

EDUCATION IN THE SCHOOL OF GENUINE HUMANITY: PASTORAL CARE FOR PERSONS LIVING WITH DISABILITY AND THEIR FAMILIES IN NIGERIA

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Abstract

Disability is an inescapable reality of life. Many families who have a disabled member among them face serious emotional, psychological and socio-economic challenges. Some of these persons living with disability are also members of the church. However, in spite of their sizable numbers in many worshiping communities, they are basically sidelined in the pastoral outreach of the church. The reasons for this are either ignorance, prejudice or the absence of adequate pastoral training on how to reach out to this group or perhaps their seeming neglect is a symptom of a deeper theological problem. Could the pastoral 'invisibility' of persons living with disability in ecclesial life not be due to a theological uneasiness regarding God's goodness, the problem of evil, etc. The goal of this article is to examine the parameters of a pastoral care plan. This article will be predicated on the fact that persons living with disability form part of the body of Christ and are full human subjects with the corresponding innate, sacred and inviolable rights. They too have unique gifts which can be at the service of communion. Harnessing these gifts will require an education in the school of genuine humanity whereby able members of the church will create a conducive atmosphere of pastoral integration for people living with disability and their families. The goal is to make people with disabilities equal partners in the Christian community. This pastoral care plan will include but may not be limited to designing churches that are disabled friendly (mobility) creating opportunities for ministry by persons with disability, pastorally reaching out to families with disabled members and examining how the laws of state protect the disabled and how these can be harmonized with the pastoral ministry of the church.

Keywords: Education, Humanity, Pastoral, Disability, Families, Nigeria

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Introduction

No family is ever fully prepared to welcome the birth of a child with any form of disability. This is due to the fact that the arrival of a child with even the mildest form of either physical or mental disability alters the dynamics of family relationships. For a culture which glories in physical appearance and where physical beauty or attractiveness is held in high esteem, the birth of an “abnormal” child is perceived as an aberration. Parents of such children may feel embarrassed, humiliated or let down by God. The gradual coming to terms with the disability of their children can become a crushing burden for parents. They soon discover that the duty of care they owe their offspring is a journey without an immediate end. In fact, it demands a lifetime commitment. In addition, disability stigmatizes both the individual and the family. Persons with disabilities and their families experience a lot of emotional and psychological turmoil. This is often a result of societal prejudice, social ostracism, isolation and discrimination. To tell it as it is, persons with disabilities form a significant proportion of the marginalized in many societies.¹ If the church is to fulfil its mission as salt of the earth and light of the world then it has a bounden duty to minister to the pastoral needs of this *anawim* of Yahweh. The goal of this paper is to examine the parameters of intervention by the church in catering to the pastoral needs of persons living with disability and their families. It is common knowledge that in spite of the sizable numbers of many persons living with disabilities in our worshipping communities, they and their families are basically sidelined in the pastoral outreach of the church. In fact, they are pastorally 'invisible'. A combination of ignorance, prejudice, fear and perhaps lack of adequate pastoral training on how to respond to the needs of this group may be partially responsible. Perhaps too, there is some theological uneasiness regarding God's goodness and the problem of evil which disability confronts us with. Pastoral care is a multidimensional intervention which includes advocacy, inclusion, presence and solidarity. It will also entail attitudinal changes and constant education of the lay faithful on fulfilling the duties of care they owe to the least of their Christian brothers and sisters.

Current Status of the Literature

Research revealed that there is not much published material in the area of pastoral care for persons with disabilities in Nigeria and their families. In the area of magisterial pronouncements not too much has been done either. Following the declaration of the International Year of Disabled Persons in 1981 by the United Nations, the Holy See on 4 March, 1981 issued a statement to that effect. A few articles and books on the issue appear to focus more on how the church can become accessible to those with physical handicaps. A study among a particular group in Nigeria dealt extensively with the need of incorporating the physically challenged in the liturgical life of the church.² This lacunae further reinforces the invisibility and anonymity

¹David Anyaele, Director of Centre for Citizens with Disabilities estimates that there are no fewer than 21 million Nigerians with disabilities. See *The Guardian*, Thursday, July 9, 2015, p. Xvi.

