

World Congress of Families II
Geneva, Switzerland
14-17 November 1999

On the Dignity and Worth of Human Life
By Charles R. Solis, Jr.
©Charles R. Solis, Jr. 1999

Often, speeches about the dignity and worth of human life are given from the perspective of the philosopher or the theologian. I wish that I could speak to you in philosophical or theological terms but I am afraid that it is beyond the scope of my abilities to do so. Instead, I come to you today to speak, if you will, from the trenches of my everyday experience.

For the past 24 years, my wife Conceição and I have had the extraordinary privilege of participating in, and bearing witness to, the most beautiful love story in all of creation - that of the love between parents and child. The story that we have watched over and over again is particularly poignant because it involves families struggling to cope with the often devastating reality of a child who is less than that "normal" child that every parent dreams about throughout the nine months of pregnancy - the brain-injured child, the child with retardation, the child with Down's Syndrome - those children who Christ called "the least of my brothers". It is even more poignant still because it involves not only families who have the education to understand their child's problems and the financial resources to secure help, but also and more importantly, many hundreds of families who are uneducated and in many cases very poor. Thus making their children the "least of the least of my brothers", because if there is anything worse than being born brain-injured, it is to be born both brain-injured and poor.

What makes the story so extraordinary is that it illustrates, as perhaps nothing else can, the central role that love plays in the blossoming of a flower that would otherwise remain a closed bud and in the healing of wounds that would otherwise remain open festering sores. And of course, the story speaks directly to the dignity and worth of all human life.

The world in which we work and in which our families live is alien territory to most people. Until you have actually experienced what it is like to care for and raise a child with disabilities, whether they be physical, mental, social, or a combination thereof, and whether they be profound or mild, it is difficult, if not impossible, to understand what this world is like. It is a world that no parent expects and for which it is almost impossible to prepare.

In his splendid book *The Power of the Powerless*, a veritable love story about his profoundly brain-injured brother Oliver, author Christopher de Vinck includes an article written by his mother in which she tries to describe the experience of discovering for the first time the condition of her baby:

It's hard to express what such a verdict means to a mother. It pierced me to my depth, ripped apart the very fabric of life when we discovered how severely different Oliver was going to be all his life. It was not something one could put aside or escape. The world darkened: It was as if the whole of reality had been covered with a gray film. I didn't understand yet.

This is a world that is often filled with fear and devoid of hope, in which the days are

spent cleaning up vomit, reacting to convulsions, administering medication, relaxing rigid muscles, calming temper tantrums, repeatedly teaching the same simple skills; and the nights are spent quieting edgy nerves and praying for a few hours of sleep or, at the very least, a few hours of rest. It is a world into which few people venture willingly.

It may seem reasonable to someone who has never felt the "power of the powerless" to conclude that children who are brain-injured or retarded are nothing more than burdens on our society and that they should therefore be eliminated for the good of all concerned. Indeed, because of the undeniable suffering that is sometimes involved, many see this as the compassionate thing to do. And, if compassion doesn't enter into it, at the very least it is the logical thing to do. In a world of finite resources it simply doesn't make good economic sense to spend money on someone who can not give something back in return. As we near the end of the millennium, in an age when materialism and utilitarianism rule the day, this mentality takes on the form of prenatal screening, abortion, infanticide, and euthanasia, as ways of saving money, ending the suffering, and avoiding the life that is not worth living. The death toll, my friends, is frighteningly high.

The tragedy of this mentality is that each of these children is born to carry out a life's purpose, however obscure that purpose may seem to the family in the early days of the child's life. Each is such an unbelievably precious gift and therein lies the extraordinary mystery.

In his book on euthanasia *Denial of the Soul*, psychiatrist M. Scott Peck discusses what he calls his "God theory" that behind the scenes God is, in some hidden and mysterious way, intimately involved in our creation. Peck says that there are three implications to this "God theory". First, that we are more than our genes, our childhood, our culture, more even than our self. That at the core of our being we have a soul. Second, that we are not mere accidents, rather we have been designed. Third, that we have been designed for a purpose. It is, perhaps, a purpose yet unknown, yet undiscovered, but a purpose nonetheless.

