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The Handicapped Child and His Family

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In addressing an audience on the subject "The Handicapped Child and His Family," it is easier than it otherwise might be to know that I am talking to a group of physicians who have espoused Christian values both regarding the sanctity of life and the integrity of the family. Therefore, what I have to say will be based upon fundamental premises on which we will assume we agree: first, that the family was instituted by God as the basic module around which society and therefore civilization is built, and secondly, that each newborn infant, perfect or deformed, is a human being with unique preciousness because he or she was created in the image of God.

The family in America is in jeopardy in a way that never before has existed in our particular kind of culture. We have seen the family deteriorate in other cultures and perhaps the best example is that of the Soviet Union. Its basic family module was essentially destroyed by the state by many attacks, both overt and subtle. The Soviet Union may seem to be as strong as ever and one of the greatest threats that exists to your future, but I think there are many who believe it has cracked. *Newsweek* Books has just recently published a book entitled *The Decline of an Empire*, as a case in point.

The situation in the United States is a little different. The background is that so many of the movements so-called in this country in the past several decades have been anti-family: free life styles, sexual permissiveness, easy divorce, homosexuality, lesbianism, abortion, sexual education of youngsters without morality, population control, concerns about pollution and ecology, the test tube baby, and finally,

even though it is not yet the threat that it will be, the abuse of genetic manipulation.

I could go on and on but I am sure you could write the scenario just as well as I could.

When it comes to an assessment of the present situation in reference to handicapped children, I am more in a field with which I have intimate familiarity. As many of you know, I have spent the major part of the 34 years I have been in the active practice of pediatric surgery being concerned primarily with the surgery of the newborn in an attempt to correct those congenital defects incompatible with life but amenable to surgical correction and to carry out, in the long and the short term, those rehabilitative efforts which restore a child to society, perhaps not pristine in form and function, but loved and loving, innovative and creative, and with a zest for the old fashioned life that I find lacking in the cynical, manipulated, so frequently to-be-pitied, normal children of today.

Let me review briefly the life history of the development of one of the tragic problems that we are here to discuss today. A family having endured a pregnancy looks forward to the birth of its child who, in its mind's eye, resembles nothing so much as the rosy-cheeked, blond baby seen in the Gerber's baby food advertisements. Instead the youngster is born with a visible defect which may have not only physically handicapping potential but perhaps even mental retardation. The whole expected world has crashed down around the family. It is even possible that the mother awakes from anesthesia to find that her long-expected cherub is far less cherubic than anticipated, or that her baby has been whisked off to another hospital which to her can only be hostile. Worse than that, the support she would like to have from her husband is lacking because he has accompanied the baby to its new environment.

The manner in which the family is told has to be positive and have built into it every single possible supportive system and promise that it is possible for the primary physician to accomplish whether he be pediatrician, obstetrician or family practitioner.

What do I mean by being supportive? I am always realistic, and in reference to the deformity in question, tend to be pessimistic, if anything, so that if things work out better than my experience would indicate, then that is a positive dividend for the family rather than a disappointing descent to reality. On the other hand, as the pediatric surgeon into whose hands the problem has been delivered for at least immediate attention, I feel certain responsibilities and I feel them deeply. I recognize the family's tendency to believe that it is responsible for the defect, perhaps guilty about it, and certainly angry and frustrated in the bargain. I feel I must be authoritative, transmit a sense of competence based upon experience, and give the impression that, having been through this situation before with other families and

their defective child, I know my way around the morass of private and government agencies that can give aid. I will act as the pilot through these troubled waters to see that every conceivable supportive effort that is available is brought to bear upon the eventual outcome in this specific instance.

It has been my custom for several decades to practice this kind of supportive therapy. I telephone the mother in her lying-in hospital and assure her of all the things that I think will be supportive. I repeat these things to her husband and ask him to go and also transmit them to his wife. We have a built-in nursing and social service communication system that underlines what I have tried to do personally. I might also add that my colleagues involved in the same type of surgical endeavor practice medicine in this same way.

