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Treatment for Every Child and Family

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Your Excellencies Cardinal Lopez Trujillo and Cardinal Lozano Baragon, members of the clergy, distinguished ladies and gentlemen, I am deeply grateful to the Pontifical Council for the Family and the Pontifical Council for Pastoral Care to Health Care Workers for this opportunity to speak to you today. It is a distinct honor to be here with you. What a joy to spend these days in this marvelous setting, with such sensible people, discussing a subject so dear to all of our hearts.

My objective today, in the short time that I have, is to explain to you the principles upon which the Programa Leopoldo in Venezuela is based and to try to give you a glimpse of children using the glasses through which I see them.

I want to begin by telling you, in one sentence, my essential belief about the children that we are discussing during this conference. It is that ***all*** children have innate value and dignity, regardless of their level of function, and that all deserve the opportunity to achieve their highest potential. This simple principle forms the foundation of everything that I believe about children and it influences everything that I do with them.

While we might agree that every child has the right to be born intact and to enjoy good health and development, it is not, unfortunately, every child's good fortune. As we sit here today, somewhere in the world, probably even somewhere here in Rome, a child is being born with some degree of neurological problem. Perhaps somewhere else in Rome, another child is losing function as a result of an illness or accident that has damaged his good, well developed brain. At this very moment, a profound drama is beginning its first act, a drama that will plunge the child's family into the depths of despair and that will in some way affect every person who has contact with this child throughout his life. Often, he will be an enigma to his parents, brothers and sisters, extended family, friends, teachers and even doctors. It is precisely because this child was so poorly understood for so long that we tend to view his situation as one with no hope for improvement. Indeed, professionals are especially careful not to enkindle any hopes whatsoever in the fear that those hopes might prove to be false ones. The effect of telling parents that nothing can be done is devastating. One of the things that is most important to mothers and fathers, and that indeed is part of the very nature of a parent, is the sense that they have some measure of control over their child's well being. This is true whether we are talking about a child faced with an illness, a difficulty in school, or a problem in behavior. Parents naturally want to be involved in the solution to the problem. However, when confronted with a brain-injured child, the parent's natural desire to be of help is frequently suppressed. Consequently, a desperate situation becomes worse as the parents, perhaps for the first time in their lives, feel completely powerless and therefore can only see themselves as inadequate. For parents there is nothing in the world that is more painful or more frustrating.

What I bring to you today is the good news that this need not be so. It may come as a surprise to many of you, but far from being hopeless, the brain-injured child, even the child with severe problems, is a child with enormous potential. Certainly it is a potential as yet unrealized and a potential that will only be realized with special effort. But it is a potential that is there just the same. There are, I think, only two questions that we need to consider. First, how do we know that this potential exists, and then how do we bring it to realization?

The answer to the first question has to do with what neuroscientists call brain plasticity. Brain plasticity is the ability of the brain to modify its structure and chemistry in response to stimulation from the environment, the use of motor ability and presence of adequate nutrition. It has, in fact, been very much in the news lately. In recent years, the popular press in the United States and other countries has featured brain development research with cover stories and special features in virtually every major publication. Just recently, on April 17th of this year, United States President Bill Clinton hosted an historic conference at the White House on "Childhood Development and Learning". The big news was the announcement that neuroscientists now have solid scientific proof that the human brain goes through measurable structural and biochemical changes particularly in the first years of life, a discovery that contradicts nearly everything that scientists have always believed about the brain.

And yet, the idea that this is new news is actually quite mistaken. Brain plasticity has been an area of scientific interest for many decades. Boris Klosovskii, a Russian neuro-physiologist, started his work in this field in 1934. Neuro-physiologists have known since the 1950's that increased environmental stimulation will create structural changes in the brains of animals.

For at least three decades, brain plasticity in human beings has also been suspected by many neuro-physiologists and by a small number of people who pioneered new approaches to the developmental problems of brain-injured children. Glenn Doman, one of the great pioneers in work with brain-injured children, said in his 1963 book, How to Teach Your Baby to Read,

"It had always been assumed that neurological growth and its product, ability, were a static and irrevocable fact: This child was capable and that child was not. This child was bright and that child was not. Nothing could be further from the truth. The fact is that neurological growth, which we

had always considered a static and irrevocable fact,
is a dynamic and ever changing process".

Neuro-physiologist David Krech, who performed many classic experiments with rats, said in a 1966 paper titled "In Search of the Engram",

"Although it would be scientifically unjustified to conclude at this stage that our results do apply to people, it would, I think, be socially criminal to assume that they do **not** apply - and, so assuming, fail to take account of the implications".

