Disability and Pastoral Theology

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Research projects of the Melanesian Institute have provided me with opportunities to meet many families with members who are considered "disabled".[3] Some had congenital impairments that people are born with, such as cleft palate or club foot. Others had impairments following accidents such as falling from a tree or being pecked in the eye by a bird. Accidents as true causes of impairments are considered rare in Papua New Guinea. People might identify a biomedical cause in a fall or in contracting an illness such as malaria; but then would come the further question: why did he fall from the tree? Why did the bird peck out her eye? Why was he affected intellectually after becoming ill with malaria? Such questions seek answers at different levels, including the moral and religious dimensions. It is not just a question of "who" is responsible, but also whether the disabled person or their parents are being punished by another person, a spirit, or by God. This paper will address such questions from a Christian perspective.[4]

In the Wosera area of the East Sepik District, several people said how "smoke" had affected a person's eyes or "water" had got into their ears and that this was the "cause" of sight or hearing impairments. As we noted in our report, the implication was that this was not by chance, but that the smoke or water had been bespelled (Gibbs 2003:158.) Of thirty two interviewees in Lufa in the Eastern Highlands District, eight mentioned sorcery (*posin*) as a cause. Four of these sorcery cases were perceived as associated with jealousy, three were a form of revenge and one was accidental (unknowingly trespassing through a bespelled area targeted for another person). A significant number of physical, sensory or mental impairments are thought to be due to possession by demons, sorcery or witchcraft spells. From this perspective people with impairments are disabled due to external malevolent non-empirical forces, which require some form of ritual or reconciliation to counter or reverse the malevolent force.

Linking wrong-doing or "sin" and disability fits with aspects of the Biblical worldview in which bodily or intellectual impairments are seen to be caused by demons or to be punishment for wrong-doing. Nancy Eiesland (1994:71) interprets the Biblical story in which a paralysed man is lowered into a house by his companions (Lk 5:18-26) as an example of equating forgiveness of sin and physical healing. "Which is easier to say, 'Your sins are forgiven you,' or to say, 'Stand up and walk'?" Jesus tells a man at the pool at Bethesda: "See, you have been made well! Do not sin any more, so that nothing worse happens to you" (Jn 5:14). Passages such as these may be cited in support of claims that disability is a sign of moral laxity or divine retribution for sin.[5]

However, passages seemingly linking disability and moral laxity should not be taken in isolation. Paul conveys a very different message to the Corinthians when he tells them that "power is made perfect in weakness" "Whenever I am weak, then I am strong" (2Cor 12:9-10). Paul is not romanticising weakness, but pointing to God's loving concern for us in Christ. People are accepted as they are. Jesus did not focus on curing people with lack of ability.[6] Rather he paid particular attention to those who were socially excluded – such as the ten lepers (Lk 17:11-19). Jesus encountered the blind Bartimaeus by the roadside (Mk 10:46-52; Lk 18:35-43). He was healed and then found new meaning in life following Jesus along the Way.

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[3] I refer primarily to the time in the Wosera area of the East Sepik Province in 2002, and in the Yagaria speaking part of the Lufa District of the Eastern Highlands Province during 2006. Reports from these two projects are part of this volume.

[4] Physical, sensory and intellectual impairments vary greatly. Bringing them all together under the banner of "disability" is somewhat problematic. For example a child with an intellectual impairment and a child with sight impairment might both be classed as having a "learning disability" when in fact their needs are very different. I will try to refer to specific forms of impairment, however associating such diversity under the term "disability is acknowledged as a limitation in this brief paper.

[5] Such passages may be interpreted differently. For example a statement from the Brisbane Archdiocese sees the paralysed man's friends pulling the tiles off the roof out of compassion for and in solidarity with their friend so that he could meet Jesus and be in he midst of the gathering (Archdiocese of Brisbane 2009:7).

[6] The Archdiocese of Brisbane statement notes how in the letter to the Galatians (Gal 3:28) Paul writes, "There is no longer Jew, nor Greek, slave nor free, there is no longer male and female…" "To this we could add "able" and "disabled." In Christ we have a new relationship with one another (Archdiocese of Brisbane 2009:13).

