

Who or What? The Exclusion that Knows No Name

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A STORY OF EMBRACE OR EXCLUSION?

It's early one morning the day after I had attended the consecration of an Australian bishop. I sit in the car and, as a light shower falls, cry tears that well up from deep within. I struggle to understand why. It has all been sparked by the headlines I am reading and the experience of the consecration service the day before. On reflection, I recognise a deep sense of pain and exclusion, an ongoing grief, as issues that I feel deeply about are not even recognised as issues.

Yet the triumphal headlines seem so positive as I review the paper. They talk about how, at a service of consecration and installation, the new bishop had a ceremony which saw him greeting the state's Aboriginal people, receiving a gift of soil from Aboriginal elders. Yet I remember being appalled at the way in which this was done, and at how it reflected an ableism¹ that is not even recognised.

At the ceremony several elderly and obviously disabled Aboriginal elders had to clamber up stairs, carrying a heavy tub of earth, and then go to greet the bishop who was sitting on his cathedra. Rather than arrange a ceremony where the Aboriginal people could participate on an equitable basis and not have the obvious barriers of stairs, and rather than arranging for the non-disabled bishop to take the metaphorical first step towards the Aboriginal community, yet again I was greeted by a Church which practises ableism — and does not even realise it. Likewise, a media which does not even recognise ableism, and certainly doesn't put it on the front page as a media moment.

My tears were testimony to an ongoing spiritual pain that many of us who live with or care for someone with disability know: a searing pain of exclusion. A pain whereby — despite my many articles, the amount of speaking about what we claim as the issues, and the way in which those of us with disability have sought to change the Church's attitudes — here in the midst of a ceremony which should be truly about reconciliation and affirming Christian virtues, we see ableist values perpetuated.

Thinking about the last twenty years, I reflect that the Church listens quietly, makes a few pious statements about 'the disabled' — those people fortunately over there (... 'thank God') — and proceeds onwards with its ableist values largely unchanged. That particular moment — and its portrayal the following day — said everything to me about a spiritual community which excludes modern-day lepers, and a media which sees disability as a special interest filler as opposed to a headline leader.

Of course, the exclusion I was experiencing was to some extent not different from exclusion within the general population, except a lot of secular venues have actually become wheelchair accessible; whereas many Church venues have not even bothered, despite the ageing nature of church attendance and anti-discrimination laws.² Yet it was also a spiritual pain — a pain about

¹ Ableism is a concept similar to sexism and racism.

² For early commentary on this, see for example: Newell, C. 'Reflections on the Church and people with disabilities',

how disability is to be excluded from any notion of the sacred or shared humanity. That's brutal. That's painful. That's life.

As I reflected, I had to recognise that my tears were not just about a particular moment of exclusion, and certainly not about an evil bishop, but an unacknowledged history and continuing experience of apartheid. As Kathleen Ball reflects on the 20th anniversary of the International Year of Disabled Persons:

We have made some legitimate gains in terms of physical access but the real problem is yet to be fully addressed. Negative attitudes towards people with disabilities are rife in the community. If we are to achieve any sense of true emancipation, we must fight attitudinal barriers to equal participation in all aspects of community life. Nothing is really going to change until we do.³

By now, some in this room who do not have disability may well have responded strongly to my suggestion that disability is a form of apartheid. For me, the interesting thing is that Christian and other faith communities have largely tended to mirror secular values, rather than actually taking on board and living some of the better aspects of theology. If in doubt that we don't just have spiritual apartheid but also a secular apartheid, and that these are inter-related, let's reflect upon a few recent moments in Australia's history.

AUSTRALIAN HISTORY AND ABLEISM

For me, the ultimate experience of segregation was found on the road to the triumphal Opening Ceremony of the 2000 Olympics. We forgot about people with disability — something which might be risible except, of course, that it is quite normal.

