was the intent of 504.

So without 504 there is no duty of nondiscrimination that emanates from Federal law anyway on the hospital and the health care providers themselves. So I would disagree with my colleagues on this panel with the notion that the Child Abuse Act standing alone would be an adequate Federal response to the problem.

MR. MANN. What else do you think is needed?

MR. COOPER. Well, I don't think anything in addition to 504 is needed, but I do think that it is a perfectly appropriate Federal response to this problem to outlaw, as we believe Congress has, discrimination in the provision of health care services on the basis of handicap. And without 504 there would be no such restriction on health care providers themselves. Again, there may be State law requirements, and those requirements, under the Child Abuse Act, would presumably have to be enforced. At least the States would have to have procedures, and they would have to receive complaints, and they would have to investigate them.

Again, I think it is important to keep uppermost in mind that 504 is the only Federal law that places any duty whatsoever on the health care providers themselves.

MR. MANN. Would you like to see section 504 amended if the courts disagreed with your interpretation of it?

MR. COOPER. That is an issue I think we would have to wait to see what the Supreme Court actually did in the AMA case, and it would require a lot of reflection and decisionmaking by people throughout the government. So I would certainly not want to take a position for the administration on that point. We'll just have to wait and see what happens.

MR. CARUSO. If I might add, it was the feeling of Congress that, in fact, the child abuse statute as it stood prior to the amendments of 1984 did, in fact, cover handicapped infants. It was the court and the judicial system which did not interpret it as such. And I think the same problem exists with 504.

There is a parallel there. When a parent, on their constitutional religious rights, feels that no medical treatment should be given to their child, the courts have been consistent across the line in giving the State custody of that child. And the committee felt that if, in fact, you can do it on religious grounds, you can also do it on the basis of a handicapped individual. But the courts didn't see it that way. And one of the intentions of Congress was to put something on the books, on the statutes, last year to address that.

If you look at the whole evolution of the child abuse regulations and the law, you see that every time it's been reauthorized something new has been added. It was sexual abuse of children at one point, and now it's the Baby Doe aspect of it as well.

So I think as this bill goes forward and this law is reauthorized again, you may see another phenomena occurring as we as a society evolve.

MR. COOPER. Mr. Mann, I'd like to emphasize that when Congress passed these amendments to the Child Abuse Act, it in no way intended to supersede, supplant, detract from, or otherwise affect 504 or the application of 504 in the area of health care services to handicapped infants. In fact, the act explicitly contains a disclaimer of any such intention, and it reads as follows: "No provision of this act or any amendment made by this act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973." So no one should have any misimpressions that Congress thought that when it amended the act recently it was somehow rendering 504 inapplicable or otherwise affecting its applicability.

CHAIRMAN PENDLETON. I just want to make a point. My impression of the organizational panel the day before yesterday was that they felt that the Child Abuse Act supplanted 504, and especially since the decision of the Second Circuit came into view they felt 504 no longer applied in these instances. Am I correct?

COMMISSIONER DESTRO. Yes.

MR. CARUSO. Well, that, in fact, was not the intention of Congress.

CHAIRMAN PENDLETON. I just wanted to let you know that that is the impression that the organizations who were here a couple of days ago testifying gave. As our Counsel says, with their lawyers. They interpreted it as saying that doesn't apply. There was some feeling as though it did not apply even while the case was being litigated.

MR. CARUSO. That is not the intention of Congress, and that is one of the reasons the committee put that disclaimer in there.

CHAIRMAN PENDLETON. I only wanted you to be informed of that.

MR. RUST. Mr. Chairman, our Department was enjoined by the Second Circuit not to apply 504 regulations that we promulgated. But that doesn't mean the Department doesn't continue to assert that we have the right to do so, and we're looking to the Supreme Court to reestablish that.

MR. D'AGOSTINO. I'd like to say one thing about that. Despite the Second Circuit decision, that's only one circuit, but I don't think that precludes the application of 504 directly to the States and through the various Federal grants for child dependency laws. I mean there are other ways to reason around this. And I don't believe that the Child Abuse Act stands alone. I don't believe that alone it is necessarily sufficient although it is an adequate response.

I think, in conjunction with applying 504, which is something I advocated—in fact, the Justice Department threatened to do with the State of Illinois when I was there—that the State could not discriminate against a baby because it's handicapped—understand we're taking control of an alleged abuse-neglect case. They have to apply laws across the board. I think that gets around the Second Circuit reasoning on one level, and secondly, it makes the direct application of 504 to the States and indirectly, of course, to the hospitals because the States support the hospitals.

**Mr. Mann.** It seems to me that the difference between the approach of the Child Abuse Act and the approach of section 504 is that section 504—at least the application of it today—implies that this is a problem of discrimination, whereas the Child Abuse Act has a different type of approach.

Clearly, Mr. Cooper believes, has just stated that he believes, that 504 does address a problem of discrimination in this area. Do the rest of you agree with that?

**Mr. D'Agostino.** Yes, I agree that that's correct, although I don't agree necessarily that it's addressed in the way the government is now saying it's addressed. I think there are program-specificity problems and what have you with 504 as applied directly to a hospital. But if you apply it through the State, which does give aid to the hospitals, and you threaten the State with witholding funds under the Dependent Children's Act or what have you, that State is not going to let a hospital discriminate. And I think that's the way to go. And that is the approach we took—one of the approaches we took—in the Illinois case which came to Justice's attention back in '82, I think it was.

**Mr. Mann.** Do the rest of you have any comment on that?

[No response.]

**Mr. Mann.** Do you agree, then, that this is a problem of discrimination which should be addressed through civil rights laws as well as the Child Abuse Act?

**Mr. D'Agostino.** Yes, it's a basic discrimination problem. Obviously, you would give care to this child if to give the care would mean the child wouldn't be handicapped. If you don't give the care because even after the care the child will remain handicapped, that's clearly the definition of discrimination.

