Whirlwinds and Disability: A Traveller's Guide

The Reverend Dr Christopher Newell, AM

> E nga mana, e nga reo, e nga iwi: Tena Koutou katoa
> (To all backgrounds, to all languages, to all people: a very warm greeting)

It was as if I had been hit in the stomach. I reeled back as if I had been physically hit, furtively looked around the room and realised that no-one else seemed to be aware of the damage. The doubly obscene thing about this moment was that I had been hit, pulverised, decimated in the name of encountering the sacred – in the midst of prayer.

In order to explain these feelings and this experience, I need to explain the context. It had been a full day of doing theology in a church gathering, with a variety of us having been invited to give papers that dealt with the social issues confronting the world. In my paper I had asked people to identify the variety of issues. Poverty, unemployment, war, they all spilt out. I then went on to suggest that these were all symptoms of a continuing social problem – the creation of otherness. I had drawn upon the work of disabled American theologian, the late Bill Williams from the Lutheran tradition, who writes in this way about such otherness:

> I have told you about my special ailments, whined a bit. But now you need to know something. I am not terribly unique. There are plenty of folks whose *principal wound* - the point of triage - is not the church's preoccupations, but an inability to accept the way they were made. This inability feels like an unending condemnation, an especially singular punishment for reasons undisclosed.
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> For some it is a physical defect;
> Or having the wrong kind of "subhuman" skin or shape to the eyes;
> Or being "ugly" in a world that worships perfection;
> Or giving birth to a child with defects;
> Or being barren or sterile in a world that deifies parenthood;
> Or growing up in a sect that glorified shame;
> Or having the wrong gender or sexuality in a place that calls you inadequate or evil;
> Or having parents who crushed body and soul;
> Or being pushed to "excel" in a way that said *never good enough*;
> Or being dyslexic; or having a short attention span; or possessing mechanical intelligence in a school system that only recognizes agile, literate minds;
> Or being freakishly smart;
> Or being as Jewish as Christ in an aggressively Christian nation;
> Or just being human. In some circles, that's bad enough.
> The particulars of my experience are unique; but I am certainly not alone. In fact - and I admit, this might be the buy-a-van-and-see-all-the-vans-on-the-road effect - when I look around, I have this awful feeling that we may be the majority.[1]

We had come to the end of the day. A very senior churchman offered some concluding thoughts, thanked the speakers and prayed with us. In thanking the speakers, he thanked each one of them and yet when he came to me there was an awkward silence, only broken by my quipping “Well, enough said”. The tension was broken with a laugh. Then he proceeded to pray. In praying he mentioned each of the speakers and gave thanks for each of their gifts and contributions. But, when he came to name me, there was to be no expression of gratitude for my gifts. Rather, this senior cleric prayed for my healing, praying in such a way that I wished to vanish through the seat of my chair. It was as if he had heard nothing in my paper, as my conception of self was disregarded. I had not sought prayer about healing. Yes, I was having a tough week, but I was feeling okay with myself. Yet, in the moment of prayer – in invoking the sacred – all of the dominant notions of otherness that I had been speaking about were perpetuated, slammed back in my face, reinforced by a senior cleric in the name of God.

Have no doubt about it, this was a moment of violence. The sad reality is that for many of us with disabilities such violence is perpetuated in everyday accounts of theology and in dominant approaches to theology which mirror the secular. Accounts which render those of us with disabilities as the other.

Let us explore this incident a bit more: if that senior cleric had stated how devastated he was that I was a male and prayed for a change to my sex I would like to think that some people would have looked up in surprise. If he had cursed God for my racial background and prayed that I be delivered from this state to another racial background, I would like to think that there would have been some murmurs of dissent. If he’d said how sorry he was to God that I was born an Australian and prayed that I might be turned into a Kiwi, well perhaps that might have been an understandable prayer.

My point is that this is not a story about a nasty church leader and a brave crip. It is yet another case of no-one bothering to talk to us about OUR conception of self. In my case this fits with my vocation, and how my experience of the darkness of encountering my own disability, my mortality, fits as an integral part of my faith journey. The searing experience of pain. The pain of taking just one more breath ….and then stealing myself to take another … just like Jesus on the cross; of crying out at times “My God, My God why have you forsaken me”. It is part of who I am. At times I curse and swear, but I also see my experience of those very human elements as an integral part of my journey, my makeup as a human being. Indeed some of the best skills and life experiences that I have to bring as a member of a faith community, a priest, an ethicist, and as a fellow human being walking the journey of life, come from my experience of disability and brokenness.

As I pondered and processed this episode, as I added it to the list of narratives that many of you I am sure also bring with you, I started to realise some important but disturbing things. For all that I would call what happened spiritual abuse, this was not about someone who was inherently evil. It was about someone re-asserting in a powerful way his understanding of the world. Secondly, I came to realise the power dynamics associated with whose version of reality, - whose story, - will rule the day. Too often our accounts of the sacred, our claims to belonging, and our claims to have gifts to offer, have been dismissed by faith communities. Finally, I came to see this as another way in which medical discourse and the medical model with its accounts of us as being deficient have actually been taken up in uncritical ways by the Church and other faith communities. Yet, all of the major religious traditions can actually help us also to encounter ourselves as part of the dignity – the inherent worth – of the human person. What I was encountering needs to be named as disablism. As Mike Oliver, a noted disability studies theorist, observes:

> If the category disability is to be produced in ways different from the individualised pathological way it is currently produced, then what should be researched is not the disabled people of the positivist and interpretive research paradigms but the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society [2.]

Already, I've presented myself as a fellow traveller through the whirlwinds of faith communities that at times seem uncaring, through the turpitudes of disability. Yet are the foul winds, the whirlwinds that seem to accost us inherently negative? Within my Christian tradition I can't help reflecting on Job as it is written (Job 38:1) "Then the Lord answered Job out of the whirlwind." Whirlwinds figure prominently in the Bible.

When we think about such phenomenon as both whirlwinds and disability we often think of them as being inherently negative. But we can offer a different reading – perhaps even a radically different forecast. The whirlwinds are not necessarily negative. For all the problems of illness and impairment, and the damage that spiritual encounters which detract from our views of ourselves and deny our full humanness and full participation in faith communities can do, such appalling whirlwinds can create pathways, opportunities and perhaps even foster new growth and understanding of ourselves. That may take some time. It may take perspective. It may take structures. In my case it took the space provided by this conference which provided me with the opportunity to work through an incident which had been of great pain to me. Having told the story, had it believed, had it listened to, and even theorised it, I can move on. The trick is not only to tell our stories but also to find ways of having these believed and incorporated into the stories of our faith traditions

After all as the Dalai Lama suggests in *The Dalai Lama's Book of Wisdom*:

> 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 wellbeing 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).

> If you want more friends and a friendly atmosphere, you must create the basis for them. Whether the other's response will be positive or not, first you must create some kind of common ground. Then if the other's response is still negative, you act accordingly. So first, you see, we must create the possibility to react in a friendly manner (Compassion, the Basis for Human Happiness) [3]

We all come to this conference as fellow travellers along the diverse paths of disability and spirituality. Along the path of sharing our experience, our stories of whirlwinds, and a variety of other natural disasters. The irony of course is that so many of us are actually regarded as those natural disasters. We think we are experiencing the winds of adversity through alienation and illness and disability. Yet others view our very lives as inherently tragic whirlwinds, reaping destruction upon all who may be potentially touched by us. If in any doubt, we need to think about the way in which we are treated in the everyday, and in the social policy debates that seem to hit us about the head, as we are confronted with headlines about the tragedy of our lives. Often we do not know how to respond. On the one hand, which of us wishes to live with life-constraining circumstances. On the other, surely our lives are authentic, sacred, important. Surely much of the natural disaster associated with our lives is actually made by society. Do not look now, but we are doing philosophy, theology and critical disability studies all rolled into one!

We need to recognise that spiritual alienation is remarkably similar in secular and spiritual communities. The experience I had at the hands of a spiritual leader was entirely related to what goes on in the secular headlines. It was all about the creation and perpetuation of otherness. For when we think about it the media carries headlines every day which point to our lives as whirlwinds and catastrophes, rather than gentle breezes, opportunities for birds to be lifted in flight, and seeds scattered. Perhaps even opportunities to experience different altitudes, different cloud formations, views different from that which anyone else has seen. Oops, don't look now, but I am starting to reclaim the sacred in the very whirlwinds that are constructed about us. After all, Evelyn Crotty talks of spirituality in terms of "What it means to live, feel, see, experience and touch more authentically the sacred around me."[4] (Note an emphasis on a variety of ways of being, on the sacred which surrounds me if I will but notice it).

So let's have a look at some of the whirlwinds. Indeed, in terms of the weather reports that are carried we may also look at the recent stem cell debate. I think the Australian stem cell debate is particularly illustrative, especially in terms of what Tom Shakespeare, a noted UK disability studies scholar, represented recently as the "Clash between the two Christophers: Christopher Reeve and Christopher Newell".

Recently, Australian society was treated to an extremely superficial debate to do with cloning and the use of embryonic stem cells where the catastrophe, the tornado, the cataclysm of disability had a starring role. Parliamentarians burst into tears as they spoke for the first time about their constituents with disability and earnestly informed us that embryonic stem cell research would deliver us from disability. Bob Carr, the New South Wales Premier, wrote newspaper columns and created such media opportunities as door stops at spinal cord injury units when he spoke about those of us with disability. Strangely at such media opportunities those of us with disability were not invited to talk about the tragedy which was portrayed as our lives. Finally, we were treated to an almost messianic visit by the broken Superman. Christopher Reeve, whose narrative of tragedy had played such a central role, was invited, at an astronomic fee I might add, to speak in Australia. The same week that megastar Reeve arrived courtesy of Qantas in a specially modified first class cabin of a 747, Qantas managed to inflict yet more significant disabilities upon my already long suffering wheelchair. Well, my chair has been patched up, Mr Reeve has departed – yes, Superman really did fly again – and the discourse of welfare reform blaming people with disabilities for their situation continues. Australia like many other countries has successfully avoided any form of critical examination of the way in which the whirlwind of disability is created by society itself in its variety of ways, in practising disablism. Here is how one national Australian magazine controlled by an editor with disability portrayed the situation with Christopher Reeve[5]. Sadly, it did not seem to rate headlines.

Christopher Reeve and his message of stem cell research hope came to Australia earlier this year amidst much excitement and media coverage. While it remains to be seen if, or when, the cure dreams of Mr Reeve, and countless others, will ever see the light of day, it is worth remembering that there is plenty of living to be done in the meantime...

Of course, we were meant to go back to a form of mere existence, survival at best, rather than a vision of thriving through and even beyond the whirlwinds of life. The problem in the secular arena, and hence the imported problem in many faith communities, is of course that there is no acknowledgement of the sacred, the spiritual, to be found in disability. Yet many faith traditions actually also really do stress the spiritual to be found in the everyday. As Frederic and Mary Ann Brussat argue:

> Life is a sacred adventure. Every day we encounter signs that point to the active presence of Spirit in the world around us. Spiritual literacy is the ability to read the signs written in the texts of our own experiences. Whether viewed as a gift

> from God or a skill to be cultivated, this facility enables us to discern and decipher a world full of meaning.
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> Spiritual literacy is practiced in all the world's wisdom traditions. Medieval Catholic monks called it 'reading the book of the world.' Muslims suggest that everything that happens outside and inside us is a letter to be read. Native Americans find their way through the wilderness by 'reading sign.' From ancient times to today, spiritually literate people have been able to locate within their daily life points of connection with the sacred. [6]

The profoundly important thing about conceptualising our lives as a sacred adventure is that we then recognise disability as part of that. We then recognise that all of us, those with and without disability, experience whirlwinds. Despite the forces of economic and technological determinism, despite all that modern science seems to suggest will inevitably be just round the corner, disability will always be with us. What I need to do – what we need to do - is to help my senior clerical colleague and so many others to grow, to recognise that disability is also part of the sacredness that we experience in life.