²See Benedict Ukutegbe, *Active Participation, the Physically Challenged in Liturgical Celebrations* (Lagos: Vinnyl Communications, 2014). This book deals extensively on the need to encourage active participation of physically challenged persons in liturgical celebrations in the diocese of Warri Nigeria.

that is the lot of persons living with disability within the institutional church. This voiceless group is yearning and groaning to be heard. But it does seem that those “able bodied men and women” who run the affairs of the church have more 'weightier matters' on their agenda. It could also be the case that many are embarrassed by the subject of disability. For how come that in a discussion of the Vocation and Mission of the Family and the Consecrated Life in the Church and contemporary Society³ the issue of disability is not considered at all? Are people aware that in spite of their invisibility they form a sizable number of the population and many of them are actually baptized Catholics?⁴

Definition of Terms

This is a complex issue. Several literature have battled with the issue of nomenclature. What terms may be used? Are persons physically handicapped or disabled? Some see the use of the term “handicapped” as condescending or degrading. Some prefer the term “physically or mentally challenged” insisting that the conditions are mere challenges which can be overcome. Should we refer to someone as a disabled or one living with disability? Should people be defined in terms of their disability or personhood? Is Mr X a blind man or a man who is blind? McColl and Jongloed have argued that when we categorize people on the basis of their disability, “the result is depersonalization and medicalization of disabled people- reinforcing a power structure that systematically disadvantages disabled people”⁵ The significant point to note in disability advocacy is that people are first persons and human before their disability. As scholars like Eiesland argue, disability is no different from other conditions of life such as gender, age or even ethnicity. Though she does not underestimate the difficulties associated with being disabled, which may be personal and social, she also sees disability “as a source of creativity and resourcefulness, and as an expression of faith and solidarity.”⁶ The United Nations Convention on the Rights of Persons with Disabilities state that, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”⁷ This descriptive definition enables us to have a comprehensive view of disability. In this article therefore, we shall use the term “disability” to refer to a smorgasbord of physical and mental defects in individuals or persons.

³This is the theme of the current edition of this journal. Of the nearly fifty topics suggested to contributors nothing is said on the pastoral needs of disabled persons and their families or how they factor in the Vocation and Mission of the Church. Is this a deliberate oversight?

⁴In the words of the president of the National Association of Persons with Disabilities, there are about 22 million persons living with disability in Nigeria out of a population of about 140 million

⁵Mary Ann McColl and L. Jongbloed, *Disability an Social Policy in Canada*, 2nd ed (Toronto: Captus Press, 2006)

⁶Mary Ann McColl and Richard S. Ascough, “Jesus and Persons with Disabilities: Old Stories, New Approaches”, in *The Journal of Pastoral Care & Counselling*, Vol. 63 No. 3, 4 Fall/ Winter 2009.

⁷The United Nations Convention on the Rights of Persons with Disabilities, 6 December 2006, Art. 1.

The Meaning of Pastoral Care

As a discipline pastoral care is not well developed in this part of the world. This does not mean that pastoral care is not being carried out by priests, consecrated persons and lay people. However, there has not been, to my knowledge, a systematic and scientific exploration of specific areas of pastoral care as has been widely done in other climes. This is evident in the fact that certain specialized areas of ministry such as geriatric care, hospital chaplaincy, ministry to divorced or separated persons, and ministry to those suffering from effects of substance abuse often do not have adequate personnel trained to render services in such areas. The hospice movement which has been able to offer palliative care for persons with terminal illnesses is at best inchoate in Nigeria. Pastoral care encapsulates the traditional concept of *cura animarum* or care of souls. Clebsch and Jaekle define pastoral care as “the ministry of the cure of souls...and consists of helping acts done by representative Christian persons, directed toward the healing, sustaining, guiding, and reconciling of troubled persons whose troubles arise in the context of ultimate meanings and concerns.”⁸ Pastoral care is not the prerogative of priests or ordained ministers alone. In fact, as Howard Clinebell argues, “pastoral care is the shared ministry of the pastor and the whole congregation- ordained ministers are like player coaches who have the responsibility of enabling the mutual ministry of lay persons and also doing their own unique and valuable ministry of caring”.⁹

Why Pastoral Care?