**Chairman Pendleton.** Repeat that, if you would. I think we'd like to hear it.

**Mr. D'Agostino.** The reason care is withheld from a child—if a child is given care and will not be handicapped after the care, it's given to the child. However, if the child will still remain handicapped in some way, it will be withheld. That is invidious discrimination. That is discrimination. That's the definition of discrimination.

**Mr. Caruso.** I might add also that Title II of the child abuse statute provided funding for adoption opportunities for those children who are hard to place. And that was complementary in figuring that we would have some of the Baby Does given up for adoption, and that is another reason Congress added that additional money; they did agree that, in fact, there should not be discrimination against the handicapped infant. And if we're going to provide care for that infant, then we also should provide some type of mechanism to follow through on it so that that child could be placed in society if the family doesn't want the infant.

MR. MANN. Mr. Chairman, I have no further questions.

CHAIRMAN PENDLETON. Commissioner Berry.

COMMISSIONER BERRY. I only have one question. I'd just like to know from these gentlemen why, at a time when the Department of HHS and the Justice Department seem generally to be in a posture consistent with the President's philosopy of trying to get the Federal Government off the backs of the people in terms of enforcing civil rights and it's in favor generally of narrowing the legal interpretations under the other civil rights statutes—why is there all this interest in this one issue and all this aggressiveness about this one issue and wanting a Federal role, emphasizing a Federal role? Is it because this issue is somehow regarded as more important than all the other issues? Or is there some reason that has escaped my notice? It seems exceptional, and I just wondered if you could give me some guidance on that.

MR. COOPER. Let me take a shot at the outset.

First, I think your question is premised on, in fact, a false premise, the notion that this administration is trying to narrow or is otherwise advancing a narrowing interpretation of the civil rights laws.

In fact, I think, if the press reports are accurate, some members of this Commission have suggested that the civil rights laws apply only to certain types of Americans. And it has been our position that that narrowing construction is inaccurate, and that in fact—

COMMISSIONER BERRY. Who are the members of this Commission that you are referring to, Mr. Cooper? Who are the members of this Commission that you have just referred to?

MR. COOPER. I understand from press accounts that you may be one of the individuals.

COMMISSIONER BERRY. What you understand is completely incorrect. I have never stated that the civil rights laws apply to only some Americans. That is the most blatant statement I have ever heard anyone make. It has never been said. And if you repeat it, I'd like you to provide some documentation that I have said the civil rights laws apply only to some Americans.

But I didn't ask you the question to debate the issue of narrowing. What I meant by narrowing was not a negative, and I didn't mean to get into that discussion. And, in fact, what I cite is what your own leader, if you're still over at the Justice Department, Mr. Reynolds, has cited as a narrowing of the interpretation of the *Grove City* case and some others. And I don't want to debate whether that's right or wrong.

CHAIRMAN PENDLETON. You should not debate the merits of all of that.

COMMISSIONER BERRY. I don't want to debate that. I just wanted to know why there was so much interest in this specific issue to the extent of HHS—you're not in HHS—going out to the hospitals and sending people and the like, and the interest in getting the statute passed, and the emphasis on there being a Federal role generally in this. I just wondered what happened and why this occurred, that's all.

MR. COOPER. Certainly, to the extent that you have been misquoted, and I have been a victim of that as well as have others in the Justice Department, I appreciate your dilemma and I will not myself perpetuate that wrong.

But again, the Federal Government is enforcing what we believe to be the congressional mandate of section 504. At least in speaking for the Justice Department, that is our effort. We regard that as our obligation.

In the cases that we have been involved with, we have determined—and most notably the Baby Jane Doe case—that that required that we litigate to obtain access to records and other information that was directly relevant to the question of discrimination.

It is no different from any access case that we would file under any other nondiscrimination statute. We file them all the time under Title VI where, let us say, a State does not want to provide records relating to racial composition in some agency or something like that, under some claim of privilege that they don't have to provide the records. Well, we sue them all the time over those kinds of issues because without information the Justice Department and HHS and other agencies that are obligated to enforce civil rights laws cannot do their job. And that's all that was involved in the Baby Jane Doe case.

Obviously, there is a threshold question, and that is whether 504 was intended to cover this issue. We believe that it was, and we have pressed that view in the courts, and we are now on petition for *certiorari* to the Supreme Court, pressing that view. But it is not a correct characterization, I would suggest, to say that we are acting in this area any more enthusiastically than we do with respect to any of the other nondiscrimination statutes.

COMMISSIONER BERRY. Thank you.

CHAIRMAN PENDLETON. Do other persons want to comment?

MR. CARUSO. If I might follow up on that, I work for the Democrats in the House and so I will disassociate myself from the administration. We believe that we are consistent and we disagree with the Justice Department in their handling of the *Grove City* case, for example. We believe Title IX, Title VI, and 504 are equal and consistent, and we disagree with the handling of it.

CHAIRMAN PENDLETON. This is not a *Grove City* hearing, but I'd like to know what your feelings are—I'm sorry, Bob, do you have something?

MR. D'AGOSTINO. Yes, I'd like to address it. I am in private practice, but I'd like to associate myself with the administration.

CHAIRMAN PENDLETON. I tried, folks, but here we go.

[Laughter.]

CHAIRMAN PENDLETON. I tried to make the discussion neutral.

MR. D'AGOSTINO. I think the question is a good one, and I think there are two answers to that.

First of all, I think that in terms of the definition of discrimination, it depends on how you define it, whether the Reagan administration is pursuing a narrowing or not. Obviously, the definition of discrimination has changed over the last 20 or so years, and the debate must start there.

I think Chairman Pendleton and Congressman Gray—when the Chairman was in Delaware he made a statement about what discrimination meant. Congressman Gray made it very plain he had a different definition. So obviously, if you start with a definition that includes results, you have a very different idea of what "narrowly" means. So I think in that sense the Reagan administration is narrow, yes.

