

# **Welcoming Children with Disability**

**Comments of Bishop Kevin Doran**

**At the Conference on**

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**&**

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### **None of Us Has Arrived:**

As I look around the room here, I see people of all ages. I see women and men; tall people and others who are not so tall. We each have our unique gifts and strengths. We also have what the psychologists sometimes politely call our "areas for growth". We are all on a journey; none of us has arrived.

We read in the Book of Genesis that "*God made man in his own image; male and female he made them*". Have you ever wondered what that means? It has nothing to do with our appearance, or any of our physical attributes. There are no two of us the same. When we say that we are made in the image and likeness of God, it is another way of saying that we share in the goodness and beauty and truth of God. God's love is part of our DNA; we are created for relationship with God who, in partnership with our parents, has willed us into existence and wants to share his life with us.

### **A New Way of Looking at Disability**

Back in the jubilee year 2000, the Archdiocese of Dublin published a little booklet called "it's my church too". It was an invitation to parish communities, at the dawn of a new millennium, to imagine how people with disability, who had often been hidden away in the past, could be facilitated in participating more fully in the life of the Church. We installed loop systems, ramps, accessible entrances. People with hearing impairment not only had interpreters at the International Eucharistic Congress, but a number of them presented workshops in the main Congress programme. We began to talk about people with disability, rather than about disabled people. The focus now is on the person, not on the disability. And people with disability, like the rest of us, are all different. Just like the rest of us, have their gifts and their strengths and their personal "areas for growth". They, too, are made in the image of God and called into relationship with him.

While it is possible to approach the inclusion of people with disability from the perspective of faith, I think we need to say quite clearly that this is not just a nice religious idea. It is a

basic operative principle of our civil society and has the force of law.

In 2003, Ireland hosted the Special Olympics, World Games. People with intellectual disability from all over the world were welcomed in every corner of Ireland, not primarily because of what they might achieve, but because of who they were.

In 2005, the Oireachtas passed the Disability Act, which defines disability, in relation to a person, as “*a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment*”. The Act makes provision for people with disability to have access to buildings and services, including education and transport, and to be facilitated in gaining employment.

The point is that, in the matter of how we respond to people with disability, there is no huge gap between faith and reason. As Pope John Paul II was inclined to remind us, both faith and reason seek the same truth. They simply approach it from different directions. Just as reason leads us to recognise the continuity of every human life from fertilisation to natural death, so faith allows us to see each person as having his or her origins in the intention of a loving God and his or her fulfilment in eternal life. While Christian morality is inspired by the Gospel, it is always in keeping with reason. Morality, in its essence, *is* practical reason.

### **Welcoming Children With Disability**

In his letter of encouragement “Amoris Laetitia” (The Joy of Love), Pope Francis tells us that “The gift of a new child, entrusted by the Lord to a father and a mother, begins with acceptance, continues with lifelong protection and has as its final goal the joy of eternal life” ( AL, 166). In the midst of all the short term objectives and long-term goals which we have for our children, Pope Francis identifies the “final goal”, which gives meaning to all the others and by which we are in a very real sense defined.

Elsewhere in the same letter, the Pope speaks about how the Church “with special gratitude.... supports families who accept, raise and surround with affection children with various disabilities” (AL 82). There is a recognition here that welcoming a child with disability involves significant challenges for parents, which they should not be expected to carry alone. “These challenges include the understandable apprehension which accompanies a diagnosis of disability either before or after birth. There may be added challenges around communication, mobility, or even physical survival. There is the concern to protect the child from exposure to any kind of negative social reaction, while at the same time launching him or her, to whatever degree is possible, into the wider world. And then there is the anxiety about what will happen to him or her “when we are gone”.

The answer to many of these questions is a supportive community and so, when Francis speaks of the Church “supporting” parents with gratitude, he is not just talking about smiling at them as we pass by. Alongside a tangible decline in our sense of community, there has been an increasing dependence on “society”, which is really a poor substitute. (Cf Karol Wojtyla).

### **Unborn Babies with Disability**

Unborn babies with disability, like adults with disability, are first and foremost people. If the inclusion of people with disability is a characteristic of a civilised society, why would we accept discrimination against unborn people with disability, simply because of their disability. Their disability certainly limits their capacity to act, but it doesn't define them. On the other hand, the manner in which they are welcomed and cared for often enhances their capacity in ways that people might never have imagined, not least their capacity to be a focus of love in the family and in the community.