If disabled persons are full members of Christ's mystical body by virtue of their baptism then they too deserve all the spiritual benefits that accrue to other members of the faith community. Some people argue that there is no need for singling out disabled persons for pastoral care. This they believe would negate the practice of inclusion. However the reality is that these groups of people are basically invisible in the church's liturgical and pastoral life. If their spiritual needs and other temporal needs were well catered for then there would be no need for this intervention or any other. The year 1981 was declared by the United Nations as the International Year for Disabled Persons. In the light of this declaration the Holy See issued a statement on March 4, 1981 setting out guidelines on the church's response to the plight of disabled persons worldwide. However, before this time attention to disability issues became a priority for Christian communities globally when in 1968 the World Council of Churches began to explore avenues to make the Church a more inclusive community. Landmark progress was made in 1998 with the establishment of the Ecumenical Disabilities Advocates Network with headquarters in Kenya.¹⁰ As it is today various faith communities and civil authorities have become more aware of the need to respond to the needs of persons living with disabilities and their families.

⁸William A. Clebsch & Charles R. Jaekle, *Pastoral Care in Historical Perspective*, (New York: Harper & Row, 1967) p. 4.

⁹Howard Clinebell, *Basic Types of Pastoral Care and Counseling*, (Nashville: Abingdon Press, 1984) p. 27.

¹⁰See S. Kabue, “Disability and the Healing Ministry of the Church”, *International Review of Mission*, 2006, 112-116.

On November 16, 1978 the United States Catholic Bishops issued a Pastoral Statement on People with Disabilities. In 2006, the United Nations General Assembly published the “Conventions on the Rights of Persons with Disabilities”. Recently, the Centre for Citizens with Disabilities (CCD) a group which represents persons living with disabilities in Nigeria urged President Muhammadu Buhari to sign into law the Discrimination Against Persons with Disability bill which having being passed by parliament is awaiting his assent.¹¹ In order to properly articulate the parameters of pastoral care for disabled persons and their families we must first of all seek to enter into the world of such persons and seek a theological understanding of pain, suffering and loss. It is only when we have plumbed some of the depths of misery and agony surrounding the presence of a disabled child in a family that we can begin to speak of pastoral intervention.

Not the Child they Wanted

As we stated at the beginning of this article, no family is ever fully prepared to welcome the birth of a disabled child. In certain parts of the world where prenatal diagnosis of certain disabilities such as Down's syndrome is now possible and mothers are given a choice on whether to abort or keep the baby, it is heart-warming that many mothers decide to keep their babies in spite of the challenges that may arise in raising such children. However in many parts of the world, especially ours, diagnosis is often made at birth or shortly after. The moment parents make the painful discovery their child is afflicted with either mental or physical disability can bring their world crashing down. As the Holy See's declaration affirms, “the trauma which derives from this can be so profound and can cause such a strong crisis that it shakes their whole system of values” (No 6).¹² In parts of Nigeria, this trauma is accentuated by cultural beliefs which tends to link the birth of a handicapped child with punishment from the gods. Parents of such children facing isolation and social ostracism are forced to hide such children from public view. Added to this is the conviction by certain persons who believe that close association with the handicapped child will bring bad luck to them. Some pregnant women have a sense of trepidation and foreboding when they encounter a handicapped child. The situation is not much different in the Western world. Andrew Solomon who has written extensively on this subject affirms that, “manifest disabilities affront parents' pride and their need for privacy; everyone can see that this child isn't what you wanted, and you must either accept the world's pity or insist on your own pride.”¹³ Pastoral care should ideally begin the very moment that parents make the painful discovery that their child is disabled. Pastoral care workers should intervene with great tact and diplomacy and avoid spiritual platitudes of quickly urging the parents to accept the disability of their child as the will of God. The first ministry should obviously be one of presence and support and continual and creative exploration of possibilities. Such families at the beginning will require understanding not judgment, empathy not pity, solidarity not exclusion, and a firm commitment

¹¹ Adamu Abuh “Buhari urged to sign Disability Bill”, *The Guardian*, Thursday, July 9, 2015, p.xvi.

¹² *The International Year of Disabled Persons*, The Holy See, 4 March, 1981. Vatican Council II, *More Post Conciliar Documents*, ed. Austin Flannery.

¹³ Andrew Solomon, *Far from the Tree, A Dozen Kinds of Love* (London: Chatto & Windus, 2013), p.19.

from pastoral care givers that though the journey may be long and tortuous, they would not travel the path alone.