Contrary to what the local protective obstetrician usually wants to do, I insist that the mother come to see her child as soon as she possibly can, and even though it may be bandaged, intubated, monitored and fed with a hyperalimentation line, I want her to touch her child and, if possible, even hold it and cuddle it to establish as best we can those bonds which should have been established earlier. If I have anything to do with it, this child is going to make it, but he is going to make it ever so much better socially and emotionally if he can make it in his family.

Problems Faced by Parents

I read constantly about the problems which parents face in these situations: what it is like losing a child, how they experience a prolonged period of grief, how they feel isolated from society, how they share guilt and shame and indeed, eventually might become physically ill and mentally disturbed.

It has been my life-long experience that the support which I have just mentioned actually prevents these catastrophes. When it takes so little effort and is so rewarding, I cannot see how there can be any argument about how the family should be approached.

Now I realize that my approach is very old fashioned. I recently came into a situation in a nearby hospital third hand. The opening gambit on the part of the neonatologist to the parents of a Mongoloid child with intestinal obstruction was something like this: "Your child has Down's syndrome which means he will be severely mentally retarded. He also has a surgical problem of intestinal obstruction which will kill him if uncorrected. You have several options in treatment, the first of which is to do nothing, in which case you will not have to face either of the problems that I have just outlined."

That family opted not to have its child operated on and then foolishly, that neonatologist asked for a surgical consultation by one of

my colleagues. This immediately provided an antagonistic suggested form of management, and after an unbelievable number of legal, social and personal maneuvers which I will not go into, the child was operated on (it had malrotation of the colon, not duodenal atresia and therefore the surgery was more urgently indicated than usual), recovered well, was adopted by a marvelous lady who had recently lost a child, and has entered what I think will be a lifelong, loving, supportive relationship.

Now I am absolutely convinced that the parents who opted to let their child die and only consented to its surgery when it was guaranteed that they would never have to be concerned with the child again, will have, if not now, later, the grief, the guilt, the shame, the physical problems and even the mental aberrations that come with the abandonment of one's flesh and blood.

As you might have suspected, I do not offer the option of death as a form of management of a child with a congenital defect. I can also tell you with complete candor that no family has ever said to me either before or after I have presented them with a problem they face that they wanted their child to be left unattended rather than undertake raising a handicapped child. I cannot help but think that this also is part of the way I approach a parent. I never pause between the statement of a handicap and the assurance of my support in every conceivable way to make this come out as best it can for the family and the child.

Most of you know that I am one of the few physicians in the country who is willing to call the neglect of children with congenital defects incompatible with life what it is — infanticide — and to stand before professional and lay audiences alike and condemn this practice as homicide. At the present time in the United States, most of the children on whom infanticide is practiced die from what will eventually be called passive euthanasia, and their lesions are either separately or in combination incompatible with life if untreated.

Such is not the case in the United Kingdom, where, as I am sure you know, the chief lesion under discussion is spina bifida. Spina bifida is not a lethal lesion, but families are told that it will be lethal in about three weeks. The prognosis is guaranteed by oversedating these children so that they cannot take their feedings and they die of starvation and dehydration.

I recently talked to about 7,000 people in some cities in the United Kingdom, while showing the film, "Whatever Happened to the Human Race?" In Birmingham, after presentation of our film on infanticide and after Professor Zachary (as outspoken in his country as I am in mine) had talked on infanticide, a woman rose to ask a question. This is essentially what she said: "I am a general practitioner in the National Health Service. Three years ago a daughter was born to us who had spina bifida and I was told that she would die within three

weeks. When the nurse told me that she was being starved to death, I signed her out of the hospital against advice. She is now a bright, adorable three-year-old girl who is the light of our lives. However, she has an incontinent bladder and orthopedic deformities which keep her from walking. But because I signed her out of the hospital against advice and because she was initially classified as non-treatable, there is no way that I can obtain any urologic or orthopedic help for my child. At my own expense I am keeping her on urinary antibiotics in order to protect her kidneys. What can I do?"