Christopher Reeve, like millions, longs for independence. My clerical colleague, so uncomfortable with me and my message, longs for my healing although I wonder who really needs healing. Yet within our experience of disability perhaps we have something profound to teach the rest of the world, something profound to teach our faith communities, something we are uniquely equipped to teach: life is about inter-dependence and the myth of independence is one of the most destructive ideologies around.

For many years those of us who have lived with disability have striven for independence. Yet, nobody truly is and surely that would be the most dark and appalling existence. What we were really doing in the so called independence movement is seeking a proper respect for our autonomy, a respect for our dignity, a respect for opportunities to become as fully human as possible. For what do we come to this conference for? Is it just to be a bunch of warring voices seeking to be in competition with each other – independent- or is it to create a temporary community, to recognise all that binds us together, to recognise the common spiritual dimension to our lives that transcends any faith differences, to learn and to be nourished by each other. Sounds like some pretty healthy inter-dependence to me.

We here need to note that a desire for independence and control over our lives is central to claims for Euthanasia, by which is often meant legalised medical killing. Be in no doubt that this is a crucial issue for the disability community, as many people with disabilities will inevitably be part of the categories created in legalising such a practice. In my own case I have been through the darkness of desperately desiring euthanasia and requesting it. I will always be grateful to the health professionals who supported me through this period rather than informing me that this was an understandable request and that of course in my circumstances (which met the Northern Territory legislation's requirements) I merited it. Which of us with disability do not have experiences where we want to die? A very real issue is found in tackling the reasons associated with this.[7]

So, as we wander through this conference and as we bring all of our tears and joys, excitement, diffidence, all of our human frailties, all of our human strengths to bear, I want to leave you with a few questions:

1. Will we recognise the importance of whirlwinds and other natural phenomena in creating pathways, opportunities and even new growth, for all that this may be painful?
2. Will we be prepared to claim our lives, as people with and without disabilities, as sacred adventures, worthy of not just surviving but thriving, worthy of not just being narrated by others, but told by ourselves in our own terms?
3. Will we reclaim story telling as a fundamental way of not just conveying our own realities but also as an opportunity for us to make connections with the spiritual and the faith traditions from which we come?
4. Will we recognise story telling as being an important way of reclaiming and repairing the damaged lives of those of us who have been harmed through spiritual communities which have rejected our human dignity in daily relationships and in physical and social structures?
5. Will we recognise that the creation of otherness is practised by both spiritual and secular communities, and that this is fundamentally a spiritual and ethical problem as daily we ask the tacit question “who belongs to my moral community and whom will I exclude?”
6. Will we be prepared to learn from the important example of the bi-cultural way adopted by this country? A way which learns from the wisdom of indigenous people, towards the creation of respectful structures? In so doing, will we recognise the power dynamics of what we are doing as we reclaim disability as part of the sacred?

In this conference we are being encouraged to think about the bags that we carry and whether or not the experiences that come in the narratives, the tools we are provided with, are useful for adding to our bags. As we learn from each other, remember that no matter how big the bag, how advanced its design, sometimes bags can become heavy, difficult to carry over a long time. Perhaps the most important thing we do in this conference is that we recognise that we don’t just have to carry our bag by ourselves. That is, let us recognise ways of encountering the other not just as an alien entity but also as someone who helps me as I struggle with my own heavy baggage. Sometimes that can just involve the gift of presence, a touch of a hand, an empathetic ear. Perhaps in this way we encounter the most important opportunity for any of us who feel that we are travellers alone. We have the opportunity in encountering the other, in this temporary community, of becoming and reclaiming the US.

I look forward to your stories of whirlwinds and gentle breezes, but most importantly I look forward to sharing the wisdom that each of us has to the offer

Notes:

1. Williams, B. (1998). *Naked Before God,* Morehouse Publishing, pp. 115-116.
2. Oliver, M.(1996). *Understanding Disability From Theory to Practice*, Houndmills: MacMillan Press, p.143
3. Bunson, M.E. (1997). *The Dalai Lama's Book of Wisdom,* Rider, London, pp.58-59
4. Crotty, E. (1998). Spirituality and Justice. *Ministry, Society and Theology,* Vol.12, no.2, November, p.65
5. Cartoon by Simon Kneebone originally appeared in *Link Magazine,* March 2003, Vol.12, No.1, p.28. Used with permission
6. Brussat, F and M.A. (1996). *Spiritual Literacy: Reading the Sacred in Everyday Life,* New York: Touchstone, p.15.
7. For further exploration of these issues, including an exploration of the first death under the Northern Territory's *Rights of the Terminally Ill Act*, please see: Parsons, I. and Newell, C. *Managing Mortality: Euthanasia on Trial*, Villamanta Publishing, Geelong, 1996. ISBN 0 9587635 2 6; Newell, C. and Pullin, C. Death, *Dying and Euthanasia: An Anglican Resource*, General Synod Social Responsibilities Commission, Sydney, 1998.

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"Fair winds or Foul? Chaplaincy and Pastoral Care"

The Reverend Dr Christopher Newell, AM

It was as if a huge weight had been lifted off my shoulders, my chest, my very being. The day had started so appallingly. I had been battling a chest infection in previous days, mentally gearing myself to do the 'super-crip' thing. A good night's rest, another 24 hours of elevated steroids, another 24 hours of antibiotics. I should be right I told myself, my wife, anybody else who would listen to me the day beforehand. Yet, as I opened my eyes and took those first few tentative breaths, and immediately regretted it as the coughing began again, I was no longer able to deceive myself. As my spine screamed at me that it was well and truly awake and not enjoying this experience of coughing, as my chest joined in sympathy with the spine and its complaint at having been so rudely awakened by that deeper breath, the phlegm sealed my fate. After years of infections, pneumonia, bronchitis and years in chest wards with older men coughing their lungs up, I am expert of phlegm and this deep, dark yellowy green phlegm told us I was not going anywhere this morning.

"Where are you now, social model of disability?" I ruefully reflected to myself as I tried to persuade myself that this was yet another social construct which could be overcome. The spirit was willing but the flesh was weak. It was the middle of my CPE unit and the class of clinical pastoral education had been meeting for some weeks. We were a small close-knit group. For years I had wanted to do CPE but the regular class requirements and the practical commitment (400 clinical contact hours) had made me very nervous. I had spoken about the possibility of not being able to make all of the CPE classes and it had been stressed that it was very important for me to do so. We were a high functioning group. At that stage they had all discovered my neurosis and traumas to do with my disability and I had worked through a lot of the stuff to do with doing chaplaincy on the wards.

I was well behind with my contact hours for that week but the CPE supervisor, Eric Cave, who was also Chaplain at the Royal Hobart Hospital was very understanding. Eric had been with me in some dark times before as a Chaplain. Even so, it was with great trepidation I picked up the phone and informed him that I would not be able to make it that morning. He had obviously been thinking about the situation. "Would you be well enough if we came to you?", he said. "Yes, I think so", I said. I would be just sitting around home anyway. "We don't want you missing another week" he said. (I had to miss the previous week as well) Well, by hook or by crook he managed it. A variety of people were contacted or picked up and here they were assembled in my lounge room.

Ceremonially clad in the requisite fluffy slippers and dressing gown, with oxygen cylinder at my side in order to give the appropriate "Days of our Lives" effect, we were served freshly brewed coffee and little cakes that Jill had just baked. We started with prayer. Yes, they prayed for me. But it was not the prayer I spoke of in my address last night. It was not the prayer that said what a burden I was. It was a prayer that had listened to me. It was a prayer of ministry and accompaniment. As Bill Williams puts it:

> "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:
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> *Ministry is a non-anxious presence*
>
> 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. You may be surprised by what we ask for. My friend Joan, a wise minister and gift of God, tells me that she usually is".[8]

Looking back on it the fellow CPE student who led the prayer that day was really perceptive. Those students did not just know *about* ministry. They were *doing* it. By then they had all been privy to the abuse I had suffered at the hands of priests and prelates in the name of healing and pastoral care. They knew how critical I could be. The group worked well that day. With all the coughing my pain levels were very high, and sometimes I was fighting for breath. Yet, whilst there was concern for me there was no condescension. They waited for me to indicate how we should act regarding my situation.

Of course some CPE supervisors would never have actually come to me. I remember well the story of one person with quadriplegia who had managed to get through clinical pastoral education and the traumas she had had with no accommodations being allowed for her. Yet, that day I was healed in relationship. Far more thoroughly than any pill or potion that I could have taken. For weeks they had had to put up with my critical reflection upon pastoral care. As a new PhD, I was also stuffed full of theory, spouting the social model of disability and how disability really was all social construct. Yet, here I was manifestly unwell, feeling unwell. They could have had a theological extravaganza with me. They could have had the CPE session without me. They could have given me another exemption based upon the sick role. Yet, instead they changed arrangements in order to suit my requirements, not just because of me, but because the group would have been diminished without me. We were supposed to be learning by presenting narratives and the presentation of critical incidents. I was learning just from participation in the group, experiencing the embrace of the group and even, in allowing myself to be vulnerable, experiencing the mutuality which truly marks a community.

Yet, I had come with so much baggage – and I assure you it was the negative type. As a youngster I had experienced a variety of forms of faith healing. Here is one that I subsequently wrote up in the literature as a verbatim. Those who have done clinical pastoral education will notice the format:

A Narrative

> Patient: Charles
> Date Admitted:
> Age: 18
> Denomination: Anglican
> Marital Status: Single
>
> Verbatim No. 1
> Student: Ivor Bigego
> Supervisor: Eric Cavern
> Date of Writing: Now
> Ward: 5G
>
> Observations Acute Care Ward at the Royal Hobart Hospital. Patient in four bed ward with IV inserted and nasal prongs going. Patient is an eighteen year old male who has met the Anglican priest who has appeared on several occasions before. He has been diagnosed as going to die, but the only one who doesn't know this is him.
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> Priest: "Hello Charles, I have come to save you and to bring you the Lord's grace."
>
> Patient: "Hello Father."
>
> Priest: "I know you can be healed if you have enough faith. I have come to offer you that" (Grasps patient's head with both hands and cries out aloud) "Lord Jesus, cast out Satan from this child, this sinner. Cast out the devil. We love you Lord Jesus, we love you, we love you." (Decreasing volume.)
>
> (Patient looks distinctly uncomfortable and has shrivelled into himself. Charge nurse enters.)
>
> Charge nurse: "Are you okay Charles?" (Patient says nothing but looks at nurse with eyes that show despair- or do they?)
>
> Charge nurse: "I am sorry, you will have to go. This patient needs treatment"
>
> Priest: (Slowly departs, muttering) "Praise God, thank you Lord Jesus, thank you……" [9]

Two stories, two markedly different realities. Two markedly different approaches to healing and disability which lead to extremely different accounts of chaplaincy and pastoral care. People involved in the provision of pastoral care have significant opportunities to nourish but they also can provide significant damage.

Well, we might say, there is nothing new to this situation. Do we really have anything to learn from it? We all know of inappropriate pastoral care practices and we can see the power dynamics inherent in the relationship. Well, let us go a little bit deeper. Yes, it does raise issues to do with powerful practices. For example, there are many instances of people in psychiatric wards and the community who have been abused by ministers who worked out their agenda and power upon them.

For some people this is evangelism. For me, it is one of the reasons why processes like CPE exist and why its critical reflective practices must continue. Yet, it also gives us an opportunity to think that evangelism is actually a proper and exciting part of pastoral care. When we look at the Greek verb we can see that it means to bring or proclaim good news - the Gospel of Jesus Christ. The Book of Acts (1:8) suggests that it is the task of all Christians to be witnesses to the end of the earth. For me, the appropriate evangelism is to be found in the suffering presence of the pastoral carer. The recognition of the brokenness of God and the examination of these messages with people as they ask and experience the big questions about "life, the universe and everything".