Grief Without End

The birth or diagnosis of a child with disability represents a form of loss. As we grieve for the loss of a loved one so parents grieve for the loss of sight of a child that may never see or an autistic child who may never be able to independently care for himself all his life. It is therefore not unexpected that many parents generally, though not typically, on discovering that their child is suffering from mild or chronic disability go through a range of feelings associated with imminent loss. Elisabeth Kübler Ross in her study of terminally ill patients confronted with the reality of impending death identifies these feelings as denial, anger, bargaining, depression and acceptance.¹⁴ These gamut of feelings may not necessarily present themselves in the above sequence but they are present nonetheless at different stages. What makes grieving for a disabled child unique is that it is often a grief without pending closure. This is a reality that parents with normal healthy children can never comprehend. In a 1962 article, Simon Olshansky wrote: “Most parents who have a mentally defective child suffer chronic sorrow throughout their lives regardless of whether the child is kept at home or “put away”. The parents of a mentally defective child have little to look forward to; they will always be burdened by the child's unrelenting demands and unabated dependency. The woes, the trials, the moments of despair will continue until either their own deaths or the child's death. Release from this chronic sorrow may be obtainable only through death.”¹⁵ The goal of pastoral care is to mitigate to some extent this brutal reality.

Theological Issues

Manifest disability presents us with difficult questions about the goodness of God and His creation. If as we are told in the scriptures that we are made in the image and likeness of God (Gen.1: 26) and that God saw everything that he made and it was very good (Gen 1: 31), how do we explain the reality of children born with chronic mental and physical disability? Are they too made in the image of God? Is God a dwarf? Is He autistic? Does He suffer from cerebral palsy and is he blind, deaf and dumb? Necessarily then, a hermeneutic of disabilities will alter our image of God and redefine our understanding of his goodness and love. It means therefore that we must begin to factor in brokenness, ugliness, incompleteness, etc, in seeking to grasp the mysteries of creation. Secondly, chronic disability raises the question of personhood. What does it mean to be *human*? Is a person fully *human* simply because they are free from any physical or mental defect? Why do we insist that every child has a right to life even if at the embryonic stages there is evidence that the unborn child would suffer from chronic mental disabilities? According to the Holy See's declaration for the

¹⁴Elisabeth Kubler-Ross, *On Death and Dying*, (New York: Macmillan Publishing Co; 1969) chapters 3 & 4.

¹⁵Simon Olshansky, “Chronic sorrow: A response to having a mentally defective child”, *Social Casework* 43, No 4 (1962) , p. 190-194.

International Year of Disabled Persons, “In their view of faith and in the concept of man, Christians know that in the disabled person there is reflected in a mysterious way the image and likeness which God impressed upon the lives of his sons and daughters”.¹⁶ This indubitable truth does not lessen the confusion and agony often faced by persons living with disability or their families. There are no simple theological explanations to the reality of disability. Any form of disability is a form of imperfection and limitation. To some extent every person suffers from some imperfection and limitation. This is of little comfort though to parents raising a mentally retarded child who must constantly wonder why their child's imperfection sticks out like a sore thumb. In disability we are also confronted with the mystery of pain and suffering. The lack of open discussion of disability in church circles may stem from some form of theological uneasiness about the reality of pain and suffering as manifest in the lives of persons living with disability. In a culture where everything negative is attributed to evil forces, even children born with congenital deformities have been taken for 'deliverance' by parents who are assured by miracle healers that their child's condition may be the result of 'ancestral curses' or the handiwork of the devil or other enemies. When such children fail to 'be healed' it is attributed to the parents' lack of faith. Either way, the miracle healer has the final word.