Some evangelists today place great emphasis on miraculous healing. I have been to rallies in Port Moresby in which people with severe physical impairments are assisted to the stage where they can be prayed over and "cured." This practice is very risky. What happens if there is no change? Will they think that they did not have enough faith? The principal point of Jesus' curing the disabled and socially excluded is not so much to demonstrate signs and wonders, but to reveal the loving compassion of God. Admittedly Jesus says to the Samaritan leper, "Your faith has made you well (Lk 17:19) with the implication that faith leads to healing. We see in the gospels that Jesus does associate faith with healing, but, as Reynolds (2008:38) notes, he does not reverse the logic to equate healing with saving faith. Probably many who became faithful followers were not also cured of their disabilities.

We must be careful not to trivialise disability with pious responses. I have heard sermons in which disabled persons are likened to "the least of these" – helpless people in need of grace and objects for charitable goodwill. Such an attitude leaves one open to condescending acts of care and assistance which can be disabling – reducing people to helpless victims. Such attitudes are directed less towards the disabled person and more towards helping the "helpers" feel better about themselves.

Reference to "redemptive suffering" likewise can be misguided.[7] Disability is sometimes represented as temporary affliction that must be endured to gain heavenly rewards (Eiesland 2004:72). Such an approach too easily rationalises suffering as intended, or even directly caused by God. It also promotes passivity and resignation or social exclusion. The idea of virtuous suffering has encouraged persons with disabilities to go along with social barriers and second-class status as a sign of obedience to God. It sanitises impairment by explaining it away in terms of the potential good it produces. In fact, weakness and suffering do not always yield character virtues; nor do they necessarily produce moral insight for others (Reynolds 2008:42). It could be that God enhances the spiritual capacities of disabled people, but it is not helpful to infuse disability with romanticised moral meanings. Life is a mixed blessing and we are all called to carry our cross in diverse ways.

During fieldwork in the East Sepik and Eastern Highlands and in my experience in the Enga Province, I did not encounter instances of persons with impairments being abandoned or totally segregated from the family or community. There were tales of babies born with major deformities being allowed to die, but having survived through the first months and been accepted as a member of the community, generally persons with physical, sensory or intellectual impairments are cared for. This is in contrast to accounts of stigma and discrimination against people who contracted AIDS.[8]

Disability indicates the perception of an inability to perform designated tasks or activities considered necessary within a social environment. How is disability socially constructed in Papua New Guinea?[9] Our research has found that cultural, social and personal factors intervene in defining social disability. Communal/cultural factors include: isolation and not being able to participate in communal activities, dependence, shame, fear and stigma, labels, and the type of impairment. Social factors include status, sex, age and marital status. An important personal factor is the person's own attitude to his or her impairment.

Social disability is culturally constructed, and activity limitation, impairment and problems of participation depend on how the community and the impaired person him or herself defines them. Being married and raising a family and contributing with pigs, money or labour to the community appear to be important factors in defining a person as socially-abled. Some people have impairments that make it difficult for them to perform tasks that are considered "normal," yet by contributing to the community they come to be regarded as "normal" people. One must note, however, that the "normal" is relative to a group's values and aspirations, and conversely so what is considered "abnormal" (disease, disability, etc.) (Reynolds 2008:48).

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[7] I am not criticising Pope John Paul II's Apostolic Letter *Salvifici Doloris* (Salvific Suffering) here. The Apostolic letter contains many valuable insights.

[8] The early negative reaction to AIDS was one of self-defence; people thinking that the HIV virus could spread like other wind-borne or water-borne diseases. Education is helping to bring greater acceptance. See Gibbs and Mondu 2010, and the film, *World AIDS Day in Mendi 2008*.

[9] Social construction of disabilities will no doubt vary in different countries. For example, autism figures as a significant disabling condition in Western countries with sophisticated testing facilities. I have found little or no reference to autism in PNG. No doubt it exists, but is not recognised as such.

Personal appearance and aesthetic qualities are a factor in choice of friends and marriage partners in Papua New Guinea as elsewhere. Yet, in Papua New Guinea there is a deeper dimension associated with outward appearances. Beauty is not only in the eye of the beholder but also the result of the moral state of individuals in relation to their group. Social information is contained "on the skin" (O'Hanlon 1989). Personal appearance may convey messages not only of strength and life, but may also evoke shame and embarrassment.