Secondly, we are talking here about—the Constitution says "life, liberty, and the pursuit of happiness." Well, life is prerequisite to the other rights—

COMMISSIONER BERRY. The Constitution doesn't say this; it's the Declaration of Independence, which has no legal force or effect.

MR. D'AGOSTINO. I meant the Declaration of Independence. But life is the prerequisite to all other rights granted in the Constitution by the Founders. We do have something in the Constitution about due process. You don't take life without due process. We're talking about life. That's why I think there is a qualitative difference, in a sense, in what we are doing here.

The Reagan administration, as far as I know when I was there, has not backed off prosecuting any case which involves discrimination against an individual, no matter what the basis is.

COMMISSIONER BERRY. You don't all have to answer if you don't want to. I don't understand why someone isn't willing to give the simple answer, which is the case was publicized, everybody heard about it, the President was interested, and it is a case where discrimination might have occurred, and it was quite proper since it was in the public domain, and it came to people's attention, that you get interested in it. I expect that is the simple answer, but go ahead, give me all these other answers.

MR. RUST. You just took my answer, Commissioner. You said it better than I would.

[Laughter.]

MR. COOPER. I certainly have no problem with that characterization, either—

MR. D'AGOSTINO. I haven't, either.

MR. COOPER. —although I am bound to say that the Justice Department and this administration feel that Title VI and 504 and Title IX and all of the nondiscrimination statutes, contrary to any other suggestion, are equal, and they are deserving of the same amount of enthusiastic and vigorous enforcement.

We also believe that the views we came to on the legal question of program specificity in the *Grove City* case on Title IX applied to the other statutes that contain that language, and it was only after satisfying ourselves thoroughly that the program at issue in Baby Jane Doe was federally funded—the program, not just the whole hospital, but the program that she was actually involved in—before we took a single step.

MR. CARUSO. I might add one further comment. I think that when all these laws were written they may have been poorly written as we have Monday-morning quarterbacking now. I think the intent, though, was to cover everyone, and with the Court's interpretation being more narrow, too, I think that is probably part of the problem. We should come up with some new umbrella legislation like this, to cover it.

CHAIRMAN PENDLETON. Mr. Destro. And spare us.

COMMISSIONER DESTRO. I certainly will.

One of the things I'd like to get into the record is that there has been a lot of commentary—Commissioner Berry's preface to her question underscores it—about the application of 504 in the circumstances. We have heard a lot about Baby Doe squads; we have heard a lot about how this is enforced in a way different than other civil rights statutes.

So let me address my question primarily to Mr. Rust. When HHS gets a complaint under Title VI, does it send someone out to investigate the case, do you know?

MR. RUST. I don't know.

COMMISSIONER DESTRO. Mr. Cooper, would you know the answer to that?

MR. COOPER. Well, I can't speak for HHS in its own enforcement role, but I would strongly suspect that they investigate complaints of Title VI. I certainly hope so.

COMMISSIONER DESTRO. If the Justice Department gets complaints under Title VI, do they send someone out to investigate them?

MR. COOPER. Absolutely, both in our role as a funding agency, which is very limited so we don't have much direct complaint-gathering investigation that many of the other agencies do who have much broader funding authority than we do, but also in our role as the government's litigator. And it was only in that role that we have been involved thus far in 504.

But the case that we were asked to pursue for HHS was the garden variety, "Go get the information; they're stiffing us on the records" kind of stuff. It was not the case that has been described in most of the national media as a situation where the Justice Department was trying to get an operation for the child involved or anything of that nature, was second-guessing medical decisions that had been made. It was simply an effort to obtain for HHS so that their enforcement officials and their experts in the area of medicine—which we have none of, of course, in Justice—could make intelligent and informed decisions as to whether or not discrimination had taken place and enforcement procedures would be necessary.

COMMISSIONER DESTRO. The only thing I'm getting at in these questions—and you might be able to see where they're going—is that we heard a lot about Baby Doe squads. And what I'm asking is: Do you have Title VI squads and Title IX squads and other 504 squads that go out and investigate cases?

MR. RUST. The Office of Civil Rights in the Department has a very definite enforcement and investigative functions. The question is: Do they send someone from Washington and assert "squad"? I'm not sure in all cases. They do have regional offices that do the investigations, and I'll be glad to provide for the record some more detailed information about OCR's investigative reponses to allegations.

We think that the Baby Doe situation is a little bit different in that it is not something that you could send a team out next week, perhaps, to investigate. In these particular instances we are talking, even with the child protective services with the mechanism now in place—every State has an emergency protective mechanism that allows them, for instance, to take custody of a child in the middle of the night if the child is being severely abused, and then perhaps go to court the next morning. So the need for speed in the case of a child who may live only a matter of a few hours or a day or two in the event of nontreatment is a little different from the case where you conceivably have a regional office team go out 3 days from now and investigate the circumstances and correct the problem.

I think that is the reason for the kind of mechanism that was contained in the original 504 regulations in our department.

COMMISSIONER DESTRO. The real difference, then, is the speed with which you have to get the information, but the substance of the investigation is really pretty much the same; right?

MR. RUST. It is my understanding that it is, but I'll doublecheck that and make certain for the record.

COMMISSIONER DESTRO. The only other question I have is: Under the other antidiscrimination laws we have on the books, do you have to put up notices in the places where the discrimination might take place, like the notices about employment discrimination down near the timeclock where people can see them that gives you information about where you go if you know about discrimination?

MR. RUST. I know it's a common practice in employment discrimination and was widely required when I was the Deputy Commissioner of the

Administration on Aging, information about the Age Discrimination in Employment Act, and so forth, which was widely posted that way.

So I think the answer is yes—where you go, who you contact, what number you call for information, if you feel your rights are being violated, at least from our department point of view is a common practice.