The Scriptures and Pastoral Care for Disabled People

Does the scriptures offer us any model for caring pastorally for people with disabilities? A cursory glance at the both the Old and New Testaments reveal that not much can be mined by way of drawing models of pastoral care for disabled persons. In the scriptures generally, disability is viewed as a disease. The most frequent diseases mentioned in the bible are blindness, deafness, dumbness, leprosy and paralysis.¹⁷ As Otieno demonstrates, visual impairment is perhaps the most common form of disability in antiquity as we see in Isaac (Gen 27:1), Jacob (Gen 48:10), Eli (1 Sam 3:2 & 4:15) and Ahijah the Shilomite (1 Kings 14:4).¹⁸ However, for all these people their eyesight failed in old age. In the Hebrew worldview, disability like ill -health was often linked to sin and disobedience. Passages such as Lev. 26: 14-16 demonstrates the punishment that would accompany Israel's disobedience. Samson sinned against God through his eyes (Judges 14: 2). He was punished by having his eyes gouged out by the unforgiving Philistines (Judg 16:21) various encounters of Jesus with disabled people seems to also support the connection between disability and sin. See John 5: 14, Mark 2:1-2 where the respective healings are tied to the admonition to the person healed not to sin again. McColl and Ascough have argued that “the miracle narratives in the NT have fuelled destructive attitudes toward disability among Christians even to the present day”.¹⁹ It does seem that the Church follows

¹⁶The International Year of Disabled Persons, The Holy See, 4 March, 1981. Vatican Council II, More Post Conciliar Documents, ed. Austin Flannery.

¹⁷Pauline A. Otieno, “Biblical and Theological Perspectives on Disability: Implications on the Rights of Persons with Disability in Kenya” in Disability Studies Quaterly, Vol. 29, No 4 2009.

¹⁸Pauline Otieno, “Biblical and Theological Perspectives on Disability”

¹⁹Mary Ann McColl and Richard S. Ascough, “Jesus and People with Disabilities: Old Stories, New Approaches”, in The Journal of Pastoral Care & Counselling, Vol. 63 No. 3, 4 Fall/Winter 2009.

levitical teaching in setting the requirements for ministry. According to regulations set forth in Lev. 21: 16-23, any kind of physical imperfection constituted enough impediment to the exercise of priestly ministry. Thus, the blind, lame, the hunchback etc,` will not come forward to offer the food of his God. In spite of all these, however, there is ample evidence that people with disability are included in God's plan. When Israel is restored, the disabled would not be left out. In Isaiah 35:5-6 the author exalting in the triumphant return of the liberated Israelites says: "Then the eyes of the blind will be opened, the ears of the deaf unsealed, then the lame will leap like a deer and the tongue of the dumb sing for joy". Further passages in Isaiah indicates that disabled people factor in God's salvific plan for his people (See Isaiah 29:18; 33:23-24). The parable of the Great Banquet (Luke 14) is the most instructive of Jesus' attitude to persons living with disabilities. They like other people are welcome in the kingdom of God. In fact, he told the host who had invited him to a meal to give preference to the poor, the crippled and the lame whenever he threw a banquet (Luke 14:13). If for Jesus the kingdom of God was not complete without people with disabilities, so for us too, the church cannot be complete without them. Jesus constantly reached out to the sick and disabled with mercy and compassion. He in fact is the pastoral care giver *par excellence*. He fulfilled all the dimensions of pastoral care- advocacy, solidarity, inclusion and empathy.

Fashioning a Pastoral Care Plan

Developing a practical pastoral care plan for ministry to persons living with disability and their families is the responsibility of the worshipping community be it at the diocesan or parish level. This will entail a new way of doing things- changing of attitudes and orientation, breaking down the barriers of prejudices and discrimination. It will entail a lot of creativity and sacrifice which will require that pastoral care givers leave their comfort zones. A fundamental element in developing pastoral care for persons living with disabilities is advocacy.

A New Meaning of Advocacy

Over the years disability rights advocates have fought valiantly to ensure that the rights of disabled people are guaranteed in law and that legislations are enacted to secure these rights. In fact the UN declaration is hinged on the conviction that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person (Art. g). While this kind of advocacy is important (as we shall see later) it focuses rather on what can be done *for* persons with disability and not what can be done *with* them. Lowell G. Colston calls for a new kind of advocacy in doing pastoral care with disabled persons. For him, *advocacy* in this context would mean "calling out" the real potential of the disabled person, in other words to challenge him to become whatever is possible for him to become.²⁰ This goes simply beyond mere affirmative action or

²⁰Lowell G. Colston, "The Handicapped" in *Clinical Handbook of Pastoral Counseling*, eds. Robert J. Wicks, et al, (New Jersey: Paulist Press, 1985) p. 318

paternalistic tokenism. Disabled persons are not seeking for preferential treatment. Rather they demand equal opportunities to develop their potentials just like every other person. While the whole concept of special education is laudable, educators must realise that it is often not complimentary to be 'special' in the kind of way that disabled persons are regarded as *special*.

