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The Family with a Handicapped Newborn Child

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The most unhappy children I have known have been completely normal. On the other hand, there is remarkable joy and happiness in the lives of most handicapped children; yet some have borne burdens which I would have found difficult to face.

It is with a sense of gratitude that I speak to you today on some of the circumstances, problems, and benefits that arise when a handicapped child is born into a family. Were it not for a body such as the American Family Institute, it would be easy to become discouraged by those critics and enemies of the family, to whom truth and reality are only relative. The family used to be universally viewed as the basic moral building block in our society, a place of nurture for what an earlier and more moral generation saw to be the best things in life. That was before hedonistic life styles and worship of the nonexistent god of secular humanism undermined the foundation of the family. That foundation had provided us with the standards, the morality, and the self-giving love which enabled us to reach out to others less fortunate.

The worst threats to the family are not poverty, inadequate education, and the lack of beneficent social planning. Indeed, those deprivations, when they exist, can sometimes mold, knit, and glue together the family structure that can survive and prosper in the face of adversity.

Take the trend of the past several decades, the encroachment on the traditional family structure by all the anti-family forces abroad in the land today; add to that the narcissistic preoccupation with health; and compound it all with the economic jargon of modern medicine—"cost effectiveness"—and you must agree that the ordinary family is at risk. Deliver a handicapped baby into that family, and risk becomes a potential disaster, for the family and especially for the youngster.

Let me set the stage. A family is expecting a baby for nine long months, and their mental image is that of the bright-eyed adorable baby on the label of Gerber's baby food jars. The expected labor arrives, the delivery is difficult, and the mother wakes not to cuddle the Gerber baby in those first precious moments of bonding but to be told her baby had a congenital defect and even now is en route with her husband to a distant city where complex surgery will be performed in an effort to save the child's life, after which a long process of habilitation must take place for the youngster to assume a normal role in society. The props are gone. Hope has become despair. Joyful expectancy has been replaced by a fear of the unknown, a devastating anxiety of how to cope. She does not know whether the medical estimate of form and function is realistic or grossly deficient; and overall there is the thought of impending doom, particularly associated with economics.

It is my belief that the baby—my patient—will do best in the heart of his family and that the shattered family can be rehabilitated. I know what can be accomplished in the habilitation of a child born less than perfect. I know what can be done with that child's family. I know that these children become loved and loving, that they are creative, and that their entrance into a family is frequently looked back upon in subsequent years as an extraordinarily positive experience. I am aware that those who never had the privilege of working with handicapped children after the correction of a congenital defect think that the life of the child could obviously be nothing but unhappy and miserable. Yet it has been my constant experience that disability and unhappiness do not go hand in hand. The most unhappy children I have known have been completely normal. On the other hand, there is remarkable joy and happiness in the lives of most handicapped children; yet some have borne burdens which I would have found difficult to face.

Believing that when the family and the handicapped child are given the proper support and guidance, they will all be better for the experience, I have made it my lifelong practice to provide this support and guidance. And I know it works.

A young man now in graduate school was born without arms below the elbow and missing one leg below the knee. He was the victim of the prescription of thalidamide to his pregnant mother at the time of limb budding. When his father stood at his bassinet in the hospital where he was born, he said only this: "This one needs our love more." With that love and muddling through, it had a happy ending, which is really now only the beginning of this young man's productive life. The love they needed, they had; the muddling through could have been better.

Here is how the young man feels today: "I am very glad to be

alive. I live a full, meaningful life. I have many friends and many things that I want to do in life. I think the secret of living with a handicap is realizing who you are—that you are a human being, somebody who is very special—looking at the things that you can do in spite of your handicap, and maybe even through your handicap."

One of the so-called treatment options for a youngster such as I have just described is to do nothing and let the baby expire from inattention. The relativistic ethic in medicine which permits this has been the target of my concern and my anger and has occupied a major part of my time for the past two years. I allude to it only in passing to say that killing the patient to get rid of the defect has never been a part of responsible, moral medical practice.

For almost thirty-five years now, I have devoted the major part of my professional life to the management of children born with a congenital defect. Because I was only the sixth person in the United States to limit his surgical practice to the care of children, I was in my early years a surgeon of the skin and its entire contents. Therefore, my experience with congenital defects is broader than just the field that ordinarily is now called general pediatric surgery. Although in more recent years I have become a specialist's specialist and my interests have been confined to those congenital anomalies incompatible with life but nevertheless amenable to surgical correction, early on I was concerned with the management of cleft lips and palates, orthopedic defects, spina bifida and its complications, congenital heart disease, and major urologic defects.

There was a day when medicine was not only a profession but was considered to be an art. There were even those who considered it to be a calling as the ministry. Those who practiced medicine were called to a compassionate ethic that led them to the service of their fellow man. They worked, in diagnosis and treatment, in the realm of trust between the patient and themselves. When they dealt with a child or an incompetent adult, they dealt in the realm of trust between the patient's family and themselves.