The opening ceremony recycled an all-important Australian myth: a triumphant country where egalitarianism and mateship are truly celebrated; anyone is welcome and all can make it. The ceremony perpetuated the myth reignited on the front pages of our daily newspapers and television screens when the Torch landed in Australia: a special moment for all Australians, we were told. As it travelled across the country, the Torch, time and time again, was portrayed as healing the rifts in Australian society — one Australia; one people. The Torch, we were told by the *Melbourne Age* for instance, ignites 'the spirit of the Games'. Nowhere, however, does the Australian media name an Australia which knows apartheid in the actual presence of 'The Games' and its dominant (massively so) representations by much of our media.

This situation flags an apartheid that knows no name — the situation of people with disabilities, in relation to wider society. This deep social structure is artefactually represented in the exclusion of people with disability from the Olympics and the accompanying creation of a special separate event — the Paralympics — with its own special, small 't', torch relay. Australians with disability know apartheid — and not just because of the Olympics. We are deviants routinely given special housing, special taxis, special transport, special education, special accommodations — and, yes, even a special sporting event just for ourselves. We are so special; how could anyone complain?

While clearly not intended to do so, the Olympics and near total exclusion of people with disability from it show how far society has not come regarding disability. It has a spiritual

³ *St. Mark's Review*, no. 143, Spring, 1990, pp. 26-28.

³ K. Ball, 'Then and now: The 20th anniversary of the International Year of Disabled Persons', *Link Magazine*, October 2001, Vol. 10, no. 4, p. 14.

dimension, as it tells us what is important about humanity. For some of us, the Opening Ceremony was not a jewel in the crown of a 'relaxed', cosmopolitan Australia — efficient, friendly and creative all in the same spectacle — rather, it constituted a painful reminder of inequity and injustice. The Opening Ceremony made it plain, in the putatively democratising discourse of one of the largest global media events of all time, that the artificial divide between the Olympics and Paralympics perpetuates the discourse of 'special needs' and 'special events'; excluding people with disabilities from full membership of the moral community.⁴

Another recent key policy moment is to be found in the Constitutional Convention and resultant referendum with regard to whether or not Australia should become a republic. In all of the proceedings of the Convention — in an inaccessible venue I might add — the implications for just about every grouping except people with disability were mentioned. Do a search of the proceedings. The only reference to disability is found in derogative ableist comments.⁵ Yet 19% of the community has a disability. Nowhere did the debate explore how people who are disadvantaged or on low incomes could aspire to be president — a harsh mockery of the Australian egalitarian myth.⁶

We even know exclusion in the Disability Support Industry. As Kathleen Ball comments further:

Our lives are governed by legislation. Carers refuse to handle our bodies without the protection of latex ... our bodies remain the property of those who lift, dress and wipe. Women with disabilities continue to be sterilised and when we do reproduce, over one third of our children are removed from our care. Quite often, our pregnancies are terminated against our will. We are raped by institutional staff and yet forbidden to engage in consensual sex. Our finances are *managed* and our lifestyles are regulated by *duty of care*.⁷

I could go on and on about almost every section of society. Yet for me it is an exquisite irony that it is actually a theologian that can help us to understand the apartheid that knows no name, when the lived life of the Church can be so exclusive.

EXCLUSION AND EMBRACE

In his stimulating book *Exclusion & Embrace*, Volf⁸ reflects on the way in which being different has come to be defined as in itself evil. Whilst he doesn't address the situation of people with disabilities explicitly, he certainly does address other forms of exclusion from our moral community, including issues of ethnicity, gender and race, as he explores notions of identity, otherness and the spiritual dimension of reconciliation.

Volf recognises that exclusion has two inter-related aspects. First, it can entail the cutting of bonds that connect: 'taking one's self out of the pattern of interdependence and placing one's self in a position of sovereign independence'. 'The other' then becomes either an enemy to be pushed or driven away or even a nonentity 'that can be disregarded and abandoned'. Secondly, exclusion can involve the erasure of separation, whereby we do not recognise the other who in his or her

⁴ For further discussion see: G. Goggin & C. Newell, 'Crippling Paralympics?: Media, disability, and olympism', *Media International Australia*, November 2000, no. 97, pp. 71-84.