COMMISSIONER DESTRO. Was that the same intent for the notices that were to go up in the nurseries?

MR. RUST. I would say yes. It was to tell people what constituted the possible discrimination and what they should do about it—who they should call, who they should bring the allegation to the attention of.

MR. COOPER. In fact, Commissioner Destro, I think it is correct to say that the notice requirement was based upon similar notice requirements that have long been in existence in the employment field. I don't know how widespread or how many statutes or regulations mandate such a requirement, but it is certainly not without precedent.

COMMISSIONER DESTRO. Thank you.

CHAIRMAN PENDLETON. Mr. Guess, do you have any questions?

COMMISSIONER GUESS. I just want to make sure, Mr. Chairman and members of the Commission, that the background information is correct.

Is it true, Mr. Cooper, according to the background given us, you graduated with a baccalaureate and J.D. from the University of Alabama?

MR. COOPER. That is accurate.

COMMISSIONER GUESS. Is it also true that you clerked upon your graduation from law school for Justice Rehnquist?

MR. COOPER. It is true, although it was not immediately upon graduation. I had spent a year as a law clerk for Judge Paul Roney with the Fifth Circuit Court of Appeals before clerking for Justice Rehnquist.

COMMISSIONER GUESS. I have no other questions, Mr. Chairman.

CHAIRMAN PENDLETON. Mr. Caruso, on Wednesday, in response to a question from Mr. Bunzel, the organizational representatives said that they didn't really push for the Child Abuse Act of 1984, that they really weren't too happy about it. I think I heard from the parents who participated that some of them weren't that much involved. I'm trying to find out from whence cometh the Child Abuse Act of 1984? Who were the movers in this act, and why do we have it?

MR. CARUSO. Well, I think Subcommittee Chairman Austin Murphy and the full committee ranking minority member John Erlenborn were the two coauthors of that bill. It's a response to the Bloomington, Indiana, case where the child had Down's syndrome and a blocked esophagus and was denied surgery. One doctor said, "We can do it; it's routine," and the other doctor said, "No," and the parents chose the one who said, "Let's not do it on the basis of the quality of life for that child." The baby subsequently starved to death.

That, I think, was the impetus for those two Congressmen to put that into the statutes because, as I said earlier, the courts were inconsistent on different levels on the Baby Doe phenomenon, but were very consistent when it came to the fundamental religious beliefs of a parent that the child's life comes above religious convictions and should also come above any quality of life standard.

I think that's the purpose behind that, to just beef up the current law because, as I also stated earlier, the committee felt that that child was covered under those statutes, but that the courts were not interpreting the intent of Congress.

CHAIRMAN PENDLETON. What interest groups were pivotal in pushing through such legislation?

MR. CARUSO. Well, we never had the medical societies behind us at the beginning. They wanted a further study. They felt the Congress was intruding in an area where they shouldn't, and the rhetoric was such that Congress was mandating someone else besides the parent and the doctor to make the decisions.

In fact, the way the law is written, it parallels the child abuse laws concerning older children. It not only protects the doctors, but it protects the parents, too. If you have a doctor who comes and says, "I think we can do something for this child," the parents ultimately have to give the decision to operate or not. They are the ones who have the authority at that time. And if, in fact, the doctor agrees and the parents disagree, the doctor could then go to the State child protection agency, just as the doctors may when they disagree with parents who for religious reasons doesn't want the child treated. The committee felt those children should not be discriminated against on the basis of their handicap.

The medical societies were not with us at the beginning. The right-to-life groups, the advocates for child civil rights, and the disability groups were, in fact, favorable for some type of legislation.

As it progressed—and it took almost a year. As a matter of fact, the chronology of it was we were working on the bill when the first 504 regulations came out. So it looked like us introducing the bill a couple of weeks after the 504 regulations were first promulgated—it looked like we were responding to them when, in fact, we had begun the process earlier than that.

Those regulations did not have any State involvement and subsequently were struck down by the court. The second set of regulations paralleled our original bill in involving the States. And those also were struck down, and that's why the bill evidently was passed, because a number of Democrats and Republicans on both sides of the House and the Senate felt that this was a civil rights matter that should be addressed. And when all the groups finally saw that the Democrats and Republicans, both House and Senate, were going to act on something, they got involved.

A number of the medical communities did sign aboard, and a compromise was struck in the Senate, and what it did was expand upon the original House language by defining what withholding of treatment was, defining some other situations and circumstances. To the best of my knowledge, the American Medical Association was not involved and has not signed on to that, and that's why they are in court at this point in time.

So we did not have the majority of medical groups in the beginning. We had many more when finally the bill landed in the Senate. And we have always had the right-to-life and disability groups and the advocates for the civil rights of the child on board for some type of legislative language.

COMMISSIONER DESTRO. May I ask just a quick question on this. Do you have any sense for why the medical community might not have wanted a 504 approach? We understand from the disability groups that, at least at first, they didn't want to take the chance of opening up 504. Was there any sense that you had in dealing with the medical groups with whom you dealt that they didn't like a 504 approach and would prefer the child abuse approach?

MR. CARUSO. They never preferred the child abuse approach. In fact, some of their rhetoric was, "Now all of a sudden you are implying that doctors are potential child abusers." And our response to that was it was only when something was reported that we would have the States intervene, and the child abuse agencies in the States don't go knocking on doors saying, "Are you abusing a child today?" They wait until there's a report. I think all the groups did not want to open up section 504, but the medical community never favored the child abuse approach.

CHAIRMAN PENDLETON. Mr. D'Agostino, how do you feel about this discussion and about where the Child Abuse Act is now with respect to discrimination against the newborn?