One of the distortions in society which will not benefit any family, and least of all the family we are discussing, is a change in the semantics, and hence in the philosophy, of the practice of medicine.

The semantic change which has crept into medicine is one in which the patient is called the consumer, as though he were eating cereal. The physician is called a provider, as though he were delivering gasoline. We refer to the health care delivery system, as though it were some monolithic structure from which the patient had the right to expect only success. Such terms as "delivery systems" and "consumers" imply contracts. Contracts, in turn, imply restrictions; and the restrictions that are implied are not just on the physician but end up as limitations on the type of health care actu-

ally delivered.

One of the complications of this change toward consumerism is the expectancy of perfection. There was a day when the patient (not the consumer) had confidence in his physician in such a way that he saw him practicing in the realm of trust, knew he was going to get the best that was possible for his physician to accomplish. Now after the "provider" has outlined for the "consumer" what his expectancy is from the ensuing relationship, if the result is either less than perfection or less than the provider's estimate of his approach to perfection, then the consumer feels it is his right to be compensated for the discrepancy. The only way he can be compensated is by a financial reward following a malpractice litigation. The fallacy here is that human bodies are not like carburetors; the same thing does not affect all patients in the same way. There is an inherent failure rate in all that the physician seeks to accomplish.

With that as background, I would like to suggest to you some of the things that happen in reference to the handicapped newborn and his family. Eventually one physician assumes the responsibility for primary care; he is the overseer, the guide, and the counselor. He will be representative of one of four kinds of physicians.

First, he might be a physician who will act in support of the child and the family as I have suggested. I think this role is not only fitting and proper, but rewarding to all concerned as well.

Secondly, there will be a physician who presents death as an option in management.

Thirdly, there will be the physician who suggests institutionalization for the child in question.

Finally, there will be the physician who is in one of the previous two categories but who becomes hostile to the family if his advice is not taken.

What of the parents? They have several courses of action open to them. If they are not in the hands of a team that will do all it can to bring them into contact with the pertinent agencies, they will have to forage for themselves. These parents seek to provide on their own the assistance society should offer and usually admit that they face society in an adversary position. Most apply their learning to their own child and adjust slowly and with difficulty to the life that lies ahead of them, as does their child. Occasionally, a set of parents will become so incensed at the lack of support from society that they will try to do for similarly afflicted children all they have learned to do for their own. Out of what is initially a private exploration there comes the desire to share with others. Of such stuff are local and national foundations formed for the betterment of specific diagnostic problems.

How does an outsider view the physician? Roslyn Benjamin

Darling has done this in a book appropriately entitled *Families Against Society*. In reference to pediatricians caring for spina bifida patients who are being raised in intact families, she had this to say: "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 and 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."

I have tried to paint in broad strokes the family in crisis, particularly with a handicapped child. I would like to say a few words about solutions and nonsolutions as well as the side effects of society's proper care of the situation.

The first nonsolution I have already referred to. It is getting rid of the baby. The medical profession has traditionally made its treatment of patients a reflection of our society's concern for those who are ill or helpless. Often the profession has acted as advocate for those who had no one else to stand up for them. In the Hippocratic tradition and in line with the Judeo-Christian ethic, the medical profession formerly responded with love and compassion toward the helpless child; and I think that is the only accurate way it can function in the future.

The second nonsolution is all-inclusive catastrophic health insurance. Although I would like to study ways that catastrophic insurance might be effective, my great concern is that, with the passage of time, the definition of catastrophe becomes more and more benign. It is easy to see how catastrophic insurance could thereby get out of hand and be the thin edge of the wedge by which a national health service becomes a reality.

The third nonsolution is a national health service. I say that on the basis of long and intimate association with the national health service of the United Kingdom. I have seen it destroy the patient, not the defect, because of economics alone.

Recently when Professor Robert Zachary and I were conducting seminars in the United Kingdom, 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 she would die within three weeks. When a nurse told me 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. Her spina bifida has never been repaired.

But because I signed her out of the hospital against advice and because she was initially classified as nontreatable, there is no way I can obtain any urologic or orthopedic help for my child under the National Health Service. 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 her only recourse was to seek private care in England; and I told her 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.

For real solutions, as opposed to those nonsolutions, I would like to suggest a computer that can give courage and care; second, that experience can cut costs; third, that free enterprise can surpass the government; and finally, that ingenuity can take the handicapped out of an institution and restore them to their homes and families.

The year 1981 will see me come to the end of a thirty-five year tenure as the surgeon-in-chief of the oldest children's hospital in the Western Hemisphere. It is my hope that, after the necessary adjustment, I can make available to physicians and parents a comprehensive service to take the sting out of managing a handicapped child. What I envision is a national computerized service that could be questioned by physician or parent to provide, for any handicapping diagnosis, the most competent diagnostic service close to home, the closest competent therapeutic service, a list of all the available governmental and private agencies that could be of help to the parents and their children, and finally a readout of nearby parents with similar situations who have coped with the problem in the past.