The kind of advocacy that Colston postulates requires knowledge. Many pastoral care workers, even ordained ministers, are often uncomfortable in the presence of a disabled person. They feel awkward and are often at a loss on what to say or do. The first rule is that you don't have to say or do anything. Disabled persons are just ordinary human beings who like other humans struggle day in day out to make the best of their lives albeit under the shadow of disability. Some mothers are afraid to let their healthy children play with disabled children. Whatever this fear is borne out of it is completely unfounded. Disability is not contagious. If it is for the fear of the healthy child hurting the disabled child they can play together under close supervision. But knowledge will eradicate some of the awkwardness we may feel around disabled people. As Colston says, "having a general knowledge of the struggles of the paraplegic, quadriplegic, the sight and hearing impaired, the neurologically impaired or deficient and others as they seek to be self-sustaining and productive as possible is important to intelligent preparation for pastoral care with such persons".²¹ It is therefore not out of place to recommend that seminaries and other institutes of formation should include in their pastoral formation of candidates some elements of special education. Placement for pastoral work should also include institutions and homes for persons living with disability.

A Unique Catechesis

A key area of pastoral care for persons living with disability will be catechesis. Persons living with disability of whatever form have a right to know their faith and enter fully into the richness of the Paschal Mystery. It is still a tragedy that most parishes in Nigeria do not have interpreters using sign language for the deaf. This has led to mass abandonment of the Catholic faith by the deaf community who have found succour in denominations such as the Apostolic Church and Jehovah's Witnesses (Watchtower Society) who have included in their churches trained persons who use sign language to communicate. The statement by the US Catholic Bishops on People with Disabilities states: "Evangelization and catechesis for individuals with disabilities must be geared in content and method to their particular situation. Specialized catechists should help them interpret the meaning of their lives and should give witness to Christ's presence in the local community in ways they can understand and appreciate (No 25)."²² Catechesis will also extend to other members of the congregation raising awareness that persons living with disability are part of God's family. However, the most potent catechesis would be concrete steps taken by the parish pastoral team to include capable persons living with disabilities in parish life. There is no reason why a blind man who is able to read and write and holds down a job not be a member of the parish pastoral council or the harvest committee. Other

²¹Lowell G. Colston, "The Handicapped" in *Clinical Handbook of Pastoral Counseling*, p. 320.

²²Pastoral Statement of U.S Catholic Bishops on People with Disabilities within the Church, (USCCB) November 16, 1978.

practical catechetical steps include the following:

- Take a census to identify parishioners and those with no church affiliation who may have significant disabilities. Some priests complain that there is only one hard of hearing person in their congregation. In fact for the sake of that one person, sign language can be introduced into the liturgy.
- Ministry with and not for. Most times we think of what we can do for people with disabilities and not what we can do with them. In order to avoid the twin dangers of paternalism and condescension, pastoral care givers should consult with such persons offering suggestions and seeking inputs on how they can enter fully into ecclesial life and make their own unique contributions.
- Keep the door always open. An open door is about attitudes and disposition. The parish remains the avenue for all baptized Catholics to live out their calling. If certain people feel shut out by the church's architectural design, or by a liturgy that takes no cognizance of the visually or hearing impaired then something is wrong. Provision of wheel chair accessible churches, ramps and rails, celebration of a liturgy that takes cognizance of the needs of the visually and hearing impaired, construction of toilet facilities that are disabled friendly, etc, are subtle but significant means of advocacy. The responsibility to create an inclusive and welcoming community rests squarely on the shoulders of the pastor and his pastoral team.
- Blind lectors and deaf ministers of the Eucharist. Many blind people familiar with the use of braille can read. Unless there are liturgical norms or laws which prevents them, there is no reason why a blind person cannot be guided to the lectern to proclaim the word of God using a braille script; or why a deaf person, after adequate training and catechesis, cannot become an extraordinary minister of the Eucharist. These gestures in themselves would speak more eloquently than hundreds of homilies.