Professor Zachary told her that her only recourse was to seek private care in England, and I told her that if she would get the child to Philadelphia, we would eventually send her home walking in calipers, controlling her urine with an ileal bladder and she might even be the second lady Prime Minister of Great Britain.

Many of the so-called social advances that we have in this country have come across the Atlantic from east to west. It takes about 30 years for a National Health Service concept to cross the ocean; it takes about six years for a concept like abortion-on-request to cross the ocean; it took the mini-skirt about 13 days. I am absolutely convinced that the infanticide mentality in this country will continue until it encompasses far more defects than it does at the present time and, of course, spina bifida is high on the list. As nearly as I can assess, in this country only about 5% of children with spina bifida are neglected and not treated, whereas in Great Britain the number has now risen to 75% of those born with the defect. Very shortly it will become a moot point because our Department of HEW has laid all the groundwork for its alpha-fetoprotein screening which will suddenly be introduced to this country in one fell swoop, without any preliminary discussion, and spina bifida will rapidly become a thing of the past because very few of these babies will escape the abortionist's suction tube.

What Happens to the Handicapped Newborn

I would like to suggest some of the things that happen in this country in reference to the handicapped newborn and his or her family. To begin with, he encounters one of four kinds of physicians: first, one who will act in support of the child and family as I have suggested that my colleagues and I do; second, the physician who presents death as an option in management; third, the physician who suggests institutionalization for the appropriate diagnosis; and finally, the physician who will be one of the foregoing two but who becomes hostile to the family because his advice has not been taken.

What of the parents? They have several options. If they are not in the hands of a team which will do all it can to bring the pertinent

agencies into contact with the family for its ultimate benefit, they will have to forage for themselves. These parents seek on their own what society has to offer and, on occasion, when they find society's effort to be less than adequate, they either restructure the lives of their family to fit the inadequate provisions or they attempt to be innovative enough to start in motion supportive services which will benefit not only their child but also others with similar problems.

This reaction of families has been clearly documented by Rosalind Benjamin Darling in a study she did on 25 intact families who were raising a child with spina bifida. It is appropriate that the title of her excellent book is *Families Against Society*.

I had written to Dr. Darling many years ago after she had published a journal article on social aspects of the management of spina bifida. I told her that she would never come to an understanding of these problems unless she did an in-depth study of the families who had managed to cope with the situation. This she did, and I think her contribution has been remarkable. I only wish it were more widely understood.

Several years ago I did two studies of similar nature, each on 25 families. The first were the families who had raised a child on whom I had personally operated for imperforate anus more than 15 years before. Imperforate anus is a very far-reaching anatomic and social anomaly. Families living with a child who is being rehabilitated into society while learning to be continent have grave problems which affect mother, father, patient, siblings and contiguous society. The second group of patients I studied had another lethal congenital anomaly — esophageal atresia. These were also patients on whom I had operated personally and all the operations had taken place more than 15 years before.

Although mothers versus fathers had different perceptions of the situation, and although an occasional sibling bore early resentment to the presence of a handicapped child, and despite the fact that several families were neutral as to what the experience had done for them, on balance a great majority of the families viewed the experience of raising the handicapped child as a very positive one in the development of the family. The divorce rate among the parents of these 50 handicapped children was lower than the national average.

Several years ago I gave lecture on infanticide at York University in Toronto. I wanted to be able to accurately quote the mother of one of my patients born with multiple congenital defects. I posed the following question to her, saying that I would quote her if she gave me permission. It was, "What is the worst thing that ever happened to you in your life?" She replied, "Having our son born with all those defects that required 37 operations to correct." I said I knew that would be her answer because I had done 22 of the operations myself and had been involved in some way with all the others. I then asked, "What was the best thing that ever happened in your life?" She answered,

"Having our son born with all those defects that required 37 operations to correct."