I would suggest that a proper pastoral care presence which respects the autonomy of individuals and acknowledges the power relations present in pastoral encounters can be both ethically appropriate evangelism and pastoral care. It may also be far more likely to lead to ongoing faith and better care.

Consideration of the verbatim above may also lead us to reflecting on the fact that most pastoral care encounters happen in the community. However predominantly the model of pastoral education used in many countries reifies the medical model and acute care institutions.

In part, I would suggest we do this because the "clinical material"[10] is nicely available. The same rationale is used to justify much clinical teaching in the area of medicine, with the attendant powerful practices. Yet as a medical educator I am amongst those seeking to move our teaching out into the community. Most health care interactions also happen in the community, and we teach a powerful message to students in basing pedagogy in acute care hospitals at the expense of community settings.

Other aspects of the narrative also help us to think about the ethics of pastoral care. For example, whose narrative is it, what consent do I have to use it, to what extent is it the narrative of the person telling it as well, and how well do I do justice to the differing interpretations of reality which various partisan players would provide? How indeed do we recognise and deal with the wider social context? At this point I should admit that it is a situation which happened to me as a young man. Despite this I am still a Christian, and proper pastoral care at other times is an important part of that.

CPE narratives are perhaps one of the best learning experiences we can provide. They look at situations in context, although admittedly reduce them to text. I must admit I wonder why it is that we do not act them out, or acknowledge different ways of knowing and presenting knowledge? Here we need to acknowledge the Anglo-Celtic cultural domination of some of what we do in the name of "pastoral care" and "education".

Yet perhaps there is something further I can offer in terms of reflection upon our two narratives used today. They are both unusual because they are told by and start with the views of someone with disability. Let me complement these by offering some further wisdom from blind professor of education at the University of Birmingham, Professor John Hull, who has recently written the most wonderful book, *In the beginning there was darkness*, starting with the beginning of the creation narrative. As he writes:

> In the beginning there was darkness. 'The earth was a formless void and darkness covered the face of the deep' (Genesis 1: 2). The Bible begins with darkness and shapelessness, with the loss of form and with the experience of the abyss. Can I not say, as a blind person, that the Bible begins at the place where I now find myself? When you are in the dark, your surroundings lose their shape. As someone who has passed through the loss of sight, have I not experienced the shapelessness of the void? The first thing the Bible tells me about blindness is that there is a connection between it and the earliest creative presence of the Holy Spirit.
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> 'Then God said: "Let there be light" (v. 3). What we learn here is that God created the light and separated it from the darkness.
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> For me, the loss of sight was also an experience of separation. There is a great divide between the world perceived by sighted people and that perceived by blind people. The two realms are separate. In Genesis, we might think at first that light, once created, would abolish the darkness, but this is not what happened; darkness found a place in the night, and the night was separated from the day - separated, but joined.
>
> This is characteristic of the experience of blind people, for whom many separations in life are both sharp and blurred.
>
> One is joined closely to the very people from whom one is separated so sharply. The distinction between day and night, the distinction upon which the whole of this poem of creation depends, has a different meaning for blind people. Day is separated from night by a cycle of activity and rest, not by a cycle of light and darkness.
>
> "And God saw that the light was good" (Genesis 1:4). Now we know what we have suspected throughout this passage: God is not on the side of blind people. God pronounces as good something that means nothing to those who are totally blind, and that is a source of longing and frustration, perhaps even despair, for those who still have a little sight. Here we come upon one of the great stumbling blocks that the Bible places in the way of blind people. It speaks of values that, for them, cannot be values. It announces that God is on the side of, and has a preference for, a world that is not their world - a reality to which they have no access.

> 'And on the seventh day, God finished his work which he had done, and he rested on the seventh day .. So God blessed the seventh day and hallowed it' (Genesis 2:3). The seventh day, like the preceding days, begins at sunset. God's rest begins with the night; the night is the source of refreshment and contemplation from which the restfulness of the morning and the afternoon must spring. When God blessed the day, both the evening and the morning were blessed.
>
> We can see now how darkness has made progress. At first, it was regarded as a horrifying abyss, an amorphous nothingness, but then it was named and placed within the day. As such it was seen by God to be good. Goodness, however, was not enough. When we reach the seventh day, the darkness is not only good, it is sanctified by God's rest. It is declared to be holy. The darkness is blessed along with the morning and becomes the Sabbath of God. The God who brooded over the darkness, bringing it into the shape of separation and recognizing it, now completes this work by bringing the darkness and the light into a sacred unity.
>
> I now realize that my first thought - that God is not on the side of the blind - was too hasty. God is the one who broods over blindness, calling it out of shapelessness and confusion, giving it a place of beauty and order in the fullness of creation. God blesses blindness and hallows it.
>
> We read the Bible through the world in which we ourselves are embedded. When I was sighted, I read the Bible as a sighted person because I was embedded in the sighted world. It did not occur to me that I was sighted; I was just a normal person. Then I became blind. After the initial shock and the sense of alienation from my former life and my former world, once again I became a normal person. But the Bible seemed to have become abnormal. It came from a strange world - the world of sighted people, which was no longer mine.[11]

With such a starting point we come to radically different understanding of healing and pastoral care, of disability itself. Yet another key insight is provided by an exciting new book *Making a World of Difference* by UK writers Roy McCloughrey and Wayne Morris. Morris identifies as living with disability, and you can tell. This book provides a re-reading of theology as well as a practical guide to pastoral care for people with disability. Inspired by Moltmann they write:

> So Jesus heals through his humanity rather than his deity. He comes to be with his people and to take on himself the sickness and disability of all. He takes those experiences into God who makes them his own. “God heals us in that he participates so much in our pains that they become a part of his eternal love”. “So every person, however disabled, participates in God's divine life. Each person can have a place where they can find themselves accepted by God as they are. But we can also look forward to the joy “when God will wipe away every tear”. As Moltmann puts it, “God weeps with us so that we will one day be able to laugh with God” .

I do not however find such theology compelling. I need an account of God which is also in the here and now, one that does not however indirectly reinforce disability as inherently negative. Yet, Roy McCloughrey and Wayne Morris do go on to provide a ‘Charter for Healing and Intercession' which provides a practical guide:

> In the healing ministry we meet people at their most vulnerable. They may be frightened, anxious and in great need. They may be facing life-threatening illness, incapacity or other changes in their circumstances and relationships that are causing them distress, trauma and the need for comfort, renewal and a sign of the presence of God with them. At such times, we the Church need not only pastoral wisdom and sensitivity, but also the highest standards of integrity. Those involved in the healing ministry are asked to remember how they like to be treated when they are vulnerable. This charter is offered to all churches, Christian organizations and people involved in the healing ministry as something with which they might like to be publicly identified.
>
> We have chosen to use the word 'intercessor' rather than 'healer' to describe the person praying for someone else to be healed for three reasons. First, healing is an activity of God; the intercessor and the supplicant pray and wait. Second, those who pray for healing are not authorities but fellow-travellers. Third, it demonstrates that a Christian approach to healing is completely different from the claims of 'New Age healers'.

1. The focus of the healing ministry is the encounter between God who heals and those people who bring their requests to God. Intercessors facilitate that encounter.
2. Every person who asks for prayer for healing should be treated with respect and dignity. They should not be embarrassed or exploited, nor should their wishes be ignored. This is particularly important when the ministry of healing takes place in a public place.
3. Those who offer prayer for healing should do so with integrity. Those who come for prayer should do so without seeking to manipulate or in any way undermine those who pray for them. Mutual respect is essential to both intercessor and supplicant.
4. If an intercessor uses a particular symbol in prayer (such as laying-on of hands or anointing with oil) the significance of this should be explained to the supplicant and their consent obtained. The supplicant should, at any point, have the freedom to stop whatever is going on.
5. No pressure should be put on a supplicant, by any means, to state that they have been healed. They should feel that they have the freedom to say that they do not think they are, to the best of their knowledge. Neither should pressure be put on them to say that they feel any changes in their body (such as heat or pins and needles), unless they do so freely and of their own volition.
6. God heals as an expression of his radical freedom to do as he wishes. Healing witnesses to the wholeness associated with the reign of God and points forward

in hope to the new world coming. In healing we may have a bodily experience of renewal, but we may also have an experience of the love of God who is with us or a change in our own attitudes to the situation in which we find ourselves. Healing is not the same as cure.

7. Healing is not a matter of success or failure. Praying for somebody shows that they are cared for, included in the family of God and shows solidarity with them. Neither those who pray, nor those prayed for should carry this additional burden.
8. Where testimony is given, the supplicant should be able to deliver their testimony in their own words and from their own perspective. No pressure should be brought to bear on them, and neither should testimony be given on their behalf, either in spoken or written form, without their consent.
9. Praying for healing does not complete the Church's responsibility. It may be important to refer people for continuing pastoral care. Offering prayer for healing means that we are willing to follow people up, ensuring that the Church expresses continuity of appropriate care.
10. It is also important to recognize that there is a link between healing prayer and social justice, since those in need may also be the victims of injustice or discrimination. The love of justice is also a sign of our love for God.
11. Intercessors should see themselves as part of a team. It is helpful if prayer is offered by people in pairs. This enables responsibility to be shared, perspectives to be discussed and each person to receive support from the other.
12. Prayer takes place in a wider context than the Church. Lay people or church leaders who are intercessors in a healing context should see themselves as part of a team, which includes physicians, psychiatrists, social workers, counsellors and other health-care professionals who are also exercising gifts given them by God. Similarly those who work in a medical environment or in social services should not ignore the ministry of the local church.
13. Many claims to healing are ambiguous and cannot be verified. Where there is a claim that someone has been healed in a way that is verifiable, this should be investigated and confirmed by medical authorities. Jesus told the leper to 'show himself to the priest' in order that the healing be confirmed. When making claims to healing we should be willing to have them also confirmed by those who are medically trained, whether or not they share a Christian world view.
14. Where someone comes forward for healing prayer with an overt impairment it should not be assumed that they have come for prayer for that impairment. The supplicant may not perceive their impairment to be a problem that needs healing. There is no substitute for careful listening.
15. People with disabilities may also be intercessors for healing. The Church betrays its calling if it conducts its public healing ministry in a way that is not accessible to people with disabilities. The integrity of the healing ministry cannot be separated from access to that ministry.
16. It may be extremely harmful to be told that one is not healed because of sin (either one's own or that of previous generations), or because of lack of faith. In the majority of instances the person who is praying for healing cannot possibly know that this is true. It may be true that a person is struggling morally or with their faith. Such a person needs support, encouragement and care rather than

accusation. If there are problems, these should be dealt with privately in the context of pastoral care.

17. Intercessors who offer prayer for healing may also be those who want prayer for healing, today or tomorrow. Similarly those asking for prayer may also be those who pray for others tomorrow.
18. Intercessors who pray for healing and do so as a permanent ministry in their local church need pastoral care and accountability to exercise their ministry with confidence and integrity. They may also face situations that drain them physically, emotionally and spiritually. They need not only to receive pastoral care themselves, but also to retreat to places where they can find refreshment and new energy for their ministry.
19. Wherever possible those people who have a ministry that is recognized by the local church should be commissioned and welcomed into that ministry by the local church.
20. Where there are valid criticisms of the conduct of a church's healing ministry these must be taken seriously and not dismissed. The Church will always make mistakes but can only grow in its ministry if they are heeded and lessons learned from them.[12]

So far I seem to have focused unduly on physical disability[13] and perhaps even too much on thinking from a Christian perspective. You may care to do some further reading. To that end who can put down a recent book which will become a classic 'Riding the Bus With My Sister', a book by Jewish author Rachel Simon finding a warm reception in a variety of Christian congregations. A book of beautiful and skilful narrative about the everyday life of her sister Beth and herself riding the bus and being gifted by strangers.[14]

Finally in all that I have suggested so far I have focused on matters which tend to forget about one thing, self care. We need to be able to care for ourselves. To recognise the pressure on ourselves to be super-crips, to do so much and be too much. Australian spiritual guru and cartoonist has this to say in 'The Curly Pyjamas Letters'

> Dear Vasco,
> In response to your question "What is worth doing and what is worth having?" I would like to say simply this. It is worth doing nothing and having a rest; despite all the difficulty it may cause, you *must* rest Vasco – otherwise you will become RESTLESS!
>
> I believe the world is sick with exhaustion and dying of restlessness. While it is true that periods of weariness help the spirit to grow, the prolonged, ongoing state of fatigue to which our world seems to be rapidly adapting is ultimately soul destroying as well as earth destroying. The ecology of evil flourishes and love cannot take root in this sad situation. Tiredness is one of our strongest, most noble and instructive feelings. It is an important aspect of our CONSCIENCE and must be heeded or else we will not survive. When you are tired you must HAVE that feeling and you must act upon it sensibly – you MUST rest like the tree and

animals do.