His Holiness Pope John Paul II says, in the introduction to his landmark encyclical *Evangelium Vitae*,

Man is called to a fullness of life which far exceeds the dimensions of his earthly existence, because it consists in sharing the very life of God. The loftiness of this supernatural vocation reveals the greatness and the inestimable value of human life even in its temporal phase.

So each of these children, regardless of whether or not they have the ability to function, has inherent dignity and worth because each has a purpose and is a part of the mystery of God's creation.

Of course, this is not always easy to recognize when one is plunged into despair at the news that the child of your dreams is, in fact, the child of your nightmares. Sometimes it takes many months, even years. For some families the grief is insurmountable and the truth is never revealed. But the miracle is that with the help of understanding professionals, family, and friends, and most especially through the grace of God, many families do come to accept their child and so begins the story of the all-transforming power of love.

In keeping with my perspective from the trenches of human experience, I give you the

following passage on love from neurologist and psychiatrist Viktor Frankl's profoundly moving book, *Man's Search for Meaning*. In describing an incident during his imprisonment in Auschwitz, Frankl says;

A thought transfixed me: for the first time in my life I saw the truth as it is set into song by so many poets, proclaimed as the final wisdom by so many thinkers. The truth - that love is the ultimate and highest goal to which man can aspire. Then I grasped the meaning of the greatest secret that human poetry and human thought and belief have to impart: The salvation of man is through love and in love.

As I have said, it is not always easy for a family to open themselves to the grace of God and to accept the challenge presented by their imperfect little child. But when it happens, the child and the family is never the same again.

I would like nothing better than to spend an hour or so telling you of the extraordinary changes that we see in the children with whom we work and the technical details of how those changes are possible. Many times during my career, I have helped create vision in children who were cortically blind, hearing in children who were cortically deaf. I have helped children who could not move, eventually learn to walk. I have helped children of low intelligence, children who were called retarded, become children of above average intelligence. I have done all of this and much more. However, this is not the purpose of my time with you today. Suffice it to say that I have been able to help my children in sometimes amazing ways for three reasons. First, because of a profound respect for the potential of the human brain, which leads to a hope for the future that is grounded in reality. Second, because of a deep understanding of the laws of nature which govern the function and development of the human brain. When properly understood those laws lead the way to the transformation in the child's ability to function. And third, but perhaps most importantly, because of an unshakable faith in the anthropological reality of the family bond - the love between parents and child.

In our work with children and their families, we play a dual role as evaluators of the child and teachers of the family. Rather than being the child's therapist we are guides on the path of development. The day to day work of traveling that developmental pathway is the rightful responsibility of the family. It is an error of enormous proportions to take that responsibility away from parents. The functional changes that we achieve are the direct result of the hard work, dedication, and love of parents, brothers and sisters, grandparents, aunts and uncles, cousins, and sometimes neighbors and friends. They are functional neurological changes that are the tangible fruit of love in action.

So how does this work? If there is no purpose to the life of a severely brain-injured child then his very existence, it seems to me, is a rather cruel joke. I have always thought that God had better things to do with His time than to play cruel jokes on lowly human beings. When one has had the experience, as we have, of watching countless numbers of families, one realizes that there is indeed a plan of amazing beauty and simplicity that is enacted every time a family embraces a child with unconditional love. The child grows in unimagined ways and that is a wonderful thing. However, even more than that, and in my opinion, for the purposes of my discussion with you today, more importantly, everyone who touches the child grows also and sometimes in most extraordinary ways. This sociological aspect of our work is what I want to impress upon you. While the changes that we see in the children are often quite extraordinary, the changes in the family are equally amazing. When you recognize that the family lives in a community that sees this love in action and is

touched by it, you realize that the changes reach beyond the family home and spread to the neighborhood, the larger community, and sometimes to communities and people far removed.