Parents may feel ashamed if culturally a severe impairment such as cerebral palsy in their child would be are attributed to the father or mother having broken taboos associated with pregnancy and childbirth, or taboos on entering places inhabited by *masalai* spirits. Impairments in children can also be interpreted as a situation where the parents have tried to work sorcery on someone and the sorcery has "turned back" to "hold" their child.

To some extent disability is culturally constructed through the ways people talk about it. Often people are called nicknames connoting their impairment, for example, *hanbruk* (deformed arm). Thus there is a tendency in Papua New Guinea to define a person by their impairment. People with impairments may accept these labels, but sometimes resent it, resulting in both personal and social alienation. Terms such as *longlong* (crazy), or *hapsens* (idiot), are terms used to isolate and separate persons from what is considered whole and "normal" – that is, what fits in with the ways things "should be." Mary Douglas has written at length about the corruptions of ideal forms embedded in social conventions (Douglas 1966).

Illness can cause disability and disability involves social restrictions that follow from impairment. But it is incorrect to think of people with disabilities as "sick." Nonetheless, there is a tendency in Papua New Guinea and elsewhere to consider disability using a "medical" model. This perspective considers disability as an intrinsic problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by health care personnel. Management of the disability is aimed at curing or adjusting the individual and changing his or her behaviour to make the person as "normal" as possible.

While many people do benefit from corrective measures, there are underlying limitations to this model. The focus, using the medical model, is on what one cannot do rather than what one can do. Attention is focused on the impairment rather than the needs and expectations of the person. The perspective links to stereotypes of disability that easily lead to pity and patronising attitudes. People with disabilities themselves are led to think about how much more they might do if a cure could be found. In internalising these negative views people with disabilities can easily develop feelings of low self-esteem and enter into a cycle of dependency.

Other approaches have been tried. For example, it is now recognised that dealing with disabilities is a collective responsibility requiring the participation of the whole community. Such a perspective is not new for Papua New Guinea, but it has impacted on institutions specifically for disabled people and placed greater emphasis on the integration of students with impairments into the regular school system. I have had the joy of being present for musical items with keyboards and guitars played by blind and deaf children attending Sacred Heart Primary School at Faniufa, Goroka. The point is that if the school environment is adapted for such persons, the disability can diminish or become irrelevant.

Some people define the issue of disability as a question of human rights. The United Nations *Convention on the Rights of Persons with Disabilities* (2006) seeks to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities. The convention is based on principles such as equal opportunity, accessibility and full and effective participation and inclusion in society.

I support the human rights approach, but feel that more can be said about the inherent dignity of the human person. As Reynolds notes, "Disability does not mark an incomplete humanity – a failure, defect, or sinful nature (2008:186). Living with impairments is a way, like other ways, of being human. Starting from childhood, we are all dependent and vulnerable in various ways. As we mature most of us do attain a certain degree of independence and security, though that may diminish with old age. However, none of us are perfect. We depend on our environment to live and upon others in society in order to flourish. Even with the advances of development and science, there are still those who could be classed as "non-persons" – people disabled by the social systems in which they are marginalised. Among us are people living with physical, sensory and intellectual constraints. Yet, we are all part of the one human family and in seeking the best for individuals we contribute to the common good.

It is important to recognise grace and dignity in the experience of disability, but not avoiding the disillusionment that often accompanies a life that is different from that of many people. The painful reality is expressed well by Jean Vanier who started the L'Arche communities for people with intellectual impairments.

> Much of my life over the last twenty years has been with men and women having a mental handicap. I have seen and touched their pain: the terrible pain of being a disappointment to their parents. They feel weak, unable to cope with life which moves so fast around them. This feeling of not being wanted, just as they are, engenders a sense of guilt. They feel they have hurt their parents, because they are not a cause of joy but rather a source of worry and pain (Vanier 1988:12).