Yet tiredness has become a matter of shame! This is a dangerous development. Tiredness has become the most suppressed feeling in the world. Everywhere we see people overwhelming their exhaustion and pushing on with intensity – cultivating the great mass mania which all around is making life so hard and ugly – so cruel and meaningless – so utterly graceless – and being congratulated for overcoming it and pushing it deep down inside themselves as if it were a virtue to do this. And of course Vasco, you know what happens when such strong and natural feelings are denied – they turn into the most powerful and bitter poisons with dreadful consequences. We live in a world of these consequences and then wonder why we are so unhappy.

So I gently urge you Vasco, do as we do in Curly Flat – learn to curl up and rest – feel your noble tiredness – learn about it and make a generous place for it in your life and enjoyment will surely follow. I repeat: It's worth doing nothing and having a rest.

Yours sleepfully,

Mr Curly xxxx [15]

All of this raises Some Questions:

1. Will we assist faith communities to develop a vision of pastoral care and evangelism which utilises the wisdom of people with disabilities, including in interrogating sacred texts and scripture?
2. Will we seek to foster curriculum which recognises the contested ethics around health care and disability, and fosters skills in naming and resolving ethical issues as part of its core areas of competence?
3. Will we have a vision of theological and spiritual training which does justice to people's narratives, and to all who participate in such narrative?
4. Will we seek to have a pastoral care and theological curriculum which recognises, explores and affirms diversity (including cultural and disability difference) as a core component of its curriculum?
5. Will we seek to have a vision of continuity of pastoral care to and from a variety of settings in institutions and the community?
6. Will we assist faith communities to present a vision of spirituality as being a vital and inseparable part of health, which draws upon research to show the efficacy of skilled pastoral care interventions.
7. Will we seek to introduce pastoral care processes which move beyond individual counselling to identifying systemic issues for other agencies/parties?
8. Will we move from having pastoral care and chaplaincy about people with disability to receiving it from those of us with disability?

Today I have shared with you some narratives and suggested some alternative readings of theology, pastoral care and understandings of the role of disability in doing theological and spiritual reflection. In the end it is the readings we bring to people, encounters, relationships and sacred scripture which will markedly impact on whether or not we experience pastoral care and chaplaincy as a fair wind or foul.

I look forward to our continued conversations around this theme.

Notes:

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9. Newell, C. (1997). Pastoral Care and Ethics: Some Reflections. *Ministry, Society and Theology.* Vol.11, No.2, November, pp.102-113
10. Here I deliberately use language my colleagues in the Medical School where I teach about patients
11. Hull, J. (2001). *In the Beginning there was Darkness.* London: SCM Press
12. McCloughry, R. and Morris, W. (2002). *Making a World of Difference: Christian Reflections on Disability* p.111-114. London: SPCK.
13. To that end please read: Newell, C. and Gillespie, F. (2001). *Psychiatric and Pastoral Care: Towards a Richer Theology of Disability*, Contact (UK Journal), no.136, pp.5-13
14. Simon, R. (2001). *Riding the Bus with my Sister.* Sydney, Australia: Hodder Headline
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"Have you Recovered from that Little Lapse you had?"

Rev Dr Mary Caygill

Having just completed the induction service to induct me into the role of President of the Methodist Church of New Zealand I walked into the foyer to be greeted by people wanting to wish me well. One of these well wishers whom I had no recollection of ever having met, took my hand and with a very warm smile on her face asked very gently in lowered tone - "have you recovered from that little lapse you had some time ago? ". Taken somewhat off guard by her question I very quickly responded with as much warmth and grace as I could muster and replied – "yes I have, I'm very well thank you very much".

As she made the comment I was greatly tempted to put her on the spot and ask her as directly what lapse she was referring to. Lapse from what? Her remark, casually made, has stayed with me over recent years, seeming so symbolic of an inability to deal well with many of the issues associated with mental illness.

The lapse she was referring to had happened some 9 years ago. Having just returned from extended study leave and completing the thesis component required for a Dr of Ministry in San Francisco, and with one day left to go before starting work again in the Methodist Parish I was working in at the time, and with sermon all written for the next day, I suffered a colossal mental collapse. Looking back after the event there were signs of depression but I had put them down to a huge work load which would pass once things quietened down and I'd finished the study I was doing alongside my ongoing full time job.

On that Saturday afternoon, frustrated because I could not get my sound system to work, I got in the car to go and find a friend living nearby who could come and help me sort it out. I was desperate to fill the house with music and knew something was terribly wrong inside me. Later I learnt, upon waking on a mattress on a floor in the North Shore Hospital Mental Health Unit, that I had driven up the wrong side of the road to my friends and crashed into a fence on the other side of the road. Just over 24 hours had passed from my being admitted and then committed by close friends.

I was told I had suffered a complete mental collapse - the language of which moved between collapse and breakdown. Still to this day I find myself reacting inwardly when I hear the word breakdown used, such a mechanistic word for such a complex process and again, breakdown from what? So began a long and tortuous 3 months for my first admission in the Unit, then my attempt to return to work for 6 months before another major collapse requiring another 3 month admission. This was followed by a gradual realization that for health to be restored to me I needed to relinquish my job and allow the parish people to appoint a new minister so we could all move on.

The diagnosis given was that of acute clinical depression. A total mental and physical collapse. A very similar event that had happened to my father 20 years earlier. Along with the diagnosis and a recounting of family history came the acknowledgement of 3 generations affected by depression on both sides of the family, something I had always lived in fear of happening to myself.

I have had further recurrences of depression and ongoing daily adjustments, associated with an accompanying anxiety disorder which lay undiagnosed for many years, since beginning my current job lecturing in pastoral theology at the Anglican Methodist Theological Colleges. These I have managed with the help of professional care, supportive colleagues, and friends even though each time they recur like a squall passing over, differing in intensity. When they come I hold my breath almost fearing the worst in terms of my world shattering apart again. I consider myself lucky that I have access to such resources as I need, due to the privileged world I live in, very conscious that this is not the case for so many others living with ongoing mental illness.

As I have already mentioned, at the time the collapse happened I had just handed in my dissertation which I had been working on for over 2 years. The dissertation was entitled “A Theology and Practice of Hope in the context of ecclesial and societal ‘death’”. It was an attempt to explore a theology and practice of hope for a time when the foundations on which our life was currently based, were being shaken and in some instances collapsing. The thesis on which the dissertation was based was that in the time in which we lived (then in the early 1990’s), both in the context of Aotearoa New Zealand and the wider Western world, society was itself the outer face of a deeper spiritual ‘death’. Economic, social, and political disruption I saw as the product of a spiritual ‘death’, but was also the creator of a spiritual despair which fed that ‘death’.

I used the term ‘death’ metaphorically, describing a loss of ability to transcend the present moment and imagine a new future. As a consequence I saw there was an accompanying loss of hope, with anxiety dominating the present moment. The body of the dissertation deals with the questions of how we discern the signs of the times in which we live, and how we discern them in such a way that it will lead to appropriate Christian action and living, in particular hopeful action and living which has a depth to it that transcends the shallow optimism of the age in which we were living, coming to the end of the 20th century.

In response to the questions raised I drew on what I called a number of witnesses from a variety of fields, social commentators, writers of theology, spirituality and the biblical witness of the prophet Jeremiah who wrote of a people dealing with the collapse of their known world as they moved into and lived through their period of exile.

What I could never have known at the time of reading, exploring, and writing over those two years of work was that what had been such a passionate exploration in both my head and heart, on completion would then be required to be lived through with every ounce of my being as I earthed this material through the lived experience of depression. When I talked in the dissertation of Jeremiah witnessing with his people the destruction of Jerusalem and their beloved temple, which together epitomized their entire world as they knew and symbolized it, little did I know that my own known world was to enter into its own colossal collapse, moving me into a period of what felt like an interminable exile. When I wrote in the dissertation about the West being in a state like a corporate dark night of the soul, using the imagery of the 16th century Spanish mystic John of the Cross, little did I know that this would be the imagery that would match with my own lived experience and would in itself provide me with the imagery and spiritual resources to emerge from the darkness into the dawn after a harrowing encounter with the darkness and despair of depression.

Without exception the witnesses I had drawn on would become my own witnesses through my own process of 'death' to the authentic hope of new beginnings. The "death" in this case was the collapse of a personal narrative which up until that point had brought with it seeming cohesion. The process of recovery required me to find myself in the midst of my own 'chaos story'. If you like, my body in its entirety set in process the need for a new story when the disease of depression completely disrupted and shattered that which for so many years had provided the points of connection and cohesion.

Like so many others living through the experience of depression, I dwelt in exile for a significant period of time. And like the biblical people in exile as they had to let go of their known world of Temple and King which were no longer viable, I too had firstly to let go of a world which was no longer viable, and secondly face the task of receiving from God's hands a new world which at the lowest points of the journey I did not even conceive as possible, such was the tenuous hold on life.

As an aside, having used the word God here I do so with the preface that there are so many words that can be given to what we experience as the 'divine', and my own journey into what has been very mysterious and open ended has made me more suspicious than ever of any boxed definitions that are impervious to the reality of lived experience.

In commenting on this word 'depression' William Styron, novelist, spoke of his own experience. The word 'depression' he writes is "a true wimp of a word for such a major illness*"*. He compares the word to a slug, "slithering innocuously through the language…leaving little trace of its malevolence, and preventing by its very insipidity, a general awareness of the horrible intensity of the disease when out of control". [1]

Jim Cotter, an English Anglican Priest, writing of his own experience in his most recent book entitled "Brain Squall - Soundings from a deep depression", likens depression to that of being in "a prolonged squall" which I found to be of immense value living in Auckland where squalls are a very natural phenomenon and enjoying any opportunity to be out on the water. He says,

> There is meteorologically a black squall, with a rapid build-up of dark clouds giving warning. But more apt is a white squall, a sudden violent tempest whipped up seemingly from nowhere, 'out of the blue', wreaking havoc and threatening

> destruction in its path. It may not last long: the effects of its passing last a very long time.[2]

For me the motif of darkness and night became crucial images and words that took on symbolic meaning. The all-encompassing nature of the dark which seems to go on interminably, and with the darkness a sense of nakedness and extreme exposure accompanied by the constant scrambling of thought and affect.

Having spent such time with the thinking and writing of John of the Cross with his concept of dark night of the soul it was this imagery which provided such a source of meaning and a depth of spiritual framework to assist with the establishing of new meaning.

Dark night of the soul is essentially a process of disillusionment - ridding oneself of illusions. Every significant human relationship with God, in community, self, every significant human love comes to a point of dark night where the relationship demands a new vision, a new experience of God, a quieter, freer, more committed love. It comes when all seems dead, all imagination, all desire, all intimacy dead.