MR. D'AGOSTINO. Well, I've always favored an approach that heavily relies on the States and the State agencies. I feel that is the only practical way of doing this. So I'm in favor of the Child Abuse Act, but also—and I state it again—I also think 504 applies. I think 504 applies if not directly to the hospitals in most cases, it applies to the States and how they take cases, how they pursue cases, under the dependency, neglect, and abuse statutes.

So I am very favorable toward this approach, as long as we understand that 504 still does definitely apply, and that we can reason around the Second Circuit decision.

CHAIRMAN PENDLETON. Mr. Cooper, do you have any comments?

MR. COOPER. No, Mr. Chairman.

CHAIRMAN PENDLETON. I have just one more question.

This morning we heard testimony from the support services, and I think we saw quite a difference in the assessment or the treatment modality that they go through.

I am wondering whether or not under the Child Abuse Act, as you discussed it and as you know it, that somehow hospitals get accused of neglect at the State level because they have decided to do something for the child and the child was handicapped, and so forth. If there is treatment or nontreatment, can there be litigation on the part of an aggrieved party?

MR. CARUSO. There can always be litigation, Mr. Chairman. The way Congress set up the system was that it should follow the same pattern within the child protection agency in the State as other cases.

It was also agreed upon that we should not let a parent go out and shop for the doctor who would give the answer they want; it should be a consensus. And the only criterion that remains is: If there is a decision to withhold treatment, if that hospital has an ethics or review type of committee, it should be referred there so there is a consensus and agreement with the original diagnosis. If, in fact, someone disagrees from there, they can always go to the State child protection agency.

If the hospital does not have a review mechanism, it will automatically be referred to the State child protection agency. So we're only dealing with those cases where a decision to not treat comes into play.

CHAIRMAN PENDLETON. Are you saying that the child protection agency in the State is the ultimate protector in these cases?

MR. CARUSO. Yes.

MR. GREEN. I'd like to ask a few questions.

Mr. Cooper, in Title VII the Justice Department rightly, in my opinion, cites the legislative history. What is there in the legislative history of 504 which indicates that Congress specifically wanted to include treatment of newborns in the coverage of 504?

MR. COOPER. I know of no reference in the legislative history of section 504—which incidentally is extremely sparse—that discusses specifically newborns or discrimination against handicapped newborns. By the same token, I know of no legislative history in Title VI which discusses in any way infants and discrimination against them on the basis of race. Yet, I have never heard anyone maintain that Title VI, for want of specific discussion of infants or young people, excludes them from coverage.

You know, it is an ancient canon of statutory construction that you don't exclude from coverage instances or situations or people who are plainly within the language of the statute simply because there is no specific discussion of that instance or those people or that episode in the legislative history. In this circumstance, the statute protects all handicapped individuals, and even the Second Circuit in the Baby Jane Doe case had to concede that infants are individuals.

MR. GREEN. Another question is: You stated that the purpose of 504 and the Child Abuse Act was to prohibit discrimination against the handicapped. I'm a little confused about this. What is the difference between a handicapped condition and an otherwise similar condition caused by something other than a birth defect?

For example, is there something different in kind between mental retardation caused by Down's syndrome and some kind of mental retardation caused by a terrible accident that a 5-year-old child or a 35-year-old man might suffer? Is there any difference in kind between paralysis resulting from spina bifida and paralysis resulting from a swimming pool accident?

MR. COOPER. Well, Mr. Green, I can't pretend to testify with respect to the medical differences that may exist in the situations that you have described or the handicap that the people that you describe would have suffered. And there may be medical differences. I just have no idea.

But I would suggest that all of the individuals you described were handicapped, regardless of what gave rise to the handicap or what the origin of the handicap was; and as handicapped individuals, it would certainly be the Justice Department's view that they were protected from discrimination based upon that fact in any federally funded program or activity.

MR. CARUSO. I might also add, if I may, that when a 5-year-old or 35-year-old has some debilitating condition occur, you don't stop caring for and feeding that person. The same thing applies to a 5-minute- or 5-hour-old baby.

MR. COOPER. Certainly, if there was an episode where such a decision was made, the Justice Department would, if referred by the HHS, certainly pursue it as we have in the Baby Jane Doe situation.

MR. GREEN. So it is your position that the act of discrimination, which is or should be illegal, and the decision of whether or not to perform surgery, a physician takes into account any physical or mental condition other than the specific one that can be corrected by the specific surgery being contemplated at that very moment.

MR. COOPER. I don't understand that to be the Justice Department's position, or HHS's for that matter.

MR. GREEN. In other words, they take into consideration the total health condition of the patient? For example, if they're contemplating heart surgery, is it an act of discrimination to say, "Well, we're not going to do that due to the fact that this patient has an incurable lung cancer." Is that discrimination against the lung cancer patient, not to perform heart surgery?

MR. RUST. Mr. Green, the law says that there are three or four circumstances under which extraordinary treatment or heroic treatment doesn't have to be applied. If the child is irreversibly comatose, if it would merely prolong dying, if it would be futile because it would only correct, say, one of several life-threatening conditions, the others of which are not correctible, or if it would be on its face inhumane.

I think you could say in that particular case that a heart transplant would be futile in the sense that the person had terminal cancer or something of that nature. I don't want to get into it particularly because I'm not a doctor, but the point is, even this law, which says basically all babies are entitled to food, water, and appropriate medication, does not presume that we have to make an extraordinary effort on behalf of each one. There are cases where the law specifically says if it will be futile, if it will inhumane, if it will not protect the child from dying, if you cure one condition and another one is going to kill that child and is not correctible—so the law recognizes that some Baby Does cannot be saved, but they still are entitled to food and water, appropriate food and water and appropriate medication.

MR. CARUSO. I'd like to follow up on that, if I might. That was one of the sections that was agreed upon during the Senate considerations by all the groups involved, the outside organizations. That was one of the stipulations in that compromise package. So that came specifically from all the groups involved and was agreed upon.