An important dimension in relating respectfully with people who have disabilities is one's attitude and the terminology used. In English one hears reference to people being "crippled," or "confined to a wheelchair." In Papua New Guinea, people often use the Pidgin term *nogut* as a modifier: *lek nogut* (literally "bad leg"), or *ai nogut* (literally "bad eye"). Local languages also tend to talk about what people aren't rather than what they are. In Wosera in the Sepik, people with physical impairments are referred to as *kaprae*, meaning bad/ruined/not good. They also used modifiers meaning "blocked" or "dead". In the Lufa district of the Eastern Highlands, people with mental disorders or persons with epilepsy are called *degi*, meaning dumb/deaf/crazy/unknowing. Those with hearing difficulties who cannot speak are called *degi*. An abled person who does something wrong can also be called *degi* meaning that they are very foolish. People use the term *degi* after a person's name to identify them as *degi*, eg. John Degi. What does it mean for a person to be continually labelled with a negative term such as that?

Fortunately, in Papua New Guinea, there are a number of sources of assistance and support. Callan Services with branches throughout the nation is a leader in this field. There is a PNG Assembly of Disabled Persons with its primary focus on advocacy and promotion of the rights of people with disabilities, and also the PNG National Network of Women with Disabilities. The Network of Women is asking for an initial five percent quota to increase the numbers of women with disabilities in government departments. There is an excellent quarterly newsletter called *The Network* coming from Divine Word University. A recent edition of the newsletter (#20) lists a number of myths about people living with disabilities whereby it is assumed that they are not at risk of contracting sexually transmitted infections, but in fact they are at risk. Indeed some disabled people live with the "triple burden" of disability, poverty and HIV&AIDS.

Community Based Rehabilitation (CBR) programs are in place in various parts of PNG. This is an area where one would expect churches to be particularly supportive of programs that enhance the quality of life for people with disabilities. Most often such programs rely on voluntary service – which can be both their strength and their weakness. Ideally they are embedded in the community creating a sense of ownership, yet care givers need support too lest they tire and become discouraged.

Ultimately pastoral work with disabled people is not about "them" but about "us". People with disabilities call us to acknowledge our own human weakness and vulnerability. As Jean Vanier says,

> I have learned more about the Gospels from handicapped people, those on the margins of our society, those who have been crushed and hurt, than I have from the wise and the prudent. Through their own growth and acceptance and surrender, wounded people have taught me that I must learn to accept my weakness and not pretend to be strong and capable. Handicapped people have shown me how handicapped I am, how handicapped we all are. They have reminded me that we are all weak and all called to death and that these are the realities of which we are most afraid (Vanier 1998:39-41).

The Gospels tell us of a "Disabled God" (Eiesland 1994). "Christians do not have an able-bodied God as their primal image. Rather, the Disabled God promising grace through a broken body is at the centre of piety, prayer, practice, and mission" (Eiesland 1994:11). Jesus' wounded body retains its scars after his resurrection. So, rather than do away with impairments and the capacity to suffer, the resurrection transforms vulnerability into a communion with God. Pope Benedict XVI refers to the image of the wounded Jesus in his first pastoral letter *Deus Caritas Est*.

> Faith, which sees the love of God revealed in the pierced heart of Jesus on the Cross, gives rise to love. Love is the light—and in the end, the only light—that can always illuminate a world grown dim and give us the courage needed to keep living and working. Love is possible, and we are able to practise it because we are created in the image of God (*Deus Caritas Est* 39).

Every human being has the image of God in common expressed in variety and difference.

Are people with disabilities or their parents being punished by another person, a spirit or by God? Responding to such a question in the Papua New Guinea context opens the whole discourse on malevolent spirits, sorcery and *posin*. Responses to issues of sorcery and *posin* may be found in publications such as *Sanguma in Paradise*, *Point* 33 from the Melanesian Institute (See Gibbs and Wailoni 2009). Here I limit my response to one based on Christian faith.

I see little point in pursuing theological arguments about "the problem of evil," particularly in this context, as it would imply that disability is associated with "evil" – an argument which I do not support. Rather, it more helpful to refer to Scripture, particularly the Gospels and note how God's reign privileges the vulnerable and the weak. We are presented with an image of table fellowship as a divine banquet in which the last are first and the weak have a special place, not because they are cured and strong, but because they are more ready to accept being welcomed by God for who they are. "Wholeness and healing run deeper than the restoration of bodily function, for becoming able-bodied is not the criterion for membership in the kingdom" (Reynolds 2008:226). Everyone has something unique to offer the human family and the reign of God. We welcome people, not because of what they can offer, but for who they are, and in welcoming such persons, we welcome Christ (Mat 25:45).

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