Ministry to Families

Ministry to and with families of persons living with disability is one without end. As long as the disability remains and the challenges linger, there would always be need for pastoral care. Because children with mental retardation or those living with autism and Down's syndrome never really become independent, they in a sense, remain children forever. Such disabilities alter the reciprocity equation.²³ Mentally retarded adults require care and attention even as they grow older while their normal peers are raising families of their own. When these mentally retarded adults ought to be caring for their parents under normal circumstances, they are still being cared for. As such parents grow old they wonder what would happen to their children. For such parents, this is not an easy cross to bear. But if they receive support from the church the road to accepting the reality of their condition may not be too lonesome after all.

The first thing that pastoral care givers must offer is the ministry of presence and solidarity. Parents of chronically disabled children are smart enough to know that no *deus ex machina* is coming to take the

²³ Andrew Solomon, *Far from the Tree*, p. 23.

disability of their child away. All they require are persons who would stand by them in good times and in bad times. Knowing that there is always an abiding ecclesial presence can be a source of comfort and strength at very difficult moments. Parents of disabled children are confronted with a gamut of psychological and emotional challenges. Amongst these are fear and anxiety for the safety of their child, anger and bitterness at the reality of their condition, helplessness, hopelessness, inferiority complex, low self-esteem and sometime even a hidden delusion of reprieve²⁴ i.e., a false hope that somehow the disability would just disappear overnight. Pastoral care givers should ideally also have some experience of pastoral counselling. In the absence of such skills they must not fail to involve persons qualified to offer such services either from the pastoral or clinical perspective. It is heart-warming that a number of well-trained pool of clinical psychologists are now available in many religious institutes. Their services remain invaluable.

Ministry to Siblings

No matter how many healthy or normal children a couple has, the child with disability could become a constant source of anxiety as they seek to provide maximum welfare. The disproportionate attention given to this child can become a source of tension within the household. Siblings of children with disability cannot escape the pressures of living with a brother or sister whose physical or mental functions may be seriously impaired. They may experience a complex variety of emotions ranging from anger, frustration, bitterness, envy and guilt. For younger children, their friends may taunt and make jest of the disabled sibling. This in itself can breed inferiority complex. Siblings of children living with disability need to be helped to understand that the fault is not theirs that their brother or sister is blind, crippled or suffering from cerebral palsy. While the presence of a disabled member in a family can be a source of untold suffering and sorrow, it also has the capacity to bring out the best and noblest virtues in a family such as love, patience, understanding, kindness and empathy. A lot can be done for siblings through counselling.

Conclusion

The Holy See believes that care for persons living with disability entails continuous internship in the “school of genuine humanity.”²⁵ She declares, “The respect, dedication, the time and means required for the care of handicapped persons, even those whose mental faculties are gravely affected, is the price that a society should generously pay in order to remain truly human” (no. 1). It is a duty that can be shirked only at the risk of moral and spiritual petrification. The road of disability is a road less travelled. No matter how skillful a pastoral care giver is, he cannot completely mitigate the range of reactions, mostly negative, that the presence of a disabled person in a family generates. It is necessary however for families and pastoral care givers to set realistic goals

²⁴Delusion of reprieve is a psychological condition common among people on death row. It is that constant hope, sometime without basis, that somehow they would just be set free just moments before their execution.

²⁵The International Year of Disabled Persons, The Holy See, 4 March, 1981. Vatican Council II, More Post Conciliar Documents, ed. Austin Flannery.

and expectations. The fact of a disability may not be changed. But there can be a growth in the acceptance of the condition. New understandings may be reached, new insights gained. Attitudes may alter and meaning can be wrought out of meaninglessness. Furthermore, the current pervasive discriminatory attitude towards persons with disability is tinged with irony. Many faithful Christians who due to accident or illness are now confined to a wheelchair were perhaps those who contributed material resources for the building of magnificent cathedrals and other places of worship. Now, in their infirmity they cannot even gain access to some of those places. It can be humbling to come to the awareness that every person faces the possibility of imminent disability. It takes only an accident to turn a physically healthy person to an invalid. Perhaps at the end of it all, disabled persons and their families and their pastoral care givers may rest content in praying this age long prayer of Reinhold Niebuhr christened “The Serenity Prayer” :*God grant me the serenity to accept the things I cannot change, The courage to change the things I can, And the wisdom to know the difference.*