⁵ *Report of the Constitutional Convention*, Old Parliament House Canberra, 2-13 February 1998, 4 Volumes, CanPrint Communications, Canberra, 1998.

⁶ S. Vizard, *Two Weeks in Lilliput*, Penguin Books, Ringwood, 1998.

⁷ *Op.cit.*

⁸ M. Volf, *Exclusion and Embrace: A Theological Exploration of Identity, Otherness and Reconciliation*, Abingdon, Nashville, 1996.

otherness belongs to the very pattern of interdependence. 'The other then emerges as an inferior being who must either be assimilated by being made like the self or be subjugated to the self.'⁹ This doesn't just apply to people with disabilities but on the grounds of race, ethnicity, sexuality; whatever form of difference exists.

Volf goes on to look at the anatomy and dynamics of exclusion, exploring in fundamental ways the ministry of Jesus and how, by renaming and remaking, He fundamentally challenged any form of exclusion; calling us to embrace.¹⁰

STORIES AND FAITH TRADITIONS

By now you may be shifting uncomfortably, pondering why this person is imposing his Christian story upon me. This may be particularly pertinent for those of you who are not Christians. My point is not to suggest that Christianity is the only way. Rather, I would suggest that we need, at this conference, to engage in telling our stories found within a variety of spiritual traditions. It is not about privileging particular traditions, but actually discerning the wisdom within them. For example, as the Dalai Lama writes:

Sometimes we humans put too much importance on secondary matters, such as difference of political systems or economic systems or race. There seem to be many discriminations due to these differences. But comparatively basic human well-being is not based on these things. So I always try to understand the real human values. All these different philosophies or religious systems are supposed to serve human happiness. But there is something wrong when there is too much emphasis on these secondary matters, these differences in systems which are supposed to serve human happiness. (Address 1981)¹¹

In our telling and sharing stories, we inevitably encounter and explore the spiritual dimension of our lives; particularly as they interrelate with disability. Evelyn Crotty talks of spirituality in terms of 'What it means to live, feel, see, experience and touch more authentically the sacred around me'.¹² Think of it, despite all of the exclusion, disability is a vital component of the spiritual. In exploring the concept of spirituality, we can also learn from Miriam-Rose Ungunmerr-Baumann, an Aboriginal Elder from Daly River, who expresses spirituality this way:

What I want to talk about is a special quality of my people. I believe it is the most important. It is our most unique gift. It is perhaps the greatest gift we can give to our fellow Australians. In our language this quality is called Dadirri.

Dadirri is an inner, deep listening and quiet, still awareness. Dadirri recognises the deep spring that is inside us. We call on it and it calls to us. This is the gift that Australia is thirsting for. It is something like what you call 'contemplation'. A big part of Dadirri is listening.

In our Aboriginal way, we learned to listen from our earliest days. We could not live good or useful lives unless we listened. This was the normal way for us to learn — not by asking questions. We learnt by watching and listening, waiting and then acting. Our people have passed this way of listening for over 40,000 years. My people are not threatened by silence. They are completely at home with it.

⁹ Ibid., p. 69.

¹⁰ Ibid., pp. 72-76.

¹¹ M. E. Bunson (Ed), *The Dalai Lama's Book of Wisdom*, Rider, London, 1997, pp. 58-59.

¹² E. Crotty, 'Spirituality and Justice', *Ministry, Society and Theology*, vol. 12, no. 2, November, 1998, p.65.

They have lived for thousands of years with Nature's quietness. My people today recognise and experience in this quietness the great Life-giving Spirit, the Father of us all. We all have to try to listen to the God within us, to our own country and to one another. Our culture is different. We are asking our fellow Australians to take time to know us; to be still and to listen to us.¹³

In exploring the spirituality of indigenous people, we can see some startling similarities with the emphasis upon silence and relationship with others found in the Judeo-Christian tradition. Indeed, as I understand our indigenous spirituality and its emphasis upon the importance of the land,¹⁴ we can also find some similarities with the Hebrew Bible. Land as sacred space and as an integral part of spirituality is perhaps one of the most under-realised aspects of the Judeo-Christian tradition.¹⁵

What I am suggesting here is that we need to reclaim — via storytelling unashamedly rooted within our particular spiritual traditions — disability as an inherent and indeed vital part of the spiritual fabric of our lives. When we exclude disability, not only do we perpetuate oppression, but we actually commit a form of spiritual abuse as we deny the sacred which can be encountered within the experience and lives of those who live with disability, and those who care for those of us living with disability.