MR. D'AGOSTINO. Let me make one comment on that. You can come up with a hard case that it is impossible to answer. Well, the rules are not made for hard cases in which a certain amount of discretion is used. They are made for the usual case. What happened in Indiana was that there was a blockage of the esophagus which is 90 percent correctible. If that child had not had Down's syndrome, it would have been done. The only reason it wasn't done was he had Down's syndrome. It was nothing to do with blockage.

The Illinois situation was a very similar one. The only reason the parents in Illinois did not allow the surgery was because their child might have been somewhat paralyzed.

MR. GREEN. I'm not talking about that situation.

MR. D'AGOSTINO. But those are the kinds of situation the law is designed to protect, not the hard cases. The hard cases are always the hard case, no matter what kind of rules you have.

MR. RUST. And under this provision, Mr. Green, the State child protective service could step in and take custody of the child if need be and have that child treated. That probably could have happened in Indiana, even under the law at that time. They probably could have acted had they chosen to do so.

MR. COOPER. A lot of confusion that I think is reflected by your question, Mr. Green, is a confusion that the courts are suffering as well, and I think it's over a misunderstanding or mischaracterization of the position the government is advancing in these litigations.

Our point is that we are in no way seeking to review or to overturn bona fide medical judgments, that is, decisions made by medical people in conjunction with the appropriate other individuals, parents and hospital administrators and others—bona fide decisions that are based on medical judgment.

It may well be—and it would sound to me in the example that you cite—that a perfectly bona fide medical judgment not to do the heart transplant under those circumstances could be made, if this person is terminally ill and we don't know whether the heart or the lung cancer is going to get him first. But one of them is going to do it and rapidly.

But if the decision is not a bona fide medical decision, that is, it is not based on medical judgment, but it is based on something else, that is when these laws are actuated. If it's based on race—for example, if the Bloomington baby had had an esophagus blockage and was black, with no other handicap whatsoever, and the decision was made not to operate and open that esophagus so the child could receive nourishment because the child was black, I cannot imagine how anyone could disagree with the proposition that that was a decision not based on medical judgment, but based on the child's race. And I also think everyone would agree that that was a discriminatory decision which if the program was federally funded Title VI would embrace.

So the analysis is precisely the same in the area of the handicapped. The child had Down's syndrome in addition to the esophagus problem, and it seems to be conceded—although I had nothing to do with that Indiana case—that the decision was based on the fact the child had Down's syndrome, that the esophagus was not open, and the child was allowed to die of starvation.

CHAIRMAN PENDLETON. I want to ask one more question of Mr. D'Agostino. What do you believe is the appropriate role of the judiciary in resolving the problem of handicapped infants being denied necessary medical treatment? What is that role and do you believe it's being carried out appropriately?

MR. D'AGOSTINO. Obviously, I think the role of the judiciary is to enforce the laws, whether they are abuse laws or 504 discrimination laws. I think there is some reluctance to do that. I don't think the judiciary is immune to the kind of social pressures that we get. The standards being used—at least when doctors talk about allowing these children to die, they are quality of life standards and are not medical judgments as Mr. Cooper pointed out. And the court is not immune to those pressures. Just a reading of the cases dealing with the emerging torts of wrongful conception, wrongful birth, and the hints on wrongful life—the language the courts use, there is no question many judges discount a life if a person is going to be handicapped.

I spoke before the National Federation of the Blind, and an awful lot of those people had quite a good quality of life. I would have been very hesitant to make a judgment over their quality of life. There were prosecutors; there were businessmen; everyone was there. I had a fine old time. I think the best time I had was I love to eat bread and I ate all the bread and no one saw me.

[Laughter.]

MR. D'AGOSTINO. But being serious, the judges are letting these quality of life considerations get into their decisionmaking in the courts, and I don't have a lot of faith in the courts in this respect. I think they just ought to enforce the laws uniformly.

CHAIRMAN PENDLETON. They should enforce the law uniformly, and what else should they do?

MR. D'AGOSTINO. I don't think there is anything else they can do. Because the answer is if an action is brought, it goes to the court. If the parents want to fight a hospital or a social services agency, it must go to the courts, and the courts must act on what is in front of them.

It is almost routine for a court to give custody for medical or health reasons to the hospital, to the hospital administrator, to a social service agency when religious convictions are involved—no blood transfusions or what have you—it seems to me that if a hospital comes in and says, "This baby is going to die unless given medical treatment," the court should bend over backwards to protect the child. When in doubt protect the child. That is not happening at this time. I don't think the courts need anything else than the laws on the books if they would enforce them.

MR. COOPER. In that respect, Mr. Chairman, I think I can confidently say that in the University Hospital decision, if the Justice Department had gone in seeking records on a complaint that the hospital was rendering health care services to black children differently from those it was rendering to white children in some respects, some sinister kind of allegation such as that, we would have had those records in 10 minutes.

These access-to-records cases are just automatic. They are lay-downs. But in this area other considerations, obviously, were at work.

COMMISSIONER DESTRO. Would it be fair to say, then, that the burden of proof in those cases has been shifted over from the normal child abuse case where the question is, "Why shouldn't you treat?" to these cases where it is now, "Why should you treat?"

MR. COOPER. I think the burden of proof in this particular case, as reflected by the opinions in the University Hospital decision, was put upon the government to show: Has there been discrimination? That was the question that was asked by the judges persistently. "You haven't shown that there has been discrimination."

The answer was, "Of course we haven't. We don't have the information relevant to the inquiry."

This case is about getting information relative to a charge of discrimination, and until that information has been gathered and reviewed by people competent to understand it, no intelligent decision on the threshold question can be made.

I recall a colloquy with one judge with respect to the fact that the government had, by virtue of a State law case, medical records for 8 days of Baby Jane Doe's life. They revealed toward the end of that record that we had that certain questions were raised, questions that eminently qualified pediatricians decided were ample to prompt further inquiry and to review further records.

