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Keynote Address

"A Separation Lesson From the Slums of Caracas:
Healing Through Parental Responsibility"

by
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It is such a joy to be here with you today. More so because I get to tell you about Programa Leopoldo, my project with poor brain-injured children and their families in the country of Venezuela, and the part of my professional life that has been most meaningful to me. I am, by profession, a specialist in functional brain development. For the past 22 years, I have worked with children and their parents throughout the world and from all levels of society. During my career I have always been guided by some very basic principles - first and foremost, that every human being has innate value and dignity regardless of functional ability, education, or social status; second, that every person is a unique individual, with the promise of potential and each deserves the opportunity to fulfill this promise; third, that the family is ultimately responsible for, and is uniquely positioned to have the greatest effect on human development, which includes but is not limited to, education; and fourth, that love is the most powerful force in the universe despite the fact that we can not measure it. Obviously, in a materialistic world that devalues anyone less than perfect, that equates brain-injury with hopelessness and the sole domain of professionals, and where parents are seen as a big part of the problem, I am considered, you might say, a bit of a rebel. I admit it. I disagree with most of the myths that the medical, educational, and psychological establishments believe about my kids and their parents. Therefore, when the opportunity to work with the poor was presented to me I figured, what the heck, may as well add the sociologists to my list too. It was a challenge I just couldn't resist.

First, let me give you a bit of background about Venezuela. It is a country with an estimated population of 23 million people. According to a recent study, 17 million Venezuelans or 77% of the total population live in moderate or extreme poverty. Just to give an idea of the kind of poverty we are talking about, this study defines moderate poverty as earning under \$350/month, and extreme poverty as earning under \$174/month. While the cost of living in most of the country is relatively low, most of the population actually lives in major cities such as Caracas where a modest 1 bedroom apartment can rent for as much as \$800. The obvious result is that a large part of the population lives in terrible conditions.

It is estimated that roughly 15% of the population, about 3.5 million, are disabled in some way. This figure of course only includes people with serious

disabilities - those who are severely or profoundly brain injured for example. It does not include those with mild or moderate problems of which there are millions more. It has been my experience that in Venezuela, especially amongst the poor, virtually everybody has direct experience with brain-injury, if not in their own children then in those of family or friends. There are many reasons for this - malnutrition, little or no prenatal care, squalid living conditions, and communicable disease - all of the typical problems that result from abject poverty. To make matters worse, services for the disabled poor are in many parts of the country non-existent. In those areas where services do exist, the problems involved in reaching those services are such as to make them nearly useless. The result for most poor Venezuelans is that they are left to fend for themselves. Severely injured children become a heavy financial and emotional burden on their families while those with milder problems become easy victims of abuse and often slip into delinquency.

Exactly nine years ago, in November 1988, I began a small pilot project that eventually would become Programa Leopoldo. The birth happened very quietly with me, three brain-injured children, their families, my dear friends and supporters Alberto and Christine Vollmer, and the simple objective of trying to prove that, with proper guidance, poor families were capable of helping their children to develop, even those children with significant developmental problems. When we started, we had no idea where the project would go or how it would get to where it didn't know it was going. We only knew that there was a terrible need that nobody was addressing. Moreover, if we didn't do it probably nobody would. For the first four years of the project, I volunteered all of my time, usually 6 to 8 weeks per year, and the Vollmer's provided the financing for my travel and living expenses. The first year was very rocky but slowly, as a few of my families started to have success with their children, the word began to spread. You can't imagine how fast good news travels through the slums! In no time, my population of children reached 28 and by 1992 I had a waiting list of over 400 children. One television interview alone resulted in over 1500 telephone calls from all over the country. In 1992, in order to meet the tremendous demand, I created a training program for professionals and Programa Leopoldo was on its way. As of last Saturday, four basic courses and three advanced courses have been taught to 107 therapists, doctors, psychologists, and teachers. Working in special "Programa Leopoldo" units

located in hospitals, child development centers, schools, and community health centers, these professionals carry on the work of the pilot project. Because of their love and dedication, children in the poorest areas of Venezuela now have hope for the future. Today the project reaches over 5,000 children, at little or no charge, in fourteen centers throughout Venezuela.

So, what can the Separation movement learn from Programa Leopoldo? I think there are several important lessons. First, is that Programa Leopoldo blows virtually every myth propagated about the poor right out of the water? We've all heard them many times. The poor are lazy. They are irresponsible. They don't care about their children. They are incapable. They have the wrong priorities. They are stupid. Over 5000 poor families have shown clearly that they are none of the above. Let me tell you a few stories to illustrate my point.

On Tuesday morning of this week a mother came to see me with her 9-year-old daughter, who has Down's Syndrome. She was to have come on Monday with her therapist but was unable to do so. The therapist and I discussed the case and then later that day the mother called the office, something that probably required a 2 mile walk to a phone, to request that I see her the next day. As she was insistent, I agreed to do so. She traveled for hours so that she could come and tell me personally how much the program had changed not only her daughter's life but also that of mother and dad. Their little girl is making progress that they never dreamed possible and they are responsible for it. Mother was just bubbling over with joy about the difference it has made in all of their lives. Then she announced that if we need any help at all to please contact her and she will be happy to come. Ah, those irresponsible, lazy poor!