What disintegrates in the darkness is not our true self but the defenses, the gods which surround it. The entry into the darkness is a movement of illumination, a movement beyond the limitations of thought and concept. The darkness is that very point in our journey of life and faith when words and concepts have run their course. As Andrew Solomon, writing in his book, ‘The Noonday Demon: An Atlas of Depression’, speaks of his depression, “it was also in depression that I learned my own acreage, the full extent of my soul”.[3]

That’s how the darkness was for me - words and concepts had run their course - my most valued possessions, gifts and skills. Due to the level of brain squall I no longer found that I had access to these words and concepts. They were all muddled and inaccessible. I’d go to find them and they’d appear in jumbled form. I’d go to read them and the words blurred on the page and I couldn’t concentrate. The frustration and despair that followed seemed intolerable. More and more I was thrown back to symbol and music and the images that came in listening to familiar music. The words of friends visiting in the early stages of the illness easily became jumbled and there seemed to be so many words used that demanded a response. What I needed, and few were able to give, was silence and presence with few or no words and touch. In essence the acknowledgement of some human warmth to keep me connected.

I well recall, as Solomon states it so eloquently, there were those times where,

> I was not strong enough to stop breathing. I knew then that I could never kill this vine of depression, and so all I wanted was for it to let me die. But it had taken from me the energy I would have needed to kill myself, and it would not kill me. …Every second of being alive hurt me. Because this thing had drained all fluid from me, I could not even cry…I had thought that when you feel the worst your

> tears flood, but the very worst is the arid pain of total violation that comes after the tears are all used up, the pain that stops up every space through which you once metered the world, or the world, you. [4]

It was in one of those times when I encountered real grace embodied through the agency of one of the nurses on the unit which proved to be the turning point for me towards the dawning of the light. She had spent most of the evening sitting with me trying to provide something which would lift the worst of the dark and connect with me. She asked the question of me "is there anything else at all which would help?". Something within me said the word communion to her then the name Jack, one of my senior colleagues. I asked her to ring Jack. Up until that point I had not wanted to see much of any of my colleagues because in some way I thought I had failed them and the church.

He came and I heard myself say to him, no words, just the symbols. And so he placed the plate of bread and the chalice where I could see it and we sat in silence for what seemed to be a very long time. And then I asked him to say the words and give me the communion elements. During that point something broke within me and I found my way through gazing on those symbols to find connection with something larger than myself. A space to put my immediate confined narrative into a much larger narrative.

From then on we shared the communion elements together often with few or at times no words at all, just sitting within the embrace of the symbols and all they represented of a larger narrative through which I could find the energy to reconstitute myself.

Kat Duff writing in her book, 'The Alchemy of Illness', articulates the paradox of sickness when she says:

> We are both diminished and enlarged through the agency of our illnesses, and so opened to the possibility of new life. The losses are many and visible; the harvested grain is smaller than the standing stalks, but so much more useful.
>
> So Nietzsche observed, 'I doubt that such pain [the kind that makes us descend to our ultimate depths] makes us "better"; but I know it makes us more profound… from such abysses, from such severe sickness, one returns newborn, having shed one's skin.[5]

My task, as unwilling as I was initially with little or no choice involved, was to dwell in the night, make sense of it, learn the context of it, shed my skin in and through it, discover in Andrew Solomon's terms 'the full acreage of my soul' in order to discover the illumination of the dawn which would come.

One of the books which was absolutely crucial to my recovery and still is, is a book written by Jim Cotter entitled 'Prayer at Night - A Book for the Darkness'. It is a book of evening prayers written for the Anglican Service of Compline, held mid-evening as the darkness of night descends. Cotter speaks of prayer in the night being considerably different from prayer in the day.

> We ‘let go’ into sleep just as, one day we shall ‘let go’ into death…Prayer in the night is considerably different from prayer in the day. Whether it is ‘waiting for the dawn’ in the early hours, or ‘doing battle’ with the ‘powers of evil’ in the middle of the night, it requires a naked exposure before God - the kind of nakedness that can be clothed in the daytime by those familiar distractions which make it more difficult to stay and keep attentive to God. [6]

It is in this naked exposure, as Cotter puts it, that one needs to learn to befriend the flora and fauna of the night, a necessary task to do in order to move towards the illumination of the dawn which does come as part of the order of nature.

The following prayer states the process magnificently

> The fauna of the night,
> hidden in the grass of your neglect…
> encounter them…
> contemplate them…
> dare to look steadily at them…
> wrestle with them…
> expect to be wounded in your struggle with them…
> name them…
> recognize them…
> and be blessed by them…
>
> At the breaking of dawn
> they will be known as delectable creatures,
> no longer exiled,
> but returned to you,
> made precious again,
> moving with you into the future,
> robed as destinies…
>
> You are troubled by your dark angels…
> You seek to tame their wildness…
> But they are the potential source of creativity within
> you…
> If you deny them, banish them, seek to destroy them,
> They will drain you of passion as they retreat,
> And you will become pale and lifeless…
> And if they should return and storm your gates,
> you would then be destroyed…
> However dark, they are still angels,
> guardians and protectors too.[7]

"You are troubled by your dark angels. You seek to tame their wildness. But they are the potential source of creativity within you". So I discovered in a deeply personal way as I began to encounter the darkness as a point of illumination, beyond which there lay the possibility to move towards the dawn. There was more beyond the immediacy of the now. But to see that I had to wait in the darkness.

This stance of waiting imposed or sought-after in an active way, this way of being has always belonged to the tradition of darkness. The act of waiting is itself an act of defiance; a defiance of hope; a defiance that the present moment is not the last word. Rather, in the waiting, in the acceptance of the darkness of the present moment, comes the active choice to give the future the only chance it has to emerge. If you like, this mode of contemplation requires a waiting with a disciplined and nurtured patience that witnesses to a willingness to stay where we are, holding on to a belief that something hidden there will manifest itself to us.

Such waiting became and still is for me the stuff of hope. A hope which is not about wishful optimistic thinking but a hope which is hard won and provides the sustenance to wait for the dawn. William Lynch, Psychiatrist, in a pivotal book written in 1965 entitled, 'Images of Hope: Imagination as the healer of the hopeless' speaks of hope as being about, "the fundamental knowledge and feeling that there is a way out of difficulty …what I hope for I do not yet have or see; it may be difficult; but I can have it - it is possible". [8]

In contrast, he describes the state of hopelessness as that which:

> does not image or wish beyond the limits of the present happening. It is that which usually involves a constriction of the imagination. To escape from hopelessness it is necessary to imagine context and perspective and a way out, in other words to meet hopelessness with some enlargement of imagination. [9]

Further to this he sees imagination as,

> the sum total of all the forces and faculties in [man] that are brought to bear upon our concrete world to form proper images of it. The first task of such an imagination, if it is to be healing, is to find a way through fantasies and lies into fact and existence. The second task of such an imagination is to create perspectives for the facts it has found. It will refuse to leave facts as scattered absolutes, to preoccupy and frighten human beings. Like hope itself, it will always suppose that there is a fact and a possibility that is not yet in. The imagination will always be an enemy of the absolutizing instinct and an ally of hope. [10]

As my physical strength returned and I began to finally respond positively to medication I began, through the help of others, to find ways to harness my imagination. One of the most profound ways which baffled some of the nurses assigned to my care was to go for a daily walk across to the Hospital cafeteria to buy a daily newspaper. In the beginning stages it was a major exercise to walk the distance, and to read the newspaper was mostly an impossibility as the writing was all blurred and concentration was poor, but I hung on to the fact as an act of defiance that one day I would read more and more of it. I asked for the pile of books at home by my bed to be brought in to become a pile by my bed in the Unit as a sign that I would read them again. I ended up loaning many of them to staff and friends who came by and that brought conversation slowly back to me as my brain engaged at greater depths in less scrambled ways.

Over time I slowly worked through the facts of having depression and, whilst for a long time the facts seemed so absolute, it has become easier to see these facts as not having the last word on my life.

I dwell often in the poetry of Jeremiah, who I have come to know as one of the great poets of hope who spoke out of his own and his people's pain of the God in eclipse, as the one who had the capacity to speak newness out of nothingness thus creating hope as the ultimate act of subversion.

Someone asked me recently if I had made a friend of my depression. My instant reaction was to say never. But in a way I have learned to engage in the process of befriending the flora and fauna of the night and in so doing to know more intimately the contours of depression and anxiety and thus live with them in as productive and creative way as is possible.

So to the question that I started with - have I recovered from that little lapse I had? I believe so, although I still ponder the question "a lapse from what?" I have become less gracious about the use of language that continues to keep mental illness at arms length and in so doing limits the possibilities of understanding and the extension of human warmth to those needing to feel the humanness and hope of such connection. And finally I pay tribute to those who did understand and cared in ways that made it possible to imagine again.

I close with the words of Psalm 139 which is like a mantra for me especially in times of darkness when I can feel such aloneness and disconnection.

> Light of Light you have searched me out and known me
> You know where I am and where I go,
> You see my thoughts from afar.
> You discern my resting places,
> You are acquainted with all my ways.
> Yes, and not a word comes from my lips
> But you, O God, have heard it already.
> You are in front of me and you are behind me,
> You have laid your hand on my shoulder.
> Such knowledge is too wonderful for me
> So great that I cannot fathom it.
> Where shall I go from your Spirit,

where shall I flee from your Presence?
If I climb to the heavens you are there,
If I descend to the depths of the earth, you are there also.
If I spread my wings towards the morning,
and fly to the uppermost shores of the sea,
even there your hand will lead me,
and your right hand will hold me
If I should cry to the darkness to cover me,
and the night to enclose me,
the darkness is no darkness to you,
and the night is as clear as the day.
For you have created me, every part of my being,
Cell and tissue, blood and bone.
You have woven me in the womb of my mother;
I will praise you, so wonderfully am I made.
Awesome are your deeds and marvelous are your works.
You know me to the core of my being;
Nothing in me was hidden from your eyes
When I was formed in silence and secrecy,
In intricate splendor in the depths of the earth.
Even as you were forming you saw my limb
each part of my body shaped by your finger.
How deep are your thoughts to me, O God,
How great is the sum of them.
Were I to count them they are more in number
than the grains of sand upon the sea-shore -
and still I would know nothing about you -
yet still would you hold me in the palm of your hand. [11]

Notes:

1. Cotter, Jim (1997). *Brain Squall - Soundings from a deep depression.* Sheffield: Cairns Publications, p.xxi.
2. Ibid, p.xxi - ii.
3. Solomon, Andrew (2001). *The Noonday Demon - An Atlas of Depression.* New York: Scribner. p.24.
4. Ibid, p18-19.
5. Duff, Kat (1994). *The Alchemy of Illness.* London: Virago, p.115.
6. Cotter, Jim (1991). *Prayer at Night. A Book for the Darkness.* Sheffield: Cairns Publications. p. vii.
7. Ibid, p 68-9.
8. Lynch, William (1965). *Images of Hope: Imagination as the Healer of the Hopeless.* London: Helicon Press. p 32.
9. Ibid, p 143.
10. Ibid, p 243.
11. Cotter, Jim. Prayer at Night. p. 12-13.

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Health and Theology - Are they Related?

Rev Dr Mary Caygill

At a recent church service I was invited, along with others, to join in the prayers of intercession. The theme of the sermon had been around the issue of those estranged from society treated like modern day ‘lepers’. The Gospel reading had been of the account of Jesus reaching out to touch and heal a leper. And so in the prayers we prayed for a number of groups who were identified as being estranged and like lepers of today. We went through a range of groups and then suddenly I heard the phrase - “we pray for those with mental illness who have lost their minds”. My mind went wild at that instant with an immediate inner reaction which went something like this: where did it go to, how was it lost, how will it be found, will it be found? Very similar questions to that my young 6 yr old nephew often asks of things that get a lost label attached to them. Then I found myself thinking I wonder what my/our reactions would be if the person was equally to pray, “We pray for those with physical illness who have lost their bodies”.