Volf goes on to suggest that we may find exclusion via naming, such as the division into clean and unclean people, clean and unclean foods, whereby we know that 'X', the superior 'in group', is better than 'Non-X', the inferior 'out group'. He writes: 'Central to ... strategies for fighting exclusion is the belief that the source of evil does not lie outside of a person, in impure things, but inside a person, in the impure heart'.¹⁶

In extreme cases, we can kill and drive out. Likewise, we can assign to others the status of inferior beings and, increasingly, we can practise exclusion as abandonment. Because those of us with disability are defined by secular society as having neither the goods nor the services that they need and are inherently deficit-ridden, we are consigned to a safe distance — institutionalised either physically or in the new so-called inclusive communities. We now know a form of Clayton's De-institutionalisation — the de-institutionalisation you have when you are not having de-institutionalisation.

THE CUTTING EDGE OF OPPRESSION

Yet my concern with Volf's excellent analysis is that he fails to name or embrace the realities for those of us living with disability, or those of us who have family members or friends with disability. For most, analyses and approaches like Volf's do not really acknowledge the cutting edge of the oppression of people with disability. Specifically, that oppression is not just located within those who are born but in those who are not born. Think about it for a minute. The Universal Declaration of Human Rights talks about the dignity of the human person, but

¹³ Miriam-Rose Ungunmerr-Baumann, cited in E. Crotty, 'Spirituality and Justice', *Ministry, Society and Theology*, vol. 12, no. 2, November, 1998, p.65.

¹⁴ It is also interesting to observe that one of the most recent books by M. Scott Peck on spirituality utilises the story of a three-week trip through the British countryside looking for megalithic stones. See M. S. Peck, *In Search of Stones: A Pilgrimage of Faith, Reason, and Discovery*, Pocket Books, London, 1996.

¹⁵ For an exploration of six biblical land ideologies, see N. C. Habel, *The Land Is Mine*, Fortress Press, Minneapolis, 1995.

¹⁶ Volf. *Ibid.* p 74.

specifically does not define who or what the human person is. International law and common law tend only to extend full notions of rights to those who are already born.

If in doubt about these attitudes, just consider the following excerpt from a recent article in *The Age*:

Doctors endorse dwarf abortion

Almost 80 per cent of obstetricians would support termination of pregnancy when the foetus had dwarfism, a survey has found.

Support for termination at 13 weeks was unanimous among those obstetricians who are expert in diagnosing dwarfism by ultrasound.

However, dwarfism is difficult to diagnose early and is only usually apparent much later in gestation, approaching 30 weeks, unless there is a family history of dwarfism.

Support for aborting fetuses with dwarfism at 24 weeks dropped considerably among Victorian obstetricians, from 78 per cent to 14 per cent.

But among clinical geneticists and obstetricians around Australia who specialise in ultrasound (the main method by which dwarfism is diagnosed), who were surveyed separately from the Victorian obstetricians, support for termination at 24 weeks remained high at more than 70 per cent.

The surveys were conducted late last year by the Murdoch Childrens Research Institute.

The findings, which have been submitted for publication, come as the Victorian Coroner investigates the case of a 40-year-old woman whose pregnancy was terminated at the Royal Women's Hospital at 32 weeks after she learnt it was likely to be a dwarf.¹⁷

Alternatively, consider the following exchange featured on the ABC TV's '7.30 Report' a few months ago. It involved Dr. Tom Shakespeare (a person with achondroplasia — that is, he is of short stature — who has long been involved in the UK disability movement) and Professor Grant Sutherland (a geneticist from Adelaide).