This is a point that requires some elaboration. I return again to Viktor Frankl because his work speaks directly to what I see as the central issue. In describing the profound existential despair of life in the concentration camps Frankl says,

What was really needed was a fundamental change in our attitude toward life. We had to learn for ourselves and, furthermore, we had to teach the despairing men, that it did not really matter what we expected from life, but rather what life expected from us. Life ultimately means taking responsibility to find the right answers to its problems and to fulfill the tasks, which it constantly sets for each individual.

When confronted with the devastating news that the child of their dreams has problems it is common and indeed natural for the parents to scream why us? Why our child? What did we do to deserve this fate, this suffering? Viktor Frankl learned that, while fate and suffering may be unavoidable, "the way in which man accepts his fate and all of the suffering that it entails, the way in which he takes up his cross, gives him ample opportunity - even in the most difficult of circumstances - to add a deeper meaning to his life."

So it is with our families. They have chosen to embrace the precious gift of their child, no matter his level of ability, and they have assumed the task of playing a central role in his growth and development. In so doing, their lives become richer with meaning.

This is a constitutive characteristic of man that Frankl calls the "self transcendence of human existence." This means that part of being human is to be always pointed and directed towards something or someone *other* than oneself. The more one forgets himself - by giving himself to a cause to serve or another person to love - the more human he is and the more he actualizes himself.

Let me give you some true examples of how this incredible process works in the real world of parents and children.

Christopher de Vinck writes in ***The Power of the Powerless***,

Oliver could do absolutely nothing except breathe, sleep, eat, and yet he was responsible for action, love, courage, insight.

We breathed the same night air as Oliver did, listened to the same wind, and slowly without our knowing, Oliver created a certain power round us that changed all our lives. I cannot explain Oliver's influence except to say that the powerless in our world do hold great power. The weak do confound the mighty.

Shortly before his death, Father Henri Nouwen, a Dutch priest and former pastor of the L'Arche Daybreak Community in Toronto, Canada wrote a book called ***Adam*** about his experience of living with and learning from a severely handicapped young man. Father Nouwen writes,

Adam gave me a sense of belonging. He rooted me in my physical being, anchored me in my community, and gave me a deep experience of God's presence in our life together.

I have heard about and read about the life of Jesus, but I was never able to touch or see him. I was able to touch Adam. I saw him and touched his life. And what was said of Jesus must be said of Adam: "Everyone who touched him was healed."(Mark) Each of us who has touched Adam has been made whole somewhere; it has been our common experience.

The growth that this kind of experience creates in each parent, in every brother and sister, and in every other person who becomes involved in a child's life is, I suppose, unique to each individual. Although I have been under the spell for several decades, I still find it difficult to describe exactly what happens when one works nose to nose with a brain-injured child. It is not an earth shattering event, but rather something that happens quietly, beneath the surface of the daily activity. It is an experience that somehow makes one a bit more human and a bit more humane. I have always thought of it as food for the soul - spirit nourishing spirit.

When my daughter Juliana was a little girl, rather than place her in child care, we arranged for her to spend a great deal of time with us even when we were occupied working with families and their children. Juliana spent her entire childhood surrounded by children of varying levels of development - blind children, crippled children, retarded children, hyperactive children, children who could not speak, children who had convulsions, children who the world calls mongoloids. She began almost every morning with the same two questions. First - who is coming today? Second - can they walk? She wanted to know because the answer would determine for her what kind of games she would be able to play that day. However, for little Juliana it made no real difference. To her it was quite simple - some children could see, some could not; some children could walk, some could not. She was no better and no less a person than they simply because she could do more. I can picture her now having a delightful time, lying on the floor next to an immobile child surrounded by her dolls and toys. Many times during those years people asked what we always found to be a curious question. It was even more curious because sometimes the question came from our families who had brain-injured children. The question was, "Aren't you concerned about the effect that being around these children is going to have on Juliana?" Isn't that extraordinary? "Aren't you **concerned** about the effect that being around these children is going to have on Juliana?" - as though she might catch a mysterious disease or be somehow psychologically scarred for life! It is a question that always startled me, indeed troubled me. Rather than be scarred by her encounters with the children, Juliana was forever and irrevocably enriched by the experience. She learned about patience, tolerance, compassion, dedication, service, success, and failure. Most significantly, she learned about the real dignity and worth of human life and through that experience, she became a better person. Today she is a bright, compassionate young woman about to go off to university and I have no question but that the world is **already** a better place because she is in it. Largely, she has not her parents, but the children to thank for that.