I have to say the rest of the prayers of intercession were lost on me as my thinking continued to go in every direction until the end of the service when I was able to turn to a friend of mine and say - have you actually lost your mind - she a sufferer of mental illness over a long period of time. She said to me that her attention was also brought to an abrupt halt as she pondered where her mind might have disappeared to.

The sentiments were right and, knowing the colleague leading the service I said to him later, “I don’t think I actually lost my mind when I encountered and moved through a time of severe depression”. He acknowledged that the wording was not what he’d meant but it had just slipped out.

Health and Theology: Are they related? Or as I might restate the question - Health of theology? and Theology of Health? What’s the relationship between them?

Unequivocally yes, they are related but not always in such an interrelated way that might lead to health, however we might wish to define that. I personally prefer to speak of health as a dynamic process around the notion of wellbeing, but let me not stop too long at this point but rather I’ll come back to this toward the end of the paper and clarify this further.

The question is by no means straight forward and in itself the question reflects a strange conflict. For is not the faith tradition, and here I speak of the Christian faith tradition, about the unconditional value of each human being and the gift of life itself. Yes, at heart it is. And yes, it would be easy to say categorically that Christianity is for ‘health’, that the tradition has always believed in health and human wellbeing. But unfortunately that’s by no means the whole story.

For since the beginnings of the early Christian movement and the very establishment of the formalized early church, Christianity, particularly as it moved away from its early Hebraic roots, we see a different story emerging. A systematic story of the body and thus health becoming a problem, no more so demonstrated than in talk of the mortification of the flesh, sin as an essential flaw of the human person, and ultimately the classic dualistic thinking which has succeeded in undermining the material body as being of less importance than the purity of the disembodied soul.

You see, what I heard in that prayer of intercession was a statement which epitomizes the worst of classic western dualism which has so affected our traditional notions of theology which many of us operate out of today almost automatically. To speak of the notion of dualism is to speak of a way of thinking permanently rooted in western scholarship. Dualism manifests itself in the form of opposition, affirming the negativity or the lesser values of one pole relative to the other. One pole is favored over the other. The history of disability studies and the experience thereof speaks of those considered able-bodied being favored and thought of as being of higher value than those named as dis-abled. And these dualisms are deeply embodied.

It is within these dualisms which have facilitated and justified the domination of the lower order in each case people of color, women, disabled, varying sexualities etc, - any one or thing opposed to what at any time would be defined as the norm -everything else is then in opposition to. This is classic dualistic thinking, and with such thinking comes varying degrees of alienation and disconnectedness that can only result in a diminishment of humanity. Such a consequence is by no means healthy or emanating from the core belief about the unconditional value of each human being.

With any such dualistic thinking there comes the inevitable shift from subject to object. Let me illustrate this process with reference to the alienation and relational disconnectedness that happens for those living with and through the experience of mental illness.

The social history of persons with mental illness, especially long term, is marked by poverty, exclusion, oppression, and lack of opportunity that bestows upon them the status of non-persons within society. It is through the myriad of unnoticed social gestures and negative assumptions that persons living with mental illness find their sense of personhood and self-worth being constantly eroded . Caught in the process of depersonalization, one of the results is the withdrawal of opportunities to participate meaningfully in society and gain access to many of the sources of self-respect and self-esteem that are available to others.

The incomprehensibility of mental health problems makes it difficult for the ‘normal’ person to relate with the ‘other’. The tendency then is to engage in an ‘I - It’ relationship toward the incomprehensible individual and assume him/her to be incapable of entering into authentic relationship, to withdraw one’s relationship, and to pass responsibility for the individual on to the so called professional.

The ultimate shift then in process of moving from subject to object comes as the person is now not responded to as a person, endowed with the same gift of life, humanity as all others, but responded to as an illness. This becomes the ultimate point of stigmatization - of objectification which many of you know about intimately. Thus people who suffer from depression become depressives, those living with the illness of schizophrenia become schizophrenics and so on.

Once a human being is stigmatized and set apart by the attribution of a negative social identity, it is much easier for others to think of them as somehow less than human and to treat them as objects rather than as full-embodied persons. [1]

Jackie Leach Scully, writing in an article entitled, 'When Embodiment Isn't Good', speaking from her own experience as a person living with disability, acknowledges the reality that people with disabilities are seen by mainstream western society as something other than normal human beings. She expresses the view,

> This fundamental perception has not been much affected by contemporary programs of equality and equal opportunities for disabled people, since these can certainly be seen and may have even been disguised solely as attempts to make those with disabilities 'just like everyone else', even if, in the context of a growing self consciousness of the value of diversity and autonomy, it would not be phrased like that. Legislation, social welfare programs and the activities of disability rights groups all have the overt aim of eliminating only the negative differences between disabled and able-bodied people, by cure, rehabilitation or provision of technical aids. Nevertheless, I would argue that at a deeper level, people with disabilities are still perceived as something other than entirely human. This is most easily seen in the arts, and in images and metaphors used in discourse which unwittingly reveal fundamental beliefs. [2]

Contentious this viewpoint maybe, but again the point is being made of the ultimate alienation and disconnectedness of hierarchical and dualistic worldviews which continue to dominate the Christian church.

The other day I was having coffee with a colleague and I was wrestling with some of the ideas for this paper. She shared with me the following story which seemed so pertinent to what I am speaking of and what many of you know and experience daily.
She spoke of being in Chapel for one of the daily worship services She was seated next to one of the spouses of an international student for whom English was about the 6th or 7th language. It again came to the prayers of intercession and to the line in the prayer book, "we pray for those who are invalids"- not being used to that particular word she read it as it looked. And so my colleague heard the words, we pray for those who are in-valids. In valid. It finished the service for my colleague as she pondered on this startling revelation and the classic dualistic thinking lying in behind the word and how it has come to be used and responded to certainly in our very contemporary, post modern, competitive, obsessively productive society

Michael Wilson, English theologian writing in the 1970's wrote a ground-breaking book entitled, 'Health is for People', [3] in which he got to grips with the practical and pastoral theological challenge of health issues in the modern world. Interestingly his words written over 30 years ago seem still as relevant as we contemplate the meaning of health in the post-modern context of global capitalism. He speaks of patterns of inclusion and exclusion - again another dualism which renders the human subject valid or in valid, thus making the shift to ultimate objectification. He says,

> Inclusion is a pattern of health, exclusion a pattern of death. In social terms a society may 'kill' (may treat in a way which spells death for) those of whom it disapproves, those whom it fears, those by whom it feels itself threatened. So society excludes (kills, sometimes literally) either by its attitudes, by segregation, institutionalization or execution, the bad, the mad, the black, the widow, the leper, the aged, the underprivileged, the mentally subnormal, the rebel and the dying. This exclusive pattern of dealing with 'pollution' results in a safe and sanitized society, but not a healthy society.[4]

Wilson goes on to contrast a 'healthy' society with a 'sanitized' society. A sanitized society is produced by constant purging and cleansing - by pushing undesirable elements beyond the boundaries, and policing those boundaries to prevent them from re-entering".[5]

I believe passionately that any theology which has its feet firmly bound in classic dualistic thinking will always play into the hands of exclusive patterns of thinking thus resulting in ultimate acts of exclusion, and as Wilson expresses it, of 'creating and perpetuating a sanitized society'. The only way I can see for there to be significant movement towards a healthy relationship between theology and health or, as I prefer to call it, 'wellbeing' is by a deliberate move away from a dualistic world view to that of a world view which has images of relatedness at the heart of its thinking and imaging. A worldview, which sees the interconnectedness and ultimate relatedness of all being which is, in essence, a return to Christianity's earliest roots in Hebraic thinking, which today is paralleled by many indigenous worldviews.

Ivone Gebara, Brazilian woman theologian, seeking to heal the rupture of dualistic patriarchal theology that has rendered women particularly in her indigenous context as invisible and objects of abuse speaks of relatedness as meaning,

> the connection, the correlation, the interdependence that exists between and among all things. It refers to the very stuff that creates and sustains life that nourishes life and allows it to grow.[6]

She speaks in terms of the need for circular concepts not of hierarchical, dualistic concepts which will always consider the other to be either inferior or superior and therefore inevitably exclude others at every level of human relationship. "In a circular concept, everything depends on everything else, and if one element is affected the whole is affected". [7]

She speaks of the imagery of a living human web, imagery that is being used extensively by women pastoral theologians. In this worldview a human being is first of all a being-in-relationship, then consciousness, then personal creativity. "In the Beginning God", the foundational statement on which the Christian scriptures rest. We are born as human beings into an interrelated context and it is from that context that life flows. We are not born into a broken relationship as flawed beings that need the ultimate connection of relatedness to be redeemed or saved. I'm not saying in this that sin is not a reality for I believe it very much is, but rather I see sin in terms of the conscious or unconscious breaching or shattering of connection which can take place at multiple levels.

As Gebara sees it, a model defined by relatedness sets forth a different anthropology.

> No longer will it be possible to identify women's bodies with nature and men's with reason or spirit. This kind of dualism will have to be banished because it justifies the oppression of women. No longer will it be acceptable to control the bodies of women, indigenous peoples and people of color (my addition, people with disabilities, people who have 'lost their minds') as if this control over those considered inferior were actually legitimate. No longer will it be possible to develop a historical theory of the superiority of some over others as being God's will.[8]

It will only be through such models of relatedness at the heart of our theological thinking that will make it possible to be open to different models of being in community. As a consequence I believe then and only then can we begin to articulate in a more authentic way what wellbeing might be about.

Alison Webster, English Anglican, writing on issues to do with social responsibility for the Church of England in a very recent publication entitled, 'Wellbeing', speaks of the opposite of wellbeing as being not that of illness, but rather of dis-ease, in the sense of unease - being ill-at-ease with ourselves. From her perspective wellbeing is,

> not the result of 'cure' but of the incremental building of networks of relationships and human connection, self-esteem, self-belief, purpose, meaning, value, and good relationships.[9]

She articulates what she understands to constitute wellbeing and I have found her thinking has been helpful in taking me further in my own thoughts. [10]

Firstly, she speaks of wellbeing having to do with the interweaving of the psychological, the physical, and the spiritual. No one aspect elevated over the other as we have noted occurs in classic dualistic thought. Thinking very akin to that of Gebara and much indigenous thought in relation to world view. Thinking akin to what I have already acknowledged as the early Hebraic view before it was captured and dominated by Greek thought.

Secondly, there is an element which has to do with how we inhabit our personal histories and how we negotiate these in the present. We all live with our own personal histories containing within them differing ways and attitudes in which we have been taught and pretty much programmed to confront life. No one of us is impervious to these attitudes. If one has been scarred by personal history in one form or another, that may well impair the possibilities of accessing maximum opportunities for wellbeing by limiting the possibilities for human connection.

Following on from this Webster speaks of wellbeing as being dependent on our inter-relationships with one another - relationships which offer the possibilities of either harm or flourishing. Relationships based on perceptions as Scully referred to where people with disabilities continue to be perceived as something other than entirely human can only continue to harm and prevent the kind of flourishing and ultimate connectedness which wellbeing is pointing towards. Relationships which are abusive where the person is robbed of their subjectivity and treated as an object to be used and abused can never create the conditions for wellbeing.

And finally wellbeing, as put forward by Webster, includes crucial questions of identity. Wellbeing must be about naming oneself, not being named by others; naming our limitations as we understand them, not as others do. This dimension I believe is crucial to issues being discussed within the life of this Conference and relate to the very nature of doing theology in ways that are healthful and create wellbeing.

As I understand it personhood is bestowed by God in and through relationship. The dimensions of that personhood are discovered through community by its members. Again through relationship. This gift of personhood includes the right to be named and to be included in the memories and hopes of the community. The question then follows, what does it mean to bear a name and be remembered? In remembering someone, we acknowledge the person as worthy of memory and acceptable as a full person. The opposite of memory is not to forget but to dismember, to take something apart.