I know exactly what that woman meant. I have followed this whole family in its development. I know where it lives. I know the impact it has had upon the society around it, and I know this family believes that the parents are better people and that the three siblings have grown to be outstanding young men and women because of the love, understanding and sacrifice they experienced in order to raise my patient. I can tell you without question that the recollection of this family is one of the warmest rewards I have had in the practice of pediatric surgery.

What are the positions of the physicians? I think Darling has put her finger on it as she summarized the in-depth interviews she had with 15 pediatricians who were caring for spina bifida patients being raised in intact families. She said, "Some doctors were quite sympathetic toward parents of handicapped children. Others were not. A few were decidedly hostile toward parents who kept such children at home. These doctors' views are understandable within the context of their socialization in the stigmatizing society and their training in medical school, where success is typically equated with curing and normalcy of function, and problems are treated on an individualistic rather than on a societal basis."

To that I would add that the basic tenet upon which our inadequate approach to the treatment of the handicapped child and his family rests, is the ethic of the quality of life being the criterion upon which our decision to treat or not to treat is based.

I come this year to the end of a 35 year tenure as surgeon-in-chief of the Children's Hospital of Philadelphia and I will leave my administrative post in June of 1981. It is my hope that, after a short interval which allows my successor to establish his position in the hospital, I will be able to return to operative surgery and the care of families. I would like, in addition, to investigate the possibility of making available to physicians and parents, for every congenital lesion and syndrome, a comprehensive computerized service which could inform them of the most competent diagnostic service closest to their home, the closest competent therapeutic service, a list of all the available governmental and private agencies which could help parents and children and finally, a readout of parents with similar situations who have managed the problem successfully. If we could make this service available to parents and physicians alike, I think we would remove the terrible fear that the odds are too great against the handicapped child and his family to make any effort worthwhile, and to slay forever the myth that only perfect quality of life is life worth living.

I was addressing the oldest society on the campus of the University of Pennsylvania last year and someone said to me: "You have made it very clear that the most dangerous physicians in pre-World War II

Germany were the psychiatrists. Who are the most dangerous physicians in America today?" I was somewhat taken aback, and my answer was not immediately forthcoming. Then I said: "No one ever asked me that question before, but I guess I would have to say the geneticists and the neonatologists." To this she replied: "I am a geneticist" (and after a long pause) "and I think you are right."

'Cost Effectiveness' Discussions Annoy

I guess if anything annoys me more than discussions of the quality of life as the criterion for survival, it is cost effectiveness, because I have never been able to bring myself to put a price tag on a human life. We are constantly bombarded, not only in the lay press but also in medical journals, by propaganda concerning the cost to society of the handicapped, the retarded and the otherwise mentally disadvantaged. I would submit to you that the cost for all of the physically handicapped and all the mentally handicapped individuals in our society today and in the future is but a drop in the bucket compared to the cost to our society for the morally handicapped.

I never read anything in the newspapers about how the physically handicapped have perpetrated tremendous crimes against society. The same could be said about the mentally handicapped. But newspaper headlines and the commentaries in our news magazines constantly bring to mind the fact that we are burdened almost beyond our ability to stand it, with the cost of the morally handicapped. These people are never called the morally handicapped, but these people who are defended by the American Civil Liberties Union are the ones who perpetrate our crimes and kill our citizens. These are the people for whom we are asked to provide every conceivable rehabilitation program, to see that they have easy sentences when convicted. We are informed about the advantages of plea bargaining, and for some of them there is not even an ultimate penalty because capital punishment has been abolished. Why, then, do we demand perfection for those who have physical handicaps and those who have mental handicaps, when we do not even ask for normal behavior from those who are morally handicapped?

If you do not think the morally handicapped are in full force, read the account in *Newsweek* recently, concerning the cheating by colleges, universities, coaches and players in reference to college athletics.

