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How Can We Be Present To the Handicapped?

by

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A handicap is a painful human situation. It has a direct effect on the incapacitated person as well as on those who relate to him. The handicap can come from a birth defect, an accident or a disease. But it always comes as a shock; and as a limit imposed upon us. A handicap is usually unexpected and comes as a profound disruption of our whole existence. A handicap is above all a state from which there is no possibility of healing. But whenever it comes, a handicap is always an experience of suffering, anxiety, fear and uncertainty.

While a handicap may come about in a number of ways, there is always the inevitable question: "Why did this happen to me?" There is never an adequate answer. This often gives rise to anger, and depression. Once the reality of handicap is accepted, there is further question: "Is it possible to live with a handicap?" And if so, how?

There is no answer which can adequately explain a handicap. A handicap is a condition which is imposed on us, as it were, from without and it gives rise to powerful and contradictory emotions. Through a handicap, reality is experienced as adversity.

We must first consider the culture in which we live. Our society has come up with different terms for the handicapped: disabled, physically deprived or impaired, exceptional, etc.; in addition, modern science has also come up with some therapeutic possibilities for certain handicaps. Our culture has rethought the whole concept of handicap and of sickness, even a definition of life as "the quality of life."

Thus, sickness has tended to become an injustice (universal medical care for all as a right), death an obstacle (euthanasia when we can no longer avoid suffering) and a handicap, is seen as scandal (such people are pitied because if detected earlier, the handicap could have been resolved by abortion). Handicap then represents pure chance which is beyond our control and therapeutic possibility. Religious meaning of handicap has all but been excluded, even ridiculed. What we are really questioning in all this is the relationship to our limits: when is a life worth living? Are weakness and frailty any longer acceptable? Why should we live with

suffering and disability? Does suffering have a meaning? Why me? Why death?

The handicapped person is therefore forced to live with his suffering and his visible limits. The presence of the handicapped forces all of us to look at our own lives and face the reality which we try to avoid: our own suffering and limits. We are mortal and the handicapped person in our midst radically reminds us of this basic reality. No wonder he or she is rejected or pitied.

With or without a visible handicap, the life of every person must pass through solitude, limits, suffering and uncertainty. And finally death. All these experiences are radical limits to our self sufficiency, our all-powerfulness and our desire to master and control. All our projects and ideals come up short. We each discover a terrible loneliness at the core of our being. Whether this loneliness is unconsciously hidden or recognized, it is always a place of suffering. In fine, it is our final rendezvous where we come together into a radically common experience.

Contrary to appearances, suffering helps us to become who we are. In fact, we cannot be without it. Not that suffering is desirable in itself - it is not - but it acts as a beacon along the road of our existence. Suffering is directly inscribed in our life which gives rise to a double temptation: either to close in upon ourselves or to risk, that is, to open ourselves to others. Suffering demands that we find meaning in our lives; it also reveals to us that we cannot exist without the help and mediation of others. We can find hope only in our relationships to others and in not denying the reality of suffering in our life.

Relationship supposes the existence of someone capable of understanding the person who suffers without identifying with his handicap, that is, a person who has no ready made solution or reassuring principle but who accepts the fact that he does not know before hand what is going to happen or what he is going to do. A person who takes the time to truly listen to what the other says, has discovered something in his own life.

When we realize, for example, that a child is handicapped, when we have diagnostically confirmed it and when there is no further therapeutic possibility available for the condition from which it suffers (which is the case for most genetic disease) we are finally faced with a painful situation which can anger us. We are situated between knowledge and not being able to do anything about it. This is agonizing for parents.

There are different forms of handicaps:

1. Serious handicaps such as an anencephalic condition. Nothing can be done for these as yet. Probably never.
2. Genetic disorders such as Cerebral Palsy and Spina Bifida. There are some therapeutic possibilities but they are limited. They will be improved in the future.
3. Various physical handicaps which may be seen by others as unsightly. Much has been done in this area.
4. Various mental handicaps or a combination of 3 and 4. Here, too, there are some therapeutic possibilities available and they are improving.