If we could make this service available to parents and physicians alike, I think we would remove the terrible fear which now exists that the odds are too great against the handicapped child and his family to make an effort worthwhile. We would slay forever the myth that only perfect quality of life is life worth living. That is what I mean by a computer that can deliver care and courage.

The first time that anything is done in medicine will almost always be the most expensive time. As experience grows, as techniques improve, hospital care is shortened, rehabilitation is quicker, and the economic impact is far less. There is a major bony defect of the chest wall in children that requires correction if one is not to be a cardiac cripple in adult life. During the operation in days gone by, I used to transfuse these patients; post-operatively they were in oxygen tents; their hospitalization consumed three weeks; and their return to normal activity was delayed for three months. Now when in

I never use a blood transfusion, post-operative oxygen is almost unheard of, hospitalization varies from three to seven days, and full activity is resumed two weeks after discharge. That is an example of how experience cuts cost in medicine.

In the extraordinary care which is absolutely essential to the surgical management of any congenital defect incompatible with life but amenable to surgical correction, there will be certain patients who become respirator dependent. As such, they live in hospitals, they are extraordinarily expensive, and they are deprived of the nurture of the family because they cannot live at home. It does not have to be this way. Taking our cue from a remarkable French experience in a northern suburb of Paris, we now have sent a number of respirator dependent patients home. We have had to revise the technology of their care; but in addition to the tremendous human benefits to the family and the patient, the cost has been cut from \$600 a day for care in a respiratory unit in the hospital to \$40 a day at home. As the numbers increase, I am confident that this cost can be reduced to \$50 a week. Incidentally, the process of weaning the youngster off the respirator is better accomplished in the loving environment at home than it is in the caring but nevertheless non-family atmosphere of the hospital.

Moreover, the care of those youngsters at home does not even have to be done at the cost of the government. Given enough patients at home on respirators, the French experience has shown that competitive free enterprise can deliver a superior service to patients and families than that provided by the government and can do it more cheaply.

This is only one instance where ingenuity can restore a child to his home and family at a savings through free enterprise over the cost of governmental medicine.

There are beneficial side effects to all of us that come from our attention to the care of the handicapped newborn. First of all, as the patient is benefited, so is his family. Secondly, the necessity for the special care required raises up a new type of paraprofessional, which makes the care of the next patient easier and cheaper, but which also has a spinoff to the care of patients with similar or related problems. Finally, every so often there comes a time when the experience and sometimes the sacrifice of one child will provide untold benefits to other patients.

A number of years ago, a newborn child was operated upon in the Children's Hospital of Philadelphia and almost her entire bowel was found to be gangrenous; the unaffected bowel was not long enough to support life. In an institution aggressively seeking innovative procedures and trying desperately to push back the frontiers of pediatric surgery, one of my colleagues resected the gangrenous

bowel and kept the child alive on total parenteral nutrition. She never ate by mouth; all her nutrition was supplied by vein. The hope was that a small bowel transplant would eventually be possible to restore this child to satisfactory existence. Before that technique could be achieved, the patient succumbed; but until then she had been on total intravenous feedings, gaining weight and developing according to acceptable standards over a period of 400 days. The cost was enormous. The patient died, but because she was the first to ever be maintained on total parenteral nutrition, medical science learned a great proportion of what it now knows about hyperalimentation or total parenteral nutrition from this one little girl. It is without doubt one of the greatest medical advances of the past several decades.

I stress what we learned from that experience was intended for her own good and not for the good of society. But it did provide society with a now recognized nutritional technique which has saved the lives of thousands upon thousands of children and hundreds of thousands of adults around the world. In addition to that, hospital stays have been shortened, wounds have healed more quickly, rehabilitation has been possible sooner, and hitherto almost unmanageable situations like small intestinal fistulae have come under surgical control. Hospitalization for this nutritional support alone averages about \$300 a day and now can be done at home for about one-tenth of that cost.

I have spent my life professionally in the care of what the world calls handicapped children. All of these had a physical defect to start with, some were habilitated to be indistinguishable from normal. Others were not pristine in form or function. Some had a mental handicap as well. They live and do well in families. They merely exist in institutions. I have seen many childless couples become a family when they took a handicapped child by adoption. Other traditional natural families have expanded by the same process. It all takes a tremendous investment in vision, time, effort, and money. There are tragedies and triumphs. But blessings frequently come with braces.

I would like to close with an anecdote.

Some time ago, in preparation for a speech I was going to give in Toronto, I interviewed the mother of one of my patients and told her I would like to quote her answers to two questions.

The first question I asked was: "What is the most awful thing that ever happened to you in your life?"

And she said: "Having our son born with all those defects that required 26 operations to correct."

Having performed 22 of those operations and having stayed with her during the other four, I said, "That was an easy answer, and I

expected it. But now tell me, what is the best thing that ever happened to you?"

And she said: "Having our son born with all those defects that required 26 operations to correct."