

**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 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

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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.”⁶The 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.

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.¹⁰As 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. 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.¹¹In 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).¹²In 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

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 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 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.