"This child will not be like other children." Some parents do not want to deal with a handicap and so they abort. Others are confronted with the child's handicap only after birth because it was undetectable before birth. The

unexpected has happened. This is also the case with adults who suddenly become handicapped through stroke, accident or illness.

Whatever way the handicap comes, each handicapped person is brutally confronted with some basic questions which directly affect his existence as well as his relationship to others. Without ever challenging what another considers unbearable for him, is it still possible to share or participate in his suffering? We can never subsume the handicap on to ourselves - that simply is not possible. At the same time, we must never abandon the one who suffers ("That's his problem"). Together, we must look for an opening which can lead both of us to find a meaning to his suffering. What is that opening?

We do not know everything. Hardly. We cannot do everything. Clearly. The handicaps of a child as well as of an adult confront us with the question of evil and of the meaning of human existence in its encounter with evil.

Today we have exchanged the concept of evil for that of error or mistake; we have gone from personal responsibility for what we have done to a lottery of reality. Evil is error (as Plato would say) and so there is no personal responsibility. In such a view, it is up to the medical profession to correct and cure reality (genetic lottery). When it cannot, we sue for malpractice. We are deceived by the reality we have made up for ourselves. When doctors cannot cure, they made a mistake. And mistakes must be compensated for in money damages.

We often hear that it is horrible to have a mentally retarded child or that it is difficult if not impossible to live with a husband or wife who is severely handicapped from illness or accident. These are terrible verdicts on the reality which has befallen the handicapped. But these are excuses by which we try to escape human solidarity. The one who flees the handicapped person instead of identifying with him or her, is really saying that to relate to the disabled is beyond his strength. More importantly, such a person is really saying that there is no human solidarity.

Between these two concepts or interpretations of evil - error and horror - there is a third option: The tragic experience of confronting evil. In a child or adult who will never again be like others, it is possible to recognize our other self, as human solidarity with that person who now has a wounded life but which has a meaning nonetheless. There is something common and communal which unites the two of us in a common humanity which makes us both partners in a combat which forces us, together, to confront reality in adversity. In this crucial rendezvous of our mutual vulnerability, there is a hoped for presence: a similarity and solidarity rooted in a refusal to abandon the other to his isolation all the while respecting his solitude. It is possible to accompany the handicapped and to be there with him because of our common wounded and vulnerable humanity.

In every singular person, the humanity of all is present. We are called upon to respond to the condition of the handicapped. In our responses to the handicapped, we meet the complexity of reality with its inevitable conflict of values. But we must sustain each other in what each considers the source of meaning of his existence.

When we are present to the handicapped, we are also led to re-evaluate our own lives and our own relationship to life. Before this wounded and handicapped

reality which resists us, a new understanding of our autonomy is required which must not be confused with self-sufficiency. There is a lot of confusion between these two concepts today. The illusion of autonomy is that real power exists in our lives when we can do everything ourselves; when we are completely self sufficient by pretending that we need never ask for help. The logic of this definition of autonomy leads to self enclosure, which is a self sufficiency as a true isolation from others. This is profoundly false. It is a denial of our common humanity.

It is one thing to be autonomous; it is another to be completely self sufficient. Autonomy always includes the possibility of dependence: "Can you help me?" This word is pronounced daily by every handicapped person and implicitly as well, by every person who exists. It is our common condition: We need each other. The handicapped person's asking is simply a more explicit form of what we all must do and do every day.

There is an essential reciprocity between us all, a relationship to be built up without ceasing in each of our lives, each day of our lives. Our mutual experience of vulnerability of suffering and mortality is our crucial opening to the existence and suffering of others. We realize more and more that this bond which we have with each other reveals itself as a responsibility which can be refused or accepted in freedom, even if we sometimes are in a quandry about what to concretely do about it. Sometimes we can do nothing except be there lovingly and faithfully, for example, in the presence of a dying person. The handicapped is himself a presence who courageously faces the possible without despairing of the impossible which is also present in him. We do not always know the limits of the possible in the handicapped. The possible is that we can together deal with a handicap because we share a common humanity. The impossible is that we must accept suffering, our limits, and our solitude; but because of the possible, we must not despair over the impossible.

It is through this basic truth that peace will finally come to all, the handicapped, visible and invisible alike.
