

Evangelical Review of Theology

EDITOR: JUSTIN THACKER

Volume 34 • Number 1 • January 2010

Articles and book reviews reflecting global evangelical
theology for the purpose of discerning the obedience of faith

Published by



for
WORLD EVANGELICAL
ALLIANCE
Theological Commission

Lessons from My Daughter

Reflections of Church and Ethics

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KEYWORDS: *Utilitarianism, ethics, life, death, disabilities, handicap, Church, value, Peter Singer, compassion, personhood, church mission, strategy, theology.*

ON NOVEMBER 23, 1993 we were suddenly thrown into the unknown country of people with disabilities and their families. Our daughter Karis was born with cerebral palsy. All four hemispheres of her body suffered movement damage. She depended completely on us for all tasks like eating, getting dressed, brushing her teeth, combing her hair or using the toilet. She never talked. Communication was limited to her eyes, crying and smiling. We never knew her favourite food, her dreams or feelings, her likes or dislikes. Karis never walked, nor sat up by herself. Holding her head up was impossible. She lived her life strapped to a wheel chair or some other therapy apparatus. During her seven years of life she visited more doctors and therapists than my wife and I combined.

Slowly we realized this was a huge and wide-open country. We asked ourselves, where was it before? Why had

we not seen it? Certainly there are people with disabilities around. What does society do with such people and their families? Families bear the stigma and feel embarrassed. Therefore, these people are ignored, institutionalized, or abandoned to public charity. This forced us to evaluate our ethics of life and society.

We also noticed, with horror, that influential philosophers and ethicists have proposed that these individuals are not even persons and do not have the same rights as normal people. These scholars created a 'Quality of Life' concept and applied it to people with special needs. The argument is that since the quality of life of these individuals does not reach their criteria, their life could (and even should) be terminated. This includes people of all ages; children like our daughter, elderly who cannot work, quadriplegics, fetuses with health or mental problems and so on. Further complicating matters, the ethicists redefine personhood, adding the category of 'non-human persons' (basically primates) and bestow upon them the same rights that 'human persons' have. Therefore, technically, and legally in some coun-

tries, such 'non-human persons' have, according to this philosophy, more right to life than our daughter had.¹

This was just the beginning of our journey in this new world for us. We thought that we would find compassion, understanding, empathy, help, rest, and a friendly hand in the church and the Christian community. Instead, we found the same utilitarian ethics as in the secular world. For most believers, including the majority of our family members, there were two options: either God heals her or takes her away. They asked, 'What sense does it make to live like that? Isn't it better that God takes her away instead of letting her suffer here?' Innocent questions, but behind them we discovered the same argument secular scholars proposed. These questions also showed us the urgent need to evaluate seriously our ethics. The church, where supposedly the ethics of the Kingdom of God is proposed and practised, has bought into, consciously or unconsciously, the secular ethics of the day. The church should be the voice for the mute, eyes for the blind, hands for those who cannot produce, and feet for the lame. Rather, it seems to want to eliminate these people because they cannot contribute, or bring a monetary offering, nor can they help with numerical

growth. Some pastors even go as far as telling the parents of special needs children that they are welcome in church, but without their children.

Just think for a moment: how many congregations do you know with an intentional ministry to special-needs people and their families? How many include simultaneous translation for the deaf? How many Sunday schools include Down syndrome kids? Are people with special needs involved in the leadership of the church? We could go on and on. This reality should make us feel at least embarrassed. This shows us clearly the need for believers to consider their ethics seriously.

Such an ethical void, or ethical adaptation, became even more acute when our daughter died in January 2001. The death of a child is unnatural. It isn't normal for parents to bury their children. As believers, death makes us cry out loud from the deepest part of our heart, 'let your kingdom come'. Death is our enemy. But, in our case, for most of the believers who came to comfort us, our daughter's death was the best thing that could have happened to her and to us. For those people she was better off dead. They were not that blunt, but the message was clear, she is better off now, no more suffering and pain. That was too much for us to bear. Would anyone in their right mind say that to parents who are burying their seven-year-old 'normal child'? Yes, Karis lived with much pain and suffering, but how much better to search for ways to alleviate the pain and not celebrate death. Is not our God pro-life? Are we not supposed to promote life? So then, why did they keep telling us that it was better for our daughter to die?

1 See, Paola Cavalieri and Peter Singer, eds., *The Great Ape Project: Equality Beyond Humanity* (New York: St. Martin's Griffin, 1996), Joseph Fletcher, *Humanhood: Essays in Bio-medical Ethics* (Buffalo: Prometheus Books, 1979), Helga Kuhse, ed., *Unsanctifying Human Life: Essays on Ethics / Peter Singer* (Oxford: Blackwell, 2002), Peter Singer, *Rethinking Life and Death: the Collapse of Our Traditional Ethics* (New York: St. Martin's Press, 1994).