Personhood is enhanced when it is granted freedom to choose and power enough to choose. Conversely personhood is diminished when a person is either deprived of choice or denied power to act on a choice that affects his or her wellbeing.

Christian theology over many centuries has been preoccupied with the task of naming, whether that is of God, or how one might access God, and who might access God. As a consequence a great deal of negative control has been exercised particularly over the lives of women and those considered to be as other. For me, one of the exciting movements of theological thought that has come in recent years has to do with the ability to name, has been that thinking emanating from a variety of liberation theology movements, of which feminist theology is one, joined in recent years by the stream of thinking associated with disability theology.

These movements all have as their starting point, that of taking lived experience as the starting point of theological reflection. That action in itself lays claim to the possibility of naming oneself and one's lived experience in relation to the divine. Actually placing what we feel and experience in our everyday lives at the heart of how we begin to understand God, faith, and spirituality, is a reversal of traditional theological method which has been nothing less than disadvantageous to a relationship of health - wellbeing and theology.

This Conference and all the planning that has gone into it has come out of the belief and action that theology, faith, and spirituality must begin with the lived experience of those who live with the reality of disability. Only then can there be authenticity and the ability to exercise and live out of one's fullness of humanity, and in so doing live out of a sense of wellbeing.

And so in summary I return to the question of this paper. Theology and Health: Are they related? Intimately so, in that there is the potential for theology to undermine by its thinking and practice the possibilities of wellbeing, or enrich and prophetically challenge by engaging in counter cultural thinking and in so doing dismantle current world views and ensuing modes of living. This, as I have made claim to throughout the paper, can only ever continue to lead to the exclusion of those considered to be as 'other' by disconnecting them systematically from their vital places within the living human web of humanity. Therein lies the challenge for the Christian church and its accompanying theologies.

I began this presentation with a story about a prayer of intercession. Let me finish with another prayer of intercession which I think represents in a healthier way the relationship between health and theology which emanates from a perspective of interconnectedness. The prayer is written by one of my favorite writers Michael Leunig. [11]

> We pray for the fragile ecology of the heart and mind. The sense of meaning. So finely assembled and balanced and so easily overturned. The careful, ongoing construction of love. As painful and exhausting as the struggle for truth and as easily abandoned. Hard fought and won are the shifting sands of this sacred ground, this ecology. Easy to desecrate and difficult to defend, this vulnerable joy, this exposed faith, this precious order. This sanity. We shall be careful. With others, and with ourselves.
>
> Amen

Notes:

1. See John Swinton (2000). *Resurrecting the Person: A New Model of Pastoral Care for People with Long-Term Mental Health Problems.* Nashville: Abingdon Press. Also his more recent book, *From Bedlam to Shalom. Towards a Practical Theology of Human Nature, Interpersonal Relationships, and Mental Health Care.* New York, Peter Lang Publishing, Inc. 2000.

2. Scully, Jackie Leach (1998). When Embodiment Isn't Good*,* *Theology and Sexuality,* 9 September 1998, pg 10-28.
3. Wilson, Michael (1975). *Health is for People,* London: Darton, Longman and Todd Ltd.
4. Ibid, p.67.
5. Ibid, p.5.
6. Gebara, Ivone (2002). *Out of the Depths. Women's Experience of Evil and Salvation.* Minneapolis: Fortress Press. p.134.
7. Ibid, p.134.
8. Ibid, p.142.
9. Webster, Alison (2002). *Wellbeing.* London:SCM Press. p 41.
10. Ibid, p.21.
11. Leunig, Michael (1990). *A Common Prayer.* Australia:Harper Collins

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Indigenous Spirituality and Disability

Huhana Hickey

Kia Ora Koutou.

Hello and welcome to everyone here, especially our overseas visitors, who, through the powhiri welcoming ceremony on Thursday went from being visitors (outsiders) to members of our family.

Let me begin by saying any Maori I use, I will use the English wording for as well, simply for the sake of the sign interpreters and those not used to my culture.

On behalf of the Almighty Creator (Atua), the ancestors and elders, we the Tangata (indigenous) Maori of Aotearoa (New Zealand) welcome you, our brothers and sisters of the world. I also extend this welcome on behalf of the Maori Queen Dame Te Ataairangi kahu, who is the leader of the Tainui, the waka (canoe). My tribe is known as Tainui. My hapu (sub-tribe) is Ngati-Tahinga. Greetings to you all.

Let me begin with the words ‘Tihei Mauri Ora!’ (The breath of life) Maori often use this term in their speeches to signify the first breath of life taken by human kind.

So, then what is Tikanga Maori? Well, in plain language, tikanga basically means protocol, patterns, rules to live by. For Maori originally it simply meant normal as there were no ‘others’ before the European arrived. So in a way tikanga Maori means the normal practices of living. Today though, through colonization and christianisation of our identity some of the tikanga has become westernized/christianized and ritualistic. Originally it was simply guidelines for living that we would have grown up knowing and which became as natural to us as breathing.

I say this for Maori traditionally and I am only speaking generally here and not speaking for all Maori as there are regional/tribal differences and I can only speak for my own Iwi/hapu/whanau and from my own life experiences. Our spirituality, identity, relationships, sexuality, whanau, eating, sleeping, playing, fighting - our whole way of living was as natural to us as everything in life is.

We did have Tohunga (specialists) who would guide us and who had the secret knowledge known only to them then. It is often understood today through oral conversations with Kaumatua and those “in the know” in my community, that many of these would have been people who were identified at birth or who developed special “gifts” of insight into the realm of the Atua (the Gods). These were people who heard their voices, good or bad, some of these people may today be labeled as living with schizophrenia. Intellectually disabled Maori were also considered a gift, it all depended on the disability and how they could utilize their identity in their own community.

The ritualism aspect of our spiritual identities came when we were to remove say a tree from the forest for a new waka (canoe) or whare (building). Only the Tohunga knew the process to do this and they would carry out the proper process for allowing that tree to be cut and prepared for the task at hand. Maori generally believed all of nature had a Mauri, a life essence, and it was disrespectful to ignore or abuse this (Many Maori still believe this today, despite Christianization). Some Maori believe trees are our siblings, our brothers and sisters, and therefore deserving of our practices if we are to use those siblings for our carvings, waka or whatever other purpose it has for our community. It is true that before missionaries came, we had many Atua (Gods) such as Tane Mahuta, the God of the forest, but I tend to think the word God is not the right term as we refer to the one and only all supreme-being as Io. Io is the beginning of everything. We may have many Atua, but only one Io.

Colonization/Christianization has changed our traditional beliefs today, but there is a mix of Christian prayers (karakia/mihi), songs (waiata) etc with the traditional Let me give two examples. Consider Te Taniwha (the spirit guardian) issue over the motorway being built between Auckland and Hamilton. The media grabbed onto it, Paul Holmes and others laughed and mocked the Kaumatua claiming there was a taniwha there. Yet all the elders were doing was to explain in their own words that the land was unstable and the motorway would sink. Maori, even urbanized, non traditional and well educated Maori I knew just accepted the Kaumatua's explanations without mocking these Kaumatua. (It has since been shown the land is in fact a swamp and it cost the roads department an extra $4 million). Another example is the prison issue, where Maori say its Waahi tapu (very very sacred due to such events as a war or mass burial on that land). How can Maori "rehabilitate" if they are incarcerated on land their ancestors were buried under. Being forced to eat, sleep, defecate, live and disrespect their ancestor's bones?

Many issues like this are mocked at, but Maori know the spiritual consequences of disrespecting Atua. Examples of our spiritual issues are where we don't naturally separate ourselves spiritually from who we are, then any upheaval in nature, our Whanau, our lives, means the harmony of balance has been removed and steps must be taken to restore that balance. This may be in the form of utu (revenge) or through another traditional method where a member of the whanau has done a wrong against another whanau and the accused's whanau take full responsibility collectively and work together as a whanau to restore the balance in whatever agreed upon terms within the hui over the issue. Mason Durie's model of Maori health/wellbeing is simply put, having balance is to holistically address the issues of our physical, emotional, spiritual, whanau and mental wellbeing of ourselves. This sense of balance is important to us and any shift of any one or all of these elements creates in us a sense of disharmony that must be restored. Colonization/Christianization has, I believe reduced, altered or removed the ability for Maori to have balance. I have heard the abuse stories from Kaumatua about the early missionaries where boys and girls were abused. They were also taken and trained in the native schools to be housekeepers, cooks, maids and laborers which is typical when they were colonizing non white populations at that time.

When the Treaty of Waitangi was signed, Maori were the majority. Within ten years it had already shifted and the balance was being lost then. In the 1860-1880 Maori wars the worst affected areas were the Waikato and Taranaki. I have ancestral links to both areas and ironically one of my ancestors used his Christian teaching from the missionaries and protested passively with Te Whiti at Parihaka Marae, only to have his bones and those of his supporters/ Whanau end up in a cave in the south island where Te Whiti and Tohu were incarcerated so the empire could take their land.

In the Waikato, my Ngati Tahinga iwi said NO to selling their land to Governor Grey as they were successfully selling agricultural products in NZ and Australia. For that NO, over three thousand of my direct ancestors were massacred where they stood. The survivors became landless. Hence the reason why I was born and adopted in the way I was. I will explain more.

In the 1904 Native Lands Act, the adoption legislation began to take shape, as colonization was a process of assimilation and genocide. By removing the land from the indigenous populations, breaking down family, collective, rural and tribal structures and removing their ability for survival from the land and their language, the indigenous populations were unable to retain many of their traditional methods of living.

In the 1950's, the government had problems of too many brown babies being born to young unmarried brown parents. The 1955 Adoption Act was enacted with a specific reference to disallowing Maori/Whangai adoptions. The ministry of Maori Affairs were suppose to (in theory) be involved with all the Maori babies going up for adoption, or so the Government would have you believe.

I was born a month prematurely in 1962 to a 16 year old mother sent to the nuns in Taranaki from the Waikato. You see my mother had been chosen to marry a Maori man from another iwi, but she ran off with this Pakeha boy and got hapu with me. My mother breast fed me for two days and was then told by the doctors that I was going to die and it was better to forget about me, to consider me dead and that they had a family to care for me until I did die.

What my mother didn't know is the social workers and doctor involved in my adoption believed I was better off with a white Christian family and that I was light skinned enough to ensure this could happen. My birth certificate and information about my biological parents were falsified. They lied about my ethnicity, my mothers background, and my biological parents educational and employment backgrounds. The Ministry of Maori Affairs were also uncharacteristically invisible for all Maori babies up for adoption, not informed of my birth and my availability. The Ministry never knew I existed.

Hence, my life began that was not truly mine, it was fabricated. I didn't have a hole in the heart, although I did have and do still have respiratory problems, but back then, my disabilities were nothing compared to what they are today. My biological parents did go on to marry and have had eight children, who all live in Australia on an aboriginal reserve in the Darwin outback.

Spiritually, I always craved to know Atua (God) and to understand my role in this life. I was adopted by a white Roman Catholic family who were deeply ritualistic in practicing their belief. They also loved and cared for me in their own way, but as with many families there are skeletons and within my family on the maternal side are the issues of abuse and alcoholism. An uncle of mine and some male cousins began abusing me from the age of three. Despite all of this, I loved church as it was a sanctuary for me. I had a romanticized view of God then. I grew up wanting so much to be a missionary nun and would always grab the 'outcast' kids at school and be protective of them, not allowing others to hurt them as they were so vulnerable. But, well, my dreams were shattered once when a nun told me I was too dumb to be anything other than a mother and housewife (although I don't know what intelligence has to do with being a mother etc, it's a complex and important role, but one not valued back then.) Abuse has a way of distorting our realities and of the ability to live our lives in any sense of balance.