The difficulty has been that plasticity in human brains is very difficult to prove scientifically without actually doing a physical examination of the brain. There was a veritable mountain of empirical evidence in favor of plasticity in humans but it was all circumstantial evidence and therefore unconvincing to most scientists. The breakthrough came with the invention and later refinement of CAT and PET scanning technology which allows one to see the brain in great structural detail and to see it in

action as it is performing its functions. This technology has proven beyond any doubt that, as Doman and Krech suspected so long ago, neurological growth is a dynamic and constantly changing process. The importance of this biological reality for the brain-injured child is incalculable because it means that functional ability can be created. It means that vision can be developed in children who are neurologically blind. It means that the child who is neurologically deaf can learn to hear. It means that the immobile child can be taught to move and eventually to walk. It means that the retarded child can be brought to intelligence. We have, in fact, done all of these things many times. Obviously, we can never guarantee that we will succeed in accomplishing these extraordinary changes. Nevertheless, we at least know that the potential to do so exists. And that means that there is **always** hope, even in children with profound brain injuries. To deny this hope is to deny biological reality.

Now we come to my second question. How do we realize this extraordinary potential that exists in every child? How do we fulfill this hope for improvement? Part of my mission in life is to bring to light the myths that exist about the human brain. Scientists, as I am sure you know, are absolutely and completely in love with complexity and they are virtually always suspicious of simplicity. There is a tendency to think that if an explanation for a phenomenon is simple then it must somehow be incorrect. This is unfortunate because truth is always simple. More than anything else this is why it took over thirty years for scientists to recognize the truth in what Doman and Krech said. And it is also why the development and care of brain-injured children has been the sole province of professional therapists and educators rather than parents. Now it is certainly true that the human brain is, without question, the most complicated thing in the known universe. But what you may not realize is that its development is actually governed by very basic laws of nature. So, the brain is a great paradox, at once complex and simple. And surprisingly, the answer to this question about the realization of potential is also quite simple.

It lies, first of all, in the understanding that optimum brain function is a prerequisite to successful function in life. All functional ability is the direct result of the natural and orderly development of the brain. Any significant interference in neurological development, regardless of the reason, will result in either a significant lack of function or abnormal function. The achievement of one's potential is therefore directly dependent on the function and development of one's brain. This can be seen quite clearly in the development of human mobility. A child is not born with the ability to walk. From a neurological perspective he functions at a reflex level and any movement that he does have is completely reflex and involuntary. But, if exposed to adequate stimulation and opportunity to experiment with his arms and legs, he learns that certain combinations of movements have certain effects. Eventually, as long as we place him on his stomach and do not limit him, he will learn how to crawl on his tummy. He will then learn how to creep on hands and knees, and finally learn how to walk. It is a magnificently conceived process in which each level of ability provides the child with the tools that he will need to go on to the next highest level. The beautiful part about the system is that when children are moving about freely they are using all areas of neurological ability at the same time. This means that when a child is crawling across the room on his stomach, it is not just muscles that he is building. Indeed, that is the least important thing that he is doing. Instead, the really important thing that is happening is that he is literally building and organizing his brain. The same process happens in all other areas of function. However, if for some reason the child fails to go through this process, the development of functional ability will be affected.

Secondly, it lies in the fact that brain development is governed by several very basic principles, and that, not only can it be slowed down or stopped, as happens with

injury, but it can also be accelerated. The first principle is that the brain grows through use. This is because of a simple law of nature that says that function determines structure. We see this easily in the muscles of the human body. If I lift weights frequently my muscles will develop, becoming bigger and more effective. It is not that I grow more muscle fibers, but rather that I develop the muscle fibers that I have. They simply grow in size as a result of use. The reverse of the law, of course, is also true. If I fail to use my muscles, as happens with a broken bone placed in a cast, the muscles atrophy. So function determines structure and lack of function or abnormal function results in lack of structure or abnormal structure. The magnificent thing about the human body is that this law applies not only to muscles and bones, but also to the brain. Brain plasticity exists because function determines structure. The brain has five sensory functions - vision, hearing, tactile ability, taste and smell - and three motor functions - mobility, language and manual ability. When these functions are in use the brain grows. This means that when I talk to a tiny baby, when I tickle him or hug him, I am literally growing his brain. Sensory stimulation and use of motor function change the physical and biochemical nature of the brain. And just as with the muscles, if there is a lack of function or abnormal function there will be a lack of structure or abnormal structure. It is inescapable because it is a law of nature. The second principle that governs brain development says that the most efficient way to get information into the brain is to increase the frequency, the intensity, and the duration with which the stimulus is applied. This is essential. When the function of the brain is compromised by injury, by poor nutrition, by a poor environment, or by poor developmental opportunities, there is a barrier of sorts that forms between the brain and the environment. For this reason the normal amounts of stimulation, which are quite adequate to develop a well functioning brain, are entirely inadequate for developing the affected brain. If this were not so then the problems of these children would be solved very easily. The only way to penetrate the barrier caused by brain-injury is to increase the frequency, the intensity, and the duration of the stimuli.