The church has let the world convince her that the criterion to define the value of life is its utility, its capacity to produce. If anyone, like our daughter for example, cannot produce, her life is meaningless, worthless. The church has adopted an ethics in which utilitarian criteria are predominant.² For utilitarian ethics the moral task today is to reach the highest happiness and the lowest pain. It does not matter if that implies induced death for a terminal patient, or abortion of fetuses with genetic or other malformations. Indeed, isn't life with limitations unhappy?

The same utilitarian ethics can also be found in the church's mission strategies and theories. Most Christian mission today is about reaching the highest numbers, in the shortest time, with the lowest costs and the best profits. Such a definition of mission leaves out the weak, the orphan and the widow, the poor and displaced, because they bring only problems and meagre offerings. This is definitely related also to a deficient theology.

We need to recover the doctrine of creation. God is the Creator of everything, and all people, including people with special needs. He is also the Sustainer of the whole universe. He is very much involved in all aspects of his creation. He did not create us to abandon us. Also as important, is the doctrine of

God's providence and sovereignty. God has always had control of the universe. In his self-revelation he presents himself as compassionate, merciful, just, holy, eternal, and loving. He is the redeemer; he takes the initiative to reach us. His mission is to restore his rebellious creation through his transformed people—the church. God created human beings as his image-bearers independently of how much they produce. However, after sin entered the world, death was manifested in all areas of human life. We see the effects of death in the oppression of the poor, in economical inequality, in kidnapping, unjust laws, political corruption and violence.

My wife and I experienced the effects of death not only when our daughter passed away, but in the uncomfortable rejection of many, including believers. Today those who grieve are to be left alone. We have forgotten the biblical text, 'Mourn with those who mourn'. As a couple and as a family, we constantly grieve the death of our dreams. Our daughter will never play sports, graduate, or get married; milestones in the process of life. Death hurt us every time someone told us, that for her, she was better off in heaven. Death was better for her. Even though our daughter could not produce, neither could she invest anything in the economy, she was a bearer of God's image and that was more than enough reason to have lived. How come the church has accepted so much utilitarianism without even thinking twice about it? I think we need to return to Jesus' model of life.

Jesus' importance goes beyond soteriology. He is God's personal revelation in human form. Jesus came to

2 Utilitarianism is defined as *'the rightness or wrongness of an act or moral rule is solely a matter of the nonmoral good produced directly or indirectly in the consequences of that act or rule.'* J. P. Moreland and William Lane Craig, *Philosophical Foundations for a Christian Worldview* (Downers Grove: IVP, 2003), 433.

show us how to accomplish God's mission. He was God incarnate, dwelling among us. He came to serve, to give his life for many. Jesus constantly departed from the orthodoxy of his time. He let children come to him. He included women among his followers. He did not care about the ceremonial contamination when touching the dead body of a widow's only son. He took time to restore the dignity of a chronically unclean ill woman who had touched him. He stopped a successful meeting to heal a paralytic who came through the ceiling. He confronted the religious leaders who wanted to kill him for doing good on the Sabbath. He promoted life, and paradoxically, it was through his death on the cross that he conquered death to give us life eternal. Jesus is the Saviour of the world and the incarnate one *par excellence*.

Therefore, what can we do to stop the assimilation of utilitarian ethics by

the church? Our praxis has to follow Jesus' model of promoting life. We need to learn and practise the Kingdom's ethics. The church must be compassionate towards those in need. It has to include the poorest of the poor, the needy, orphans, widows and those who suffer daily the results of death. The church is called to respect the dignity of human life, because we are the bearers of God's image. We are to become the advocate of those whose basic rights are denied. The church needs to say 'no' to big numbers and big investments, and return to defending and promoting life in its fullness. We are called to reject any and all systems that promote death and support wholeheartedly those that respect all human life. Let's be actively searching for people with special needs in our neighbourhoods to serve them and their families with the love of Jesus.

Faith Lacking Understanding Theology "in a Glass Darkly"

Randal Rauser

In an attempt to put mystery back at the heart of Christian theology, Randal Rauser leads the reader on a riveting and, at times, unsettling journey through the major doctrines encapsulated in the Apostles' Creed. In each case he illustrates how a theoretical understanding of the doctrine as yet eludes us. We simply do not know, for example, what it means for God to be Trinity, or how Christ can be both human and divine, or how the atonement works. However, Rauser shows that the journey of thinking theologically – which arises out of a love for, and worship of God within a communal atmosphere – is as important as the end result of achieving doctrines that approximate reality. In this way the author seeks to steer us on a middle course between the twin errors of evangelicalism (heightening the doctrine) and liberalism (heightening the process). This is a gripping, clearly written and unique introduction to honest and humble Christian theology for an emerging culture.

Randal Rauser is Assistant Professor of Historical Theology at Taylor Seminary, Edmonton, Canada.

978-1-84227-547-4 / 216 x 140 mm / 192pp (est.) / £10.99

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