At fourteen, I was raped, and though I had been abused since the age of three, I didn't know it was bad or wrong until I was raped by a stranger and my world I had found safety in, collapsed around me. I recall doctors prescribing valium by the bottle as the case went to Court and I recall an Aunt slapping me across the face and calling me a slut (as it turns out the rapist was a good friend to the Uncle who had abused me as a child). I remember my mother also slapping me across the face in a drunken mood one night and showing so much venom towards me, I began to withdraw emotionally.

For two weeks I was in the local psych ward where I was beaten by staff because I refused to eat anything. I was locked in a room one night while they held me down and shoved food down my throat, they damaged my teeth permanently and threatened to give me electric shock treatment if I didn't behave and do what they said. They released me the next day saying I was just a spoilt brat and they couldn't treat me. I hit the streets after that, hating authority with a vengeance. I used alcohol, dope and speed to cope and sold myself to strangers because I had no love or respect for myself. Where was Atua? Ironically, I kept talking to Atua everyday just asking questions and never seemed to find an answer, but as I have said before, life has a way of happening where we often don't understand why until years later.

So back then, my life was a mix of all of that and periodic suicide attempts. I have been in several comas over the years and learnt quickly how to tell the shrinks what they wanted to hear so I could leave quicker, although I wasn't healing back then. I had also begun exploring my sexuality. I began moving into the gay world. Or as Maori call it Takaatapui. I was still often so stoned however, I didn't know much of what I did for long periods of time.

In 1983, I became a born again Christian. The classic story of someone finding me on the streets and well, I love music so it was what drew me to the church I attended. I never really felt comfortable but well, I tried to find the answers in it. I did however become pregnant in 1985, I was hauled up before the whole church to ask for forgiveness of the fellowship (funny how men were then seldom asked to do this, they seldom get caught and a girl can't hide her growing bump). Doctors wanted me to abort my son. I said no. I was very ill and hospitalized where I gave birth seven and a half weeks early after having seizures and nearly dying. I remember being prepped for surgery with the nurse beside me crying and in my mind I recall saying to God that I was ready to die and I wanted to but if this kid is to live and needs me, then I am leaving it up to him. Well, we survived........Josiah (meaning Jehovah supports) was skinny, long, hairy and I saw him and knew he and I were meant to be. I remember the tubes on him and the nurse gently placing him against me . I remember him being hungry and she showed me how to feed him. Once that happened, he spat out the bottle and fed directly from me. He grew fast enough to come home a month later.

I tried to stay with the church but people changed towards me so I walked away. In all this time I kept directly asking Atua some questions. I cleaned myself up and stopped the drugs and alcohol with no cravings, although I was emotionally an addict for several more years. I was hungry to know who I am and found my biological parents. Over the years she has given me info and I have learnt I am Maori. When I told my adoptive family what I knew they were horrified and I began to learn then that my adoption was not as it seemed.

Through all of this I was still a mess, I was exploring my sexuality and my spirituality. I was struggling with loving myself and Atua loving me if I made the choice of loving women intimately. My Christian experience kept me wondering if I was going to hell. My Christians friends then told me that being Maori I was doubly cursed by God as they quoted a story in the Bible of Moses to back up their belief that white Christians had an exclusive right to heaven and us "heathens" were to throw away our culture if we were going to make it to that heaven. I was also told that my short hair and wearing trousers was against God's rules.

I closed my mind to this western God and began exploring what it meant to be Maori and I can only say it wasn't easy. Being adopted meant no automatic access to my culture and I didn't have the language or people to identify in this way . What I didn't know then is that to be Maori as I understand it is to be spiritual. Our spiritual identity is linked into everything we do, say, breathe and live, its all around me. All my life is a spiritual journey. All the experiences and how I respond is also a part of that journey.

My understanding of the spiritual journey as a Maori woman really began in phases:

1. being illegally adopted at birth
2. meeting my biological family
3. being taken aside one day by a Kuia at Parihaka Marae and at the end of sitting and listening to her for over six hours, being given me the name of Huhana
4. picking up the name of Huhana and embracing it as my own
5. accepting I am a mother of a wonderful son who also identifies with disabilities. Embracing this role and learning, making mistakes, enjoying the moments and now watching as he enters into this world as an adult

6. accepting I am gay (Takaatapui) and its nothing evil. Allowing myself to be who I am and that I am not responsible for others emotions on this topic
7. accepting that being Maori for me requires collective commitments, but also being Maori with disabilities still means exclusion from old suspicions, beliefs, fears and ignorance
8. still being Maori with disabilities and proud, despite often receiving verbal abuse from some (particularly male) Maori is a challenge, but accepting I am who I am and taking up that challenge
9. knowing that Atua is in everything and therefore being aware means I am constantly in touch with my wairua Maori

I remember going home to my ancestral Marae as, ironically my mother got hold of a cousin who is a nun in her 70's. I assumed she would judge me so I came out to her expecting what I had received for years: 'rejection'. Instead she hugged me, took me home to all my cousins and as I recited my whakapapa to them, they accepted me as they knew my tipuna. The Marae is one of the few fully accessible ones in NZ and I can only assume Atua knew I was coming home one day and prepared for my homecoming.

I have learnt to understand the difference between Tikanga and Tikanga Wairua, or in other words practicing ritualism and living spiritually. I've also learnt that not all descendents of colonizers are at fault for NZ's modern colonial history, not all western Christians are non spiritual, and that my anger, at times, has been misplaced.

Being Maori for me, is to be a spiritual being who can't be separated from my spiritual self. My life is influenced by all around me and what I learnt. I was told one time by my biological mother that I have te tohunga ao te Wairua (the gift of the spirit). I have been talking to Atua and my ancestors since I can remember, it was and is as natural as breathing. I just never thought it was abnormal until I began to unravel my identity as my links gave me the clues. Living with disabilities in a Maori world is a challenge as many Maori have issues. But there's a reason why my life experiences are as they are and why I am living it. I have only just begun to understand what this is. I am a proud Maori woman, mother with disabilities, a takaatapui woman and all of these interlink with my wairua and vice versa. To take any of these from each other is to dislocate my spiritual identity from my physical self and to create imbalance.

While non disabled Maori have a lot to learn, I am encouraged by the changes slowly taking place and such identities as Hinewehi Mohi an internationally renowned Maori singer who wrote a song about her daughter Hinerakautari (Goddess of music) and has openly and proudly told the world how her profoundly multiply disabled daughter is the inspiration for her Maori focused music.

I am hoping through my PhD work to raise awareness of Maori with disabilities and improve the life expectancy and expectations of this group. This work is evolving but I would like to leave you with a poem I wrote on identity for a woman's studies paper and is the theme for a book I am writing. I named the book Whanau Whanau originally but

I have decided to change it to Te toetoenga (the left overs) because its about finding the beauty of soul/spirit of people who have often been cast aside like left overs but who still have so much to offer and give.

> Ko Wai Ahau
> (Who am I?)
> Identity… what is this?
> When we are born, we are who someone tells us we are…
> Do we know who we are?
> As we grow, we learn, copy, duplicate, experiment…
> Is this who we are?
> Our language, our skin color, our gender, our abilities or disabilities -
> do we define these?
> Our memories, our teachings guide us,
> Are they always positive?
> When I was born, someone gave me to someone else,
> My mother gave me to a stranger,
> My mother named me… she called me Tina…
> The stranger called herself mother, she called me … Susan…
> When I grew up, I grew up in a language not of my Ancestors…
> A culture not of my own.
> My skin color not their skin color. My beliefs, not their beliefs…
> My memories not always positive.
> Yet - I am affected by all of this and so alone by that which I should know.
> Identity - what is this?
> Identity - what is mine? Who am I?
> Ko Wai Ahau?
> I am as I am able to piece myself together from the pieces of the puzzle I have found and the ones still missing in my life.

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Worship without Words

Gillian Bell (Speech-Language Therapist)

Editor's note: This was a workshop that involved a lot of group participation so only an outline is available. Contact Gillian for further details.

CAUSES OF COMMUNICATION PROBLEMS

Conditions may be congenital such as:

- cerebral palsy
- cleft palate
- autism
- Fragile X and many other syndromes
- deafness
- intellectual impairment

Conditions may be acquired:

- accidents, e.g. traumatic brain injury
- surgery
- carcinoma, especially of the head and neck
- neurological diseases, e.g. Motor Neurone Disease, Multiple Sclerosis, Parkinson's Disease, Stroke, Huntingdon's disease, Alzheimer's disease etc.
- "psychiatric" illnesses like Schizophrenia, Bi-Polar disorder, Depression etc.

Disorders of communication can affect:

- the voice
- articulation
- language
- fluency
- hearing ability
- comprehension ability
- and/or a combination of several or all of these.

Cognitive, visual and physical disabilities can also mean that these people may not be able to write or use a computer to communicate with either. Along with speech problems many people have eating, drinking and swallowing difficulties and facial paralysis and dribbling. Some of these conditions are temporary, some are permanent, some may improve, some stay the same and sadly, some get worse over time.

THERAPY AND OTHER SOLUTIONS

Speech-Language Therapy (SLT) and medical interventions can be of great benefit. People with communication impairment of any sort should be encouraged to seek help. An assessment or re-assessment by a qualified SLT can mean a whole raft of treatment options or ideas for better management of the problems. There are always new and better techniques being discovered.

Similarly, an SLT can refer to an organization like Talklink or Ablenet /Abletech who can assess, trial and provide the most wonderful computerised or less sophisticated but equally workable solutions. These are often partly or wholly government funded so cost should not be an issue. The main requirement is that whatever is provided is suitable and is reviewed at regular intervals to ensure that it is still the best option available. Communication aids have come a long way over the past 30 years and new and better devices are being designed all the time.

THE GOOD NEWS

God already knows our needs, He knows the thoughts and desires of our hearts. He has a great sense of humour and His mercy is far greater than we can imagine. He even chose people with speech impediments, like Moses, to lead His people to the Promised Land.

Glorify God in other ways

- When we show love or do something thoughtful for someone else (Mary washing Christ’s feet)
- A smile, a touch.
- Looking after children, animals, plants.
- Creating something

Worship in other ways

- Sing, play or create music.
- Dance or move rhythmically
- Make something: sculpture, pottery, crafts
- Sewing, knitting
- Painting
- Write prose, poetry,

A thing of beauty

“A picture paints a thousand words …”. Something lasting created for our Maker is a way of saying thank you to Him and a lasting reminder, joyful or poignant, of our love for Him and vice versa. However difficult our circumstances are here on earth, we know that Jesus Christ himself suffered, was rejected, despised, wounded and scorned. He knew and still knows how it feels and he loves and cares for us despite our disabilities. (Perhaps all the more because of our disabilities and humility). God's mercy is everlasting and all-encompassing and in the final days when we meet him face to face we will be made whole as there will be no more suffering (Revelations 21: 4). Until that day we must continue to do our best, in whatever way we can, to worship Him and help others with communication challenges to do their best for Him.

Gillian Bell
Gillian is an English (born and trained) Speech-Language Therapist and has been a Mental Health consumer. She has worked for 30 years in her profession and was a Co-Founder of the Stroke Foundation of N.Z. Inc.
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Healing Rituals: Hocus Pocus or a Hopeful Whirlwind?

Rev Andy Calder

INTRODUCTION

This paper seeks to add to the exploration of the efficacy and power of rituals for people with disabilities. Sometimes viewed with suspicion, rituals, individual and/or public, are an overlooked response in supporting people's recovery and living with disability. For many people, myself included, ritual has in earlier years conjured up images of high church practices, empty repetition and rigid liturgy, with seemingly little relevance to societal or pastoral situations. The particular focus of this paper is from the perspective of road trauma, informed by my own experience, and in particular incorporates a description of an annual Memorial Service organised for people bereaved by road trauma, or living with its aftermath. Seven years to the day after my own accident a specially designed Celebration of Healing took place. The sense of ensuing reconciliation from that strengthened the belief in the power and efficacy of public ritual.

BACKGROUND

Some background information to set the scene may help. Motor vehicle accidents (MVA's), represent the largest cause of trauma-related admissions to Australian