There is one more example of this process that I would like to tell you about. It is the story of a boy named Leopoldo. I had the good fortune of knowing Leopoldo from the time that he was a little baby. He was a profoundly brain-injured little boy born the seventh child in a very wealthy family. As his mother so aptly describes it, his birth was a profound existential shock. She and her husband were in no way prepared for this hurt little bundle of humanity. Having had six absolutely beautiful and normal children, Leopoldo's condition - blind, deaf, unable to suck, wracked with convulsions, and totally flaccid - was completely unexpected and completely alien to their experience of children.

Placing their faith in "the goodness of God and respect for His laws of nature" Leopoldo's parents accepted their suffering with incredible courage and did their best to cope with the realities of his condition. However, despite being seen by some of the most highly regarded specialists in the world, there was no hope for Leopoldo except for an early death. Then, when things seemed to be at their darkest, they discovered our program of brain development.

As it has in so many other children, the program proved to be the key to unlocking Leopoldo's hidden potential. Over time, he learned to see, to hear, and understand, to crawl, to say a few words. He became an integral part of his family and was very aware of his family's love for him and of his love for them. He became, in short, a succession of miracles. Along with the changes in Leopoldo came the simultaneous and equally important changes in his family. As his mother explains it, working with Leopoldo brought the family closer together and brought all of them closer to God. I once heard her tell a reporter that Leopoldo taught her what being human was all about. Imagine that, a completely helpless child having that kind of an impact on a grown, fully capable adult. Mother Theresa, who met him on a few occasions, was fond of calling him "The Professor of Love". I suppose there can be no greater compliment, for if there is anybody who knew about the transforming power of love it was Mother Theresa.

For 14 years, Leopoldo fought the good fight as he struggled for every inch of progress that he ever made. He did so with quiet dignity, without complaint. Then, at the age of 14, his mission here on earth completed, he returned to his Father in Heaven.

Several months after Leopoldo's death, together with his mother and father, I began a small project to provide poor children with the same program that enabled Leopoldo to make such fantastic progress and that did so much to contribute to the growth and development of his entire family. When I first started the project, I was often met with considerable skepticism. Repeatedly I was told that it would never work because the families were uneducated and had no financial resources. How could I possibly expect poor uneducated families to succeed where professionals had failed? I was told repeatedly that I was a dreamer. I only smiled because I knew something that nobody else knew. I knew about the power of love. Love knows no university and it knows no social class. Leopoldo, and all of the other children with whom I worked, had taught me that love and dedication do indeed conquer all. In the presence of love and dedication, education and money are of little consequence. Today, 11 years later, that small project is a full fledged program of professional training and services for families that is reaching many hundreds of poor children throughout the country of Venezuela. It is named in honor of Leopoldo. More than 175 professionals (doctors, therapists, teachers and psychologists) have been trained in our methods and many of them are actively working in 23 centers and schools where they teach poor families about the miracle of brain development and the power of love. In June of 1997 at the Vatican, His Holiness Pope John Paul II, speaking to a delegation of participants in a symposium on brain-injured children, recognized Programa Leopoldo as an extension of the Gospel of Life. *There is indeed a power in the powerless.*

I believe that the Leopoldo's, Oliver's, and Adam's of the world are, in fact, our most precious natural resource. This is not because of what they can do because obviously so many of them can do nothing in a functional sense. Rather, it is because of what they do **to us**. When one sees the amazing impact that children like Leopoldo and Oliver and Adam have on the lives of everyone around them; when one sees that this impact continues long after they have left their earthly existence; there is little else that needs to be said about their dignity and worth. The children and their families speak eloquently from the trenches of their everyday experience.