We need to consider, for a moment, the possible purposes of pre-natal diagnosis. It may be possible to identify a medical condition which can already be treated in the womb, or to prepare in advance for some treatment that will be required

as soon as a baby is born. It is arguable that, in some cases, it may help a couple to be prepared in advance for the birth of a child with some genetic malformation or with special needs. Increasingly, however, pre-natal diagnosis is thought of and used as a means of screening out babies who, in the eyes of adults, should not be brought to birth. The New Charter for Healthcare Workers, published by the Vatican in 2017, has the following to say:

*The purposes for which prenatal diagnosis may be requested and performed must always be for the benefit of the child and of the mother.... Prenatal diagnosis "is gravely opposed to the moral law when it is done with the thought of possibly inducing an abortion depending upon the results: a diagnosis which shows the existence of a malformation or a hereditary illness must not be the equivalent of a death sentence. (Pontifical Council for Pastoral Assistance to Healthcare Workers, New Charter for Healthcare Workers 2017, 35)*

### **Healthcare Professionals As Agents of Healing**

I find that people are sometimes surprised when I say that the Church is not against death. The reality, however, is that death is part of the human condition. It is an essential element of the Church's mission to help people to prepare for death, in the hope of the Resurrection. The first references to this, our "ultimate end" are already to be found in the Rite of Baptism. So, we are not against death. But we do see each human life as a gift from God, which is not ours to dispose of.

I think it may be helpful to explore the difference between accepting death and causing death, with particular reference to healthcare. Healthcare professionals, of necessity, have to be able to accept death. Part of the relationship of trust that they have with their patients is that they tell the truth but, even when the truth is that they can offer no hope of healing, they continue to support life through ordinary means, until death comes. This applies whether patients are young or old, or even unborn.

Conscience is the process of making judgements based on truth, with a view to doing what is good. In healthcare, the truth concerned includes the facts of science and economics, but crucially, it must also include the truth about the human person and the meaning of his or her existence. Fidelity to the judgement of a well-formed conscience is crucial, not only for the well-being of the patient, but also for the integrity of the healthcare professional.

With the consent of the patient (or the parents, in the case of a child) healthcare professionals are given a unique access to the human body, for the express purpose of preventing and healing illness. They provide care for those who cannot be healed. There is nothing in the nature of healthcare that would suggest that the role of a healthcare professional ever includes intentionally bringing about the death of the patient, either by some action or by failing to act. Both Pope John Paul II and Pope Francis have spoken specifically about the responsibility of healthcare professionals in the light of this unique relationship of trust.

*A unique responsibility belongs to health-care personnel...Their profession calls for them to be guardians and servants of human life. In today's cultural and social context, in which science and the practice of medicine risk losing sight of their inherent ethical dimension, health-care professionals can be strongly tempted at times to become manipulators of life, or even agents of death. In the face of this temptation their responsibility today is greatly increased. Its deepest inspiration and strongest support lie in the intrinsic and undeniable ethical dimension of the health-care profession, something already recognized by the ancient and still relevant Hippocratic Oath, which requires every doctor to commit himself to absolute respect for human life and its sacredness. (Pope John Paul II, *Evangelium Vitae*, 89)*

And

*Dear friends and physicians, you are called to care for life in its initial stage; remind everyone, by word and deed, that this is sacred — at each phase and at every age — that it is always valuable. And not as a matter of faith — no, no —*

*but of reason, as a matter of science! There is no human life more sacred than another, just as there is no human life qualitatively more significant than another. The credibility of a healthcare system is not measured solely by efficiency, but above all by the attention and love given to the person, whose life is always sacred and inviolable. (Pope Francis, Address to International Federation Of Catholic Medical Associations, 20<sup>th</sup> Sept 2013)*

In many jurisdictions where abortion is already legally permitted, Healthcare professionals who refuse to take a human life for reasons of conscience are regarded as troublesome and unreliable employees and not good candidates for promotion. By contrast, the New Charter for Healthcare Workers states that:

*"Besides being a sign of professional integrity, a healthcare worker's earnestly motivated conscientious objection has the noble significance of a social denunciation of a legal injustice that is being perpetrated against innocent and defenceless lives". (New Charter, 60)*

The manner in which conscientious objection is interpreted in the so-called "Protection of Life in Pregnancy Act" gives rise to real concern. Doctors and nurses are allowed under the Act to opt out of providing or participating in abortion, provided they refer the patient to someone else who will perform the procedure. In other words, they are still required to participate in what they believe to be fundamentally immoral. Healthcare administrators have no recourse to conscientious objection.

The difficulty here is that, in our liberal democracy, people who provide services are regarded as "delivery people" with no personal investment in what they deliver. The "customer is always right". It is, of course, very necessary that "healthcare delivery" should be efficient and effective, but it is a cause of concern when society focusses to such an extent on delivery that the essential meaning of healthcare and the essential role of the healthcare professional as "healer" and "advocate for life" is lost sight of. In such a scenario there is no room for the personal conscience of the healthcare professional.