But the question was, "If you didn't find any discrimination in the records that you had, why do you say you're entitled to more?"

The logic of the proposition would suggest that if we had had records for 2 days of the child's life, and the first day as we reviewed them did not reveal any discrimination, we would be prohibited from turning the page to review the second day.

The point is that was an access-to-records case, and the government can't be put in the position of having proved discrimination before it has gathered the very information that is relevant to that ultimate issue.

MR. D'AGOSTINO. I might point out that the Title VI regulations, which are a model for the rest, allow access. When I was at Justice and suggested that access be based on a reasonable cause to believe discrimination rather than just an allegation, there was a tremendous hue and cry, and particularly that that would cripple civil rights investigations.

So Mr. Cooper was merely following the model regulations which all others are modeled around; that is, the Title VI regulations.

COMMISSIONER BUCKLEY. Does anyone else have questions?

COMMISSIONER BERRY. I want to ask Mr. Cooper: When you were framing the issue and drawing the analogy with race cases, it seemed to me the way you were framing the issue—and we all know as lawyers that, "If you let me frame the issue I can tell you what the answer is going to be," at least if you're lawyers like you are, I'm sure, able lawyers.

In any case, the issue seems to me not whether the hospital or the doctors were failing to give treatment to a child because he was handicapped that they would give to a child that was not handicapped, just like if a doctor would give certain treatment to one child and not give it to another just because of his race, but it really was that the doctor or hospital concluded that the treatment that ought to be given, for example, to an anencephalic child which we have been hearing about for the last 2 days or microcephalic or various kinds of deficiencies we have heard about—the doctors had determined that that was the kind of treatment that it ought to give to a child who had that particular deficiency or handicap without regard to who the child was—he could have been a black child or a Hispanic child or a white child—but what you're questioning is their judgment about whether that is the right treatment for that particular handicap, which is precisely the question at issue. That is different from saying that you know the treatment is right, but you're not going to give it to someone; you're going to deny it.

It's a medical question, isn't it, and not, as a doctor said to us the other day, it's not a question of discrimination. It's a question of maybe right or wrong. It may be immoral; it may be moral; but it really isn't discrimination, denying something that they think ought to go to a category of illness. You're questioning whether they ought to do that; isn't that right?

MR. COOPER. No, I don't think that is precisely right. Taking your framing of the issue, if you have a situation where the doctors have decided that a certain course of treatment will prevail and that is the decision they would have reached whether the child was black or white or female or male or anything else, then what you can say with certainty is that the decision wasn't based on race or gender. And you may be able to conclude, probably will conclude, in all but the smallest fraction of these kinds of cases, that the decision was based on a bona fide medical judgment.

I don't know all the medical ins and outs of anencephaly and things of this nature. I have a general understanding by virtue of my litigation in this area. But certainly, there are certain decisions that doctors can make with respect to not performing a certain procedure that other doctors might say ought to be performed. But, you know, there is a legitimate professional dispute.

It is not the Justice Department's position that that is a quarrel or dispute that we want to get involved in. The point we would make, though, is that there is evidence, and it has been found by bodies who have nothing to do with the administration—there is evidence that there are decisions that are made in this area which are not based on medical judgment, but which are based on the existence of a handicapping condition. And that is the way we view what took place in the Bloomington case, a situation where the course of treatment—and that's what the doctor and the court in that State case called it, "treatment"—the course of treatment prescribed was literally to do nothing, to permit the child to starve to death without any intravenous feeding, without what I have understood is a relatively routine surgical procedure to unblock the esophagus so that nourishment could be received.

That so-called course of treatment we don't believe was based on a medical judgment, but rather was based on the existence—and the doctors were quite up front on this, the ones who testified, and I have read the State court record—it was based on the fact that the child had Down's syndrome, and that doctor did not think it had any chance of leading any kind of a meaningful life.

So it is those decisions that we think 504 addresses, but only those decisions. We don't insist that medical judgments be right, but that they be based on something other than handicap in the 504 area, other than race in the Title VI area, and what have you.

**Chairman Pendleton.** I want to thank you very much for spending time with us.

We will adjourn this panel and will now take on the public witnesses.

We'll take just a 5-minute break.

[Recess.]

**Chairman Pendleton.** I would like to call Father Barry, please. Father Barry, I will swear you in, and then I'll make some other comments.

[The witness was sworn.]

**Chairman Pendleton.** I do want to make a public statement that the hearing record is held open for 30 days beyond today's date. If there is information that people want to send to us in the form of testimony, please be sure to do that. And if there is information that the witness has or anyone else has that they want to share with my colleagues—manuscripts, articles, or the like—I think you should give those to us and let us increase our library on this issue.

People have asked the question: How long will it take to make a statement? I'm saying somewhere between 6 to 8 months between the time we are able to look at the transcript, as well as to go over material that is already here before us and the material to come. That's about the time frame. Please do not expect us to come out tomorrow. This gestation period is rather long and rather protracted so we can make the best statement we can.

I think it is also important to say that this Commission looks forward not just to hearing testimony and putting it in some printed form, but to also give policy recommendations to the administration and to the Congress on issues around which we have hearings as well as other things.

So I'm certain that my colleagues join with me in that respect, and we do want to say something publicly and take some position, whether that is pro or con or neutral. That is not an issue right now. But it will be somewhere among those three.

## TESTIMONY OF FATHER ROBERT BARRY, DOMINICAN PRIEST

**Chairman Pendleton.** Would you give your name for the record.

**Fr. Barry.** My name is Father Robert Barry, and I am a Dominican priest and a Roman Catholic moral theologian.

First of all, I want to commend the Commission for conducting these hearings. A hallmark of a vital and responsible legal system is that it takes active measures to expand the rigorous, precise, and reasonable thought of the law into new areas of human life so in doing that justice, equity, and rights can be protected. You have entered into a very difficult area here for that purpose, and I highly commend the Commission for having done that.