Another story comes from the small city of San Fernando located deep in the jungle in Apure, the poorest state in Venezuela. This family traveled 24 hours by bus to come to see me with their therapist. The therapist explained to me that, because the family lives in such a remote area, mother must travel three hours each way by dugout canoe in order to get to San Fernando for her monthly appointments. She keeps her appointments religiously. The therapist also explained that because the family lives in a shack with a dirt floor, Mother found it difficult to do certain parts of the program that required that the child

be on the floor. Concerned about this she contacted a friend from another village whose house has a concrete floor to ask if she might come by a few times per week so that her little boy could get more of his program. Of course, her friend said yes. There is great solidarity in the slums. So several times per week Mom loaded the boy up on a donkey and rode for 30 minutes through the hills to get to her friend's house. However, the best was yet to come. Mother then announced to me that throughout these past six months the family had been saving whatever money they could and that when they return to San Fernando they will use that money to buy the supplies to lay a concrete floor. Then her boy will get the entire program that he needs and his results will be even better. So much for mixed up priorities and not caring about their children!

Programa Leopoldo also demonstrates very clearly that success with children is not a function of material resources or level of education. I was confronted with this erroneous assumption every time I was interviewed about the project during the early years. Journalists really thought I was crazy. "Surely, Sr. Solís, you can not believe that these people from the "ranchos" who have no education or resources are capable of changing their children". "Si, señor, that is exactly what I believe, indeed it is not a belief, it is a certainty". "But, Sr. Solís, how is it possible that poor, uneducated parents can succeed where highly trained professionals have failed". I developed a stock answer. "It is possible because the parents have the one thing that no amount of money can buy and no degree of education can provide, and that is love, the kind of love of which only a parent is capable. And that, my friend, the poor have in spades".

It is worth noting that prior to beginning my work with the poor, I had spent 4 years doing consulting in Caracas for families who could afford to pay me, which is to say the upper middle class and the wealthy. After four years of constant high blood pressure and headaches, I couldn't take it any more. Any time that I am more concerned about a child's progress than his parents are, there is something wrong. I could stay home and get all of the headaches and high blood pressure I wanted! Obviously, my way of doing things is inconvenient. It demands parental responsibility, dedication, and places the child and his needs as a very high priority. Often this means sacrifice, a change in lifestyle, a change in priorities, a willingness to put someone else's needs ahead of my own. In my experience, this is something that the rich are rarely willing to

do. The social life, the tennis game, the career, are just too important. How strange that nearly every myth that we believe about the poor is in fact one that often applies to the wealthy.

Finally, I think that Programa Leopoldo is a wonderful example of what is possible when people are free to act creatively without the constraints of government bureaucracy and establishment doctrine. With Programa Leopoldo, I have challenged virtually every belief about the brain, brain-injury, children, parents, and the poor. I have done so as an outsider and on my own terms. The result is nothing short of revolutionary. Once vilified by most of the professional community, Programa Leopoldo is now the hottest ticket in town. Two weeks ago I spoke at a conference on cerebral palsy in Venezuela and Programa Leopoldo was what everybody was talking about. It seems that now everyone wants to be a part of the revolution.

And what does all of this ultimately mean for the families I serve? Allow me one final story. A year ago, I saw a family with a 6-month old girl. Profoundly injured at birth, she was blind, deaf, immobile, and very sick, with frequent seizures and under heavy medication. Mother was in a severe state of depression, crying uncontrollably during the entire consultation. I did my best to console the parents, designed a program for the girl, and urged them to get counseling to help them through their grief. In May, they came to see me again. With just one look in Mother's eyes, without even seeing the child, I knew that things were going very well. Mother and Dad looked 10 years younger. We discussed the changes - beginning to see, to hear, to move, reduced seizures, good health - all of which I hope you understand are absolute miracles which the parents created - and then we talked about the next step. As we were concluding the consultation, Dad was telling me how happy they were with the changes in their precious little girl. His last sentence, I think, says everything that needs to be said and says it much better than anything I've ever come up with does. He said, "The best thing about this whole program is that now we know there will be a tomorrow".

Now we know there will be a tomorrow! Hope for the future based on the concrete results of dedication, effort, and love applied in the present. That is why God created mothers and fathers - so that they can ensure that their

children have a tomorrow and he didn't make any exemptions for the poor. How dare anyone, professional or bureaucrat, take this greatest of all gifts away from them. For the gift of a child is also the gift of parenthood. It is a life-transforming gift, unleashing stores of love, devotion, and compassion of which people never dreamed they were capable. When these qualities are directed towards a brain-injured child, there is a ripple effect of change that goes well beyond the changes in the child. It goes to the parents, the brothers and sisters, the extended family, the local community and eventually to the larger society. I have seen it happen everywhere that Programa Leopoldo has gone. American author Christopher de Vinck calls it the "power of the powerless". Little, crippled, hurt, hurt Leopoldo, who passed away nine years ago and for whom this project is named, still wields the power.

I will make a little prediction for you today. I predict that rather than the poor being the Achilles heel of the Separation movement, they will, ultimately, turn out to be its greatest strength. You can quote me on that.