Professor Grant Sutherland: ... I'm sure for example that Dr Shakespeare would prefer not to be handicapped.

Dr. Tom Shakespeare: I'm happy the way I am. I would never have wanted to be different.¹⁸

This emerging site of exclusion is located within the notions of deviant fetuses and deviant genes.¹⁹ Exclusion has extended to this extent, and rarely do we hear the voices of those from the spiritual communities engaging with this particular form of exclusion.

Well, so far I have started with a story of exclusion being the spiritual, and made some connections with exclusion experienced by people with disabilities in the secular world. I have, hopefully, made some connections about it and have documented the interaction between the two. Well, you may say, what are we going to do about it? To some extent that is not my task today.

¹⁷ <<http://www.theage.com.au/news/2000/07/04/A49883-2000Jul3.html>>

¹⁸ Extract from '7.30 Report', ABC TV Report Transcript, 20/02/01.

¹⁹ For an exploration of these concepts, see: C. Newell, 'Critical reflections on disability, difference and genetic testing' in O'Sullivan, G., Sharman, E. & Short, S (eds), *Goodbye Normal Gene*, Pluto Press, Sydney, 1999, pp. 58-71.

Rather, I leave that to Lorna Hallahan as she explores *how* we will embrace, and be embraced, in her keynote address tomorrow.

STORIES, SPIRITUALITY AND TRUTH

However, I would suggest to you that we are already doing it at this conference. We are telling stories. We are being true to our faith traditions. We are telling stories that not only reveal our spirituality but also dare to celebrate our lives.

To be frank, I wasn't sure whether to start with the story with which I started this community. After all, it will probably get me into a lot of trouble, and lead to further exclusion from the power centres of the Church. However, Michael Leunig makes a very important point and one which inspired me to start with the story that I started with. He observes and prays something which provides important guidance:

In order to be truthful
We must do more than speak the truth.
We must also hear truth.
We must also receive truth.
We must also act upon truth.
We must also search for truth.
The difficult truth.
Within us and around us.
We must devote ourselves to truth.
Otherwise we are dishonest
And our lives are mistaken.
God grant us the strength and the courage
To be truthful.
Amen²⁰

If we are to do anything about the spiritual exclusion experienced by people with disabilities, we need to tell the truth, be prepared to listen to the truth, and even to practise truth in our lives. We need to be prepared to tell our stories, honour our particular faith traditions, and listen to others as they tell their stories in particular ways. In so doing, I would suggest that not only will we be able to process our grief — as I did in telling a story to begin this paper — we will also be able to minister to each other, and to realise, reclaim and celebrate our common humanity. In so doing, we will reclaim reconciliation as a spiritual concept applying to all people; claiming justice to work as a perpetual dimension of reconciliation.

I leave the last word to Bill Williams, a theologian with cystic fibrosis who died in 1998:

If we disappear from your sight, it may be because our courage failed. We decided not to burden you, and ourselves, with our presence.

But I've been with people who are not made anxious by my brokenness, and I've seen the difference. It is, in fact, the best definition of ministry I have ever heard; I nearly wept when I heard it, it so defined what I needed. Engrave this upon your forehead, if you would wish to do good:

Ministry is a non-anxious presence.

²⁰ M. Leunig, *The Prayer Tree*, Harper Collins, Blackburn, 1991.

You can tell such grace by its care, by its attentive ear, by its pace. When it reaches out to heal you, it is to give relief to you, not itself — and when it prays with you, it lets you declare your own burdens, rather than declaring what it finds burdensome about you...²¹

We have the wonderful opportunity in this temporary community to *be* in non-anxious ways with each other and to move beyond exclusion, as in listening to and giving heed to other people's stories, we actually dare to encounter and embrace. For in this conference we dare, physically and spiritually, to embrace in a way which says not only that the other is actually important but the other is actually sacred, and at one with us. Peace be with you.

²¹ B. Williams, *Naked Before God*, Morehouse Publishing, Harrisburg, 1998, pp. 32-33.