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Quo Vadis? Professor Lejeune's Legacy

by

Marie A. Peeters, M.D.

The author hopes to establish a "Jerome Lejeune Center" in New York.

It is just over one year that Professor Lejeune left the laboratory because of the illness that took his life a few months later. A few weeks after his death I saw a patient of his, a man with Down syndrome. After I had finished the clinical examination, this man looked at me and asked me a very serious question: "Now that Professor Lejeune is dead, who will protect me?" This question has been engraved into my heart. Who will protect me?

A simple question: a noun, a verb and a direct object, but a question that goes straight to the heart, a question of almost Augustian density.

Let us reflect on the three parts of this question. "Who", an open invitation to each one of us, especially those in the medical profession whose vocation it must be to protect the poor and the weak. It is also a question addressed to society as a whole. Why did this man with trisomy 21 feel that it was necessary to ask "who"?

The widespread availability of prenatal diagnosis has profoundly altered the way people consider mentally handicapped people. Indeed, the birth of a child with a chromosomal anomaly is now widely considered as a medical error and in certain countries doctors face lawsuits because they failed to diagnose the "condition" in utero. In an insidious manner, mentalities are changing and people now regard persons with a handicap as someone who should not be there. Prenatal diagnosis has induced deep anguish in persons with handicaps. Indeed they know that, had their condition been diagnosed in utero, they would not have been allowed to be born. They have become true survivors of the search and destroy missions performed in our hospitals. Being survivors, they suffer from the psychopathology associated with being a survivor: existential guilt, fear, anxious attachments . . . With the availability of abortion, with the profound change in the way people consider pregnancy: the child must be a "wanted" child and has no intrinsic right to be if not wanted. When mothers can decide on which child will be terminated, society as a whole can and will decide on whether it will allow persons with disabilities to exist.

Furthermore, contraception, the decreasing value of children and abortion are

responsible for enormous imbalances in the demography of most "civilized" countries. The declining birth rate and the expanding population of older people will decrease available funds for people with a mental handicap.

The recent bioethic laws in France and those which are being currently discussed at the European Parliament as well as the United Nations conference in Cairo and the preparation of the conference in Beijing are all ominous signs. There is a clear message as to the "fate" of the poor and the writing is on the wall as to what is in store for the unborn, the handicapped and the elderly. It is the duty of the medical profession to act in response.

Such is the stage setting, but who will be the actors? We come back to the original question. Obviously there are many actors. However the main actor is the person in the medical profession. When a group of doctors will openly declare their determination to commit themselves to the mentally handicapped, their belief that these persons are not "accidents" or "burdens" but persons loved by God and who have been given a unique mission by God, then things will begin to change in our societies. When parents and friends will encounter the faith and love doctors have for those they are being asked to protect, this will do wonderful things for persons with a handicap, their parents and all those who know them. At Professor Lejeune's funeral, a man with Down syndrome went quite spontaneously to the microphone and testified in front of the more than three thousand people who attended: "Thank you Professor Lejeune, because of you I am proud of myself". Parents who encounter a person who reveals to them that their child is beautiful and will do great things for God, those parents are like the leper who was healed by Christ, they go out and are witnesses. They in turn do great things for their child, presenting their child to others and so, bit by bit, society will change. But we need a point of crystallization, a point which will start the process. Who will accept being this point? Who will protect me? Professor Lejeune left us an example, perhaps we can take up his work where he left off. Perhaps we can start a multitude of small crystallization points throughout the world, points which will eventually become confluent and be a reflection of the civilization of love.

Let us now reflect on the verb: "protect". There are many aspects to this part of the question. Of course, protect first means protect in the physical sense: protection from destruction in the womb, protection from euthanasia.

It also implies protection in a moral sense. In an effort to cut spending, more and more countries "integrate" persons with a mental handicap in the community, often leaving them alone, lost and vulnerable. When one attends international medical meetings on the topic of mental retardation one has the uneasy feeling that those who have escaped the search and destroy missions we mentioned will be "perverted". The emphasis on the need for an active sexual life is a topic in every meeting. The encouragement towards free sexuality, the lack of insight into their specific talents have increased the number of clinical depressions in alarming proportions.

Protect also has another facet. When I first met Professor Lejeune he told me: "It is our duty to find a cure for those who suffer from mental retardation". Noticing my look of skepticism, he asked me: "Why not?" Yes why not? Let us

not forget that PKU, when not treated, leads to severe mental retardation, but that excellent results are obtained with therapy. The incidence of spina bifida and anencephaly can be decreased with good preconceptual care.

The important pioneer studies done in Professor Lejeune's laboratory have demonstrated that mental retardation (particularly those associated with a chromosomal anomaly) is often due to metabolic imbalances and that some of these are amenable to treatment. These studies open a wide new field in the study of mental retardation and offer hope for the future. Much remains to be done: more advanced studies to pin-point some of the defects suggested by our studies and well documented, randomized clinical trials. Professor Lejeune opened a new avenue of research which has proven itself to be of enormous interest. It would be more than foolish to abandon the task now, especially when the dangers for the child with a mental handicap have never been as great.

Professor Lejeune, the first president of the Academy for Life, dedicated his life to the cause of the unborn and the people with a mental handicap. It would be a tribute to him to continue the work he started in these fields. His intuition was severalfold:

- 1) to provide medical "safe houses" for pregnant mothers who know that they are expecting a child with a genetic disease and for people suffering from a mental handicap;
- 2) start outpatient clinics for children and adults with mental handicaps to provide:
 - a) good medical care for this patient population,
 - b) continue the therapeutic work already started by him,
 - c) support for both parents and patients.
- 3) continue the research on the pathogenesis of mental retardation and the therapeutic possibilities.

Children and parents need support and to be given insight about the unique value of a person with a handicap. It is important to establish a collaboration with existing support groups in the community, especially with Faith and Light groups. These groups where people with mental handicaps, their parents and friends come together for a time of sharing, of celebration and prayer want to be a witness of the love of God for persons with a mental handicap and their families, a response to the call: Bear one another's burdens. Special Christian educational training courses should be provided to the family that comes to the outpatient clinic.

We now arrive at the last part of my friend's question: "me". Who is this person with a mental handicap? Why is he there? Having had the privilege of living for five years with persons with a mental handicap (three years in a l'Arche community and two years in a group home parents had started) I can understand the prophetic message Pope John Paul II sent to the Faith and Light communities during their International Pilgrimage to Lourdes in 1991. Indeed he wrote: "The person with a mental handicap is a witness of the greatness and power of God". In our broken and divided world the person with a handicap can, if he is loved and if we give him the opportunity, be a source of unity and peace. God in His wisdom and goodness has given the poor a unique mission: to be a source of unity and

peace. Unity because they bring together people of different origins: in Calcutta with the dying, at l'Arche or Faith and Light . . . They bring people together in a human sense but more than that, they bring people to God. Those who encounter and work with the poor become aware of their own brokenness and need for salvation and because of this encounter with the broken body of Christ, they experience the gift of peace. People with a mental handicap often have a unique sense of God and they can be the world's greatness witnesses of God's love. May all those who read this paper have the grace of "seeing" God's power and grace in the broken body of a handicapped person. May all feel the urgent need and become involved where they are and in whatever capacity they have.
