

The Disabled Child — The Family and the Physician*

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handicap

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After almost 36 years as the Surgeon-in-Chief of the Children's Hospital of Philadelphia, I have entered the public domain and am now the Deputy Assistant Secretary for Health and the Surgeon General of the Public Health Service in the United States. The departure from the operating theatre, the decision-making processes dealing with life and death, and the demands of teaching I miss to some extent, but not nearly as much as I had expected. I miss the actual operating almost not at all, but I do miss being able to diagnose the sore point of a family's anxiety and bring them to an accommodation with all their concerns that seems to work.

We will soon come to the end of the International Year of Disabled Persons and it is fitting, therefore, on this 25th Anniversary of the founding of this remarkable hospital dedicated to eliminating handicaps that we talk about the disabled and I would like to do so in the context of family and private initiative as well as the sometimes necessary public and institutional setting.

The Disabled

I was pleased that this International Year of Disabled Persons was not called the International Year of Handicapped Persons. Individuals are disabled. It is society or other extraneous forces that handicap them. If I am propelling myself along the street in a wheelchair, I only become handicapped when I have to go up or down steps where there is no sloping ramp, or when my arthritis makes it impossible to safely manipulate my vehicle.

I am assuming that you have espoused Christian values regarding the sanctity of human life and the integrity of the family; that the family was instituted by God as the basic module around which society and, therefore, civilisation is built and that each individual — perfect or imperfect — is

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a person with unique preciousness because he was created in the image of God.

When the family is threatened by poverty, by inadequate education and the lack of a beneficent social planning government, these deprivations frequently mould, knit and glue together the family structure so that it can survive and prosper in the face of adversity. So it is with the introduction of a disabled child into a family, provided that we build in the proper supports.

The past several decades have seen encroachment on the traditional family structure by the many anti-family forces abroad in the Western World today. Add to that the preoccupation with perfect health, and compound it all with the new economics of modern medicine — cost effectiveness — and you must agree that the ordinary family is at risk. Deliver a disabled baby into that family and risk becomes a reality in potential disaster — disaster for the family in part but 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 a baby food jar. The expected labour arrives, the delivery is difficult, and the mother wakes not to cuddle the cherubic baby of her dreams 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 medical centre 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 indeed.

No one enters the medical profession skilful in managing the problems that are generated in the hospital, in the family, and in the community by the arrival of a disabled child. The physician's role is difficult and the skills he requires are hard to learn. The physician who understands his role in the treatment of disease and the postponement of death, frequently does not understand his role in making the disability of a child free of handicaps as the child is rehabilitated into society. More than that, it may be that the physician himself is affected by the catastrophic nature of the disability and finds it difficult if not impossible to cope with the multitudinous problems that surround the diagnosis.

The problems in management are related to the patient himself, the patient's parents, the broader aspect of the patient's family, particularly his siblings, the hospital personnel, and the community. Each of these requires a different approach, a different understanding, and a different management goal but, if that were not difficult enough, it must also be recognised that these management goals vary at different times in the course of the child's disease.

The Physician's Role

While it is true that no one enjoys the management of the emotional problems surrounding the disabled child, there is, nevertheless, a satisfaction to the one who serves as guide through difficult times to the end that the family is salvaged, the community is able to get on without bitterness toward the hospital or the medical profession, and the hospital staff is able to return to the routines of care, knowing that they have played a positive role in an unpleasant situation. For this reason, the physician assigned the primary role must be chosen carefully. The process of relating to the family and to the paediatric patient must begin at the very first encounter between physician and family. He must project his integrity and his capacity for compassion and understanding, in such a way that the family will be assured during the time of diagnostic confirmatory studies that, when they are completed, the surgeon will not only be honest in his dealings with the family, but will to the best of his ability help them to understand the situation and bear the burden.

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

The manner in which the family is told the diagnosis and prognosis 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 paediatrician, 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 paediatric surgeon into whose hands the problem has been delivered for at least immediate atten-

tion, I feel certain concerns and I feel them deeply. I recognise the family's tendency to believe that they are responsible for the defect, perhaps guilty about it, and certainly angry and frustrated into 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 telephone the mother in her lying-in hospital or at home 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 home and 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 endeavour practise 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 being 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.

I read constantly about the problems that parents face in these situations: how 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 lifelong experience that the support that 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.