For the past number of years I have been deeply involved in the issues of provision of medical treatment and nutrition and fluids to various classes of patients and the impact of these issues on Roman Catholic theology. I have two concerns to which I wish to speak today.

First of all, it is clear that in the future infant care review committees will assume a greater role in the care of handicapped newborn infants. And it is my belief that, at this time, further measures are needed to assure that these committees are held fully responsible to their legal duties and obligations to these handicapped infants.

Infant care review committees, like all other citizens subject to the law, have ordinary legal obligations to protect innocent life and to assure that innocent life is guaranteed and protected. At the present time, in the medical and ethical literature, there is very little mention made of the legal obligations of these committees toward handicapped infants. And it is my belief that a sound jurisprudence would consider the enactment of further measures to more explicitly state what these legal obligations are.

A sound jurisprudence seeks to create as wide and as fine a net under vulnerable individuals to protect them from abuse and neglect. And it is my belief that consideration of further measures to explicate the legal obligations and duties of these committees would be of great benefit to handicapped infants.

Secondly, I wish to urge the Commission to study more fully the legal duties and obligations involved in the provision of nutrition and fluids to handicapped infants in particular. At the present time, in both medicine and ethics, there is a great deal of confusion and controversy concerning these legal duties, and it is my opinion that rigorous and precise and reasoned thought of the law could give great insight and direction in the resolution of these highly controversial issues.

I differ with some ethicists who previously testified in that I believe that the causes from which a person dies are very significant legally and morally. Dying from starvation and dehydration in many instances can have a very great legal and moral significance. So I would urge the Commission, if possible, to consider those few issues.

I will be submitting written articles on both of these issues in the future, and I wish to thank you very much for the opportunity to speak here.

CHAIRMAN PENDLETON. If you would allow us, pursuant to the rules we have to follow, since you have not been subpenaed as a witness, would you allow us to ask you some questions?

FR. BARRY: Yes.

CHAIRMAN PENDLETON. Commissioner Destro.

COMMISSIONER DESTRO. Father Barry, yesterday we had a number of questions about ethicists and how you got to be a member of the ethicist club, if you will. From your perspective, do ethicists among themselves draw distinctions about who is legitimate and who isn't, based on their views or education or anything else?

FR. BARRY. I'm pretty sure that they do, but I am not certain as to what the criteria for legitimacy are. I just cannot identify what those criteria are.

COMMISSIONER DESTRO. Were you familiar with any of the witnesses that we had yesterday?

FR. BARRY. Yes.

COMMISSIONER DESTRO. Did they represent, in your judgment, a spectrum of views on the issues that were before the Commission, do you think?

FR. BARRY. Yes, they did.

COMMISSIONER DESTRO. Could you, in your own opinion, place them on a spectrum from—I don't even know how you would describe them. One of the witnesses yesterday talked in terms of liberal-conservative. I don't know whether that is particularly useful. I think Ms. Warren talked about a more liberal view as being represented by Michael Tooley. Would you be able to place any of the witnesses on a spectrum?

FR. BARRY. I think you could say that some of the witnesses were more liberal on the issues which we were considering than others were. Do you wish me to name names?

COMMISSIONER DESTRO. Well, there were two Catholic witnesses. I assume you'd be more familiar with them than you would be with the others. Is that not a correct assumption? Where would you put those two on the spectrum of liberal to conservative?

FR. BARRY. I would say Father McCormick is significantly more liberal on the issues we have been discussing and other issues than is Dr. William May.

COMMISSIONER DESTRO. In terms of the question of withdrawing food and water, how would those two witnesses differ, if at all?

FR. BARRY. Food and water to handicapped infants?

COMMISSIONER DESTRO. Right.

FR. BARRY. I'm not absolutely certain of this, but my belief is that Father McCormick would generally be much more tolerant of withdrawing nutrition and fluids from some handicapped infants than would Dr. May. For that reason I would consider him to be more liberal.

COMMISSIONER DESTRO. In terms of the use of quality of life criteria in these kinds of medical judgments, is there a dividing line among ethicists that some think that it is useful, other ones think that it is not at all permissible. Dr. May used the term yesterday about certain principles being true or false.

FR. BARRY. I think there is a clear difference among ethicists concerning the utility of quality of life judgments in making these decisions. Some ethicists consider some types of quality of life judgments to be ethically unacceptable while other ethicists or moral theologians would consider them to be morally justified and tolerable.

CHAIRMAN PENDLETON. Mr. Guess.

COMMISSIONER GUESS. Father Barry, am I correct in hearing that your testimony before the Commission recommended consideration of legal liability for the ethics committees be considered?

FR. BARRY. I'm not stating it absolutely, but I think it's a possibility that ought to be investigated.

COMMISSIONER GUESS. Investigated?

FR. BARRY. Yes. I'm not an attorney; I'm not a lawyer. I would think that it would be useful to investigate that possibility, that infant care review committees could in some circumstances be legally liable for their decisions.

COMMISSIONER GUESS. Very briefly, based on your view of this possibility, what standards do you see for determining legal liability?

FR. BARRY. Again, I have very limited knowledge in this area, but as a moralist I would say the legal standards that should apply to these committees, it would seem to me, should be the common legal standards that apply to all citizens as they are ordinarily subject to the law.

Now, that is not a legal opinion, but I think from a general moral viewpoint that would be a morally justifiable standard.

COMMISSIONER GUESS. Thank you, Mr. Chairman. And thank you, Father Barry.

CHAIRMAN PENDLETON. Father Barry, thank you for your position. We appreciate the time you have spent here in the last couple of days in what we have had to do, and we thank you for volunteering your testimony.

FR. BARRY. Thank you very much.

CHAIRMAN PENDLETON. Since there is no other business to come before this Commission, these proceedings are formally adjourned.

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