I would like to ask: for whom is the handicapped child sacrificed? From all the altruistic talk, one might suspect it is for the child himself. Closer inspection reveals that is truly not the case. Then one falls back on the fact that the social planners are concerned about what the parents have to cope with in days ahead. But that is really not the

reason for disposing of the blighted child. As I have watched this over the years, I am convinced that the person who says, "Don't treat him," is saying, "If I were the father or mother of this child, I couldn't hack it and I would wish somebody would dispose of the child for me." But that is because that individual does not understand the innate love of parents for a child, even though handicapped, nor do they understand how providing the special care such a youngster needs builds a far greater love than exists between normal youngsters and their parents.

In closing, I trust you will forgive me if I step into a field that is not my own, namely, theology. One of the most commonly asked questions of someone who deals with the handicapped is: "Why did God do this?" I find myself frequently saying that no evil can come from the hand of God, yet I believe so totally and thoroughly in His sovereignty that I know the problem at hand is no accident.

I acknowledge that I take great comfort from a conversation between God and Moses at the burning bush. You will recall that God instructed Moses to go into Egypt and confront Pharaoh. Most of us, when God tells us to do something, have reasons why it cannot be done. Moses was no exception. He said, among other things, that he was not eloquent. In response to that, God said to him, "Who made man's mouth? Who made the deaf or the dumb or the seeing or the blind? Have not I?"

So I have come to take great comfort in this verse because it says to me that as hard a doctrine as it might be and as much as I personally might not like it, God acknowledges that He makes what we call the imperfect as well as the perfect. I also believe that He could have added to Moses, "Who made the child with imperforate anus, and esophageal atresia, and Mongolism? Have not I?" But Moses would not have understood Him. I think you and I can understand Him by implication.

The second thing I have to acknowledge is that what the world looks at as evil, God may not necessarily consider in the same realm. Take the mother I used as an example previously. I am sure that the world would consider anything that produced a child who required 37 operations to become functional was evil. Yet the family, in that particular instance, saw it as good, and I believe that was because of its theological insight. As I look at the effect of that child upon his family and upon the community, I think I see it with God's eyes. It was meant for good and it was good. Again, if you like a bible verse that goes along with it, there is that wonderful one in the eighth chapter of Romans: "For we know that all things work together for good to those who love God — to those who are called according to His purpose."

When our own son was killed and my wife and I wrote about it in a book entitled *Sometimes Mountains Move*, we referred to the tapestry

which God weaves around the lives of His children, and pointed out that some bone-crushing grief, some earth-shattering event like the death of one's child is but one stitch in that fabric. The one stitch means nothing of itself, but as you stand back and view the fabric, you can see how it fits into the entire tapestry.

I have read the manuscript of a book soon to be published by Bonnie Jean Wheeler called *Of Braces and Blessings*. In the last chapter, she also alludes to the fabric that is sewn by the Master Designer. Perhaps it is because of that or perhaps it is because the words say so much themselves that I would like to read the closing lines of a poem which this good woman wrote as she reflected upon the seven children under her care, some natural-born, some adopted, some white, some of other colors, but all seven handicapped:

Red and yellow, black and white,
They're at Wheeler's house tonight and woven us into a family.
Stitch after stitch
We've gone through testings,
Seen your love.
Been down to the pits and touched the stars.

Stitch after stitch
You've patiently and lovingly
Turned our sorrows into joys,
Our tragedy into triumph,
Our pain into victory,
Our braces into blessings.

Are you discouraged? I mean discouraged as you fight in reference to the inhumanities of abortion, infanticide, euthanasia and all the things that are anti-family. Don't be.

If you are fighting because of the unborn, the infant, the oldster, you might die brokenhearted.

But if you are fighting because of our sovereign God, remember He makes no mistakes. He knows the end from the beginning. Our times are in His hands. He is sovereign. Your fight can be joyful.