Treatment of the Severely Disabled Infant

One of the proofs of this is that no parent has ever come to me to say

"Why did you try so hard to save my child's life?" nor has any grown patient (and some are over 35) ever put that question to me.

Now I realise 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 their child operated upon and then, foolishly, that neonatologist asked for a surgical consultation by one of my surgical colleagues. This immediately provided a contrary suggested form of management and, after an unbelievable number of legal, social and personal manoeuvres which I will not go into, the child was operated upon (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 marvellous 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.

Last year in Birmingham after presentation of our films "Whatever Happened to the Human Race?", 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 a 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 orthopaedic 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 orthopaedic 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.

A young man of my acquaintance, 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 realising 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."

This family in crisis is a threat to itself as well as to other families; indeed, to all of society as well. It is a crisis situation which must be faced; it has a solution; indeed, it has long-term benefits even for you and me.

One of the so-called options in treating 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 for the past two years. I allude to it only in passing to say that there has to be a better way than killing the patient to get rid of the defect.

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 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 contents. Therefore, my experience with congenital defects is broader than just the field that ordinarily is now called general

paediatric surgery. Although in my 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, orthopaedic 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 such as the ministry. A man who practised medicine was called to a compassionate ethic that led him to the service of his fellow man. He worked in diagnosis and treatment in the realm of trust between the patient and himself. When he dealt with a child or an incompetent adult, he dealt in the realm of trust between the patient's family and himself.

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 semantics and, hence, philosophy in the practise of medicine.

Consumerism in Medicine

The semantic change which has crept into medicine is one in which the patient is called the consumer. The patient is called the consumer as though he were eating cereal. The physician is called a provider as though he were delivering petrol. We refer to the health care delivery system as though it were some monolithic structure from which the consumer had the right to expect only success. Delivery systems and consumers imply contracts. Contracts imply restrictions and the restrictions that are implied are not just on the physician but they end up by being restrictions on the type of health care actually delivered — the very thing that the system is seeking to avoid by the semantic change.

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 practising 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.

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 counsellor. 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 it 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 will be one of the previous two but who becomes hostile to the family if his advice is not taken.

The Family in Crisis

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 the pertinent agencies into contact with the family for their ultimate benefit, they will have to forage for themselves. These parents seek on their own what society has to 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 failure 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 early on a selfish 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 paediatricians caring for spina bifida patients 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 a societal basis."

I have tried to paint, in broad

strokes, the family in crisis, particularly with a disabled child. I would like to say a few words about solutions and non-solutions as well as the side-effects of society's proper care of the situation.

One non-solution I have already referred to 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 acceptable way it can function in the future.

I would like to tell you about a computer that can give courage and care, to remind you that experience cuts costs, and that ingenuity can take the handicapped out of an institution and restore him to his family and home.

National Advisory Service

In the years ahead of me in Government, it is my hope that I can make available to physicians and parents a comprehensive service to take the sting out of managing a handicapped child. What I envisage 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 other children and, finally, a read-out 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 that exists 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. That is a computer that can deliver care and courage.

As experience grows, as techniques improve, hospital care is shortened, rehabilitation is quicker, and the economic impact is far less. I have repaired a great many thoracic wall defects. 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 certain seasons of the year I do one of these every operating day, 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 experience that cuts cost.

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 \$1,000 a day for care in a respiratory unit in the hospital to \$120 a day at home. As the numbers increase, I am confident that this cost can be reduced to \$100 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.

And, the care of those youngsters at home does not 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 the only one instance where ingenuity can restore a child to his home and family and at a savings.

Beneficial Side-effects of Therapy

There are beneficial side-effects to all of us that come from our attention on the care of the disabled 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 that makes the care of the next patient easier and cheaper but also has a spin-off to the care of patients with similar or related if not identical 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 paediatric 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.

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 called 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.

I would like to close with an anecdote.

Some time ago, in preparation of a

talk 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 life?"

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

Having performed 22 of those operations and having stayed with her during the others, 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 37 operations to correct."

Bonnie Jean Wheeler wrote a book last year and sent me the manuscript to review. I suspect the book has been published by now. It is quite a remarkable book and ends with a prayer that this good lady wrote as she reflected upon the seven children under her care, some natural born, some adopted, some white, some of other colours, 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."*

*Wheeler, Bonnie: *Of Braces and Blessings*.