The third point is that optimum brain function is best achieved by placing importance on three fundamental areas: enhanced sensory/motor function, structural integrity, and optimum physiology. These three areas are interdependent and therefore influence each other as well as brain function in general. This is what we mean by holistic brain development. We recognize that every element of a child's constitution is unique to that child and that all elements are related to one another. We recognize also that our chances of success increase significantly when we take into consideration all factors that play a role in successful brain development and function. And we realize that our job is to follow the natural path that has been so beautifully designed for every child.

The fourth and final point is that we recognize that the child's best chances for improvement lie within the family. First of all, it is the family's responsibility to develop, educate, and care for all of its members. Professionals of all sorts have convinced us to abrogate our responsibilities. We abuse our bodies and blame the doctor when we get sick. We send children off to daycare at 6 months of age and blame the school when they don't know how to behave. We are, to put it plainly, irresponsible when we talk about our health, the education of our children and so on. And what has happened is that parents have become convinced that they are inadequate for the job of raising their own children, particularly when the children have developmental problems. This is a grave mistake because there is no greater or more dynamic learning team than that of the family. Mothers, when able to trust their instincts, know exactly what their children need and when they need it. This means that mothers and fathers are the best teachers and therapists that any child will ever have. There is a very simple reason for this. Parents love their children more than

anyone else in the world. I can honestly tell you that in the years that I have done this work I have loved, in my own way, virtually every child I have seen. But the quality of a parent's love is different from my love. I know that it is not very scientific to talk about love. You can't measure it with a ruler; you can't put it on a scale and weigh it. Nevertheless, I have watched it work miracles for many years and I long ago gave up trying to explain it. I only know that it is there and that I am a fool not to take advantage of it. We professionals need to stop looking at parents as the problem and we need to start to see them as the solution. We need to stop trying to intimidate parents and we need to start treating them as equals in the fight for their children's lives. Certainly, parents need our guidance but they are the key to victory. In short, we need to start treating parents with the respect that they deserve. From the poorest to the richest, from the most ignorant to the most educated, they deserve no less. We should do so because the children's lives depend on it.

Another reason that the family is the ideal place for our work is that when it is done in the family, we can work on a much more intense level and we can do so very economically. Our project in Venezuela is done with the poor and services are provided to them nearly free of charge. This is only possible because we are empowering parents to carry out their roles as their child's most important teachers.

So what, you might ask, is Programa Leopoldo supposed to mean. Let me tell you what I think it means. I will give you three related but different meanings, one for the brain injured child, another for the child's family, and still another for the larger society.

For the brain-injured child the meaning is obvious enough. It can mean the difference between sickness and health, between blindness and sight, between retardation and intelligence, between paralysis and mobility. Sometimes, it can literally mean the difference between life and death.

For the family, I think the meaning is also fairly obvious. It means a ray of hope in the dark night of despair. It means active participation rather than passive acceptance. It means an opportunity to become part of something larger than ourselves, what Viktor Frankl, the great Austrian psychiatrist, calls the "transcendent experience", as we give ourselves to the task of making a difference in a child's life.

But what does Programa Leopoldo have to say to society at large? What lesson is it trying to teach us? I suggest to you that the most important thing that this program has to offer the world is that it **celebrates** the idea that every human being has inherent value and dignity. This value and dignity is not based on level of education, net worth or even level of function, but simply by virtue of the fact that one is a human being. Sadly, the world today is immersed in a quality of life ethic that devalues the dignity of anyone less than perfect. For me, Programa Leopoldo is the antidote to this ethic. I don't know exactly how to describe it to you but there is something transforming that takes place when one works nose to nose with a child who has difficulties. Somehow it makes one a bit more human and a bit more humane. Such experiences are food for the soul. I truly believe that these children are our most precious natural resource. This is not because of what they can do because obviously many of them can do nothing in a functional sense. But rather it is because of what they do ***to us***. So Programa Leopoldo is ultimately about human dignity and the intrinsic value of human life.

As I finish I must say thanks to one person and that is Leopoldo. I had the good fortune of knowing Leopoldo from the time that he was a little baby. He was a

profoundly injured little boy with incredible courage. Leopoldo knew how to fight the good fight and he struggled for every inch of progress that he ever made. He did so with quiet dignity, without complaint. He had a transforming effect on virtually everyone with whom he had contact. He touched the lives of young and old, rich and poor, people who are famous and those who are unknown. He even touched the lives of Pope John Paul II and Mother Theresa, who with her extraordinary wisdom called him "The Professor of Love". I am sure that today he is as happy as I am that our lovely Venezuelan secret has been revealed to the world. Thank you Leopoldo for giving all of us who work in this beautiful program the opportunity to fulfill the prayer of St. Francis by truly becoming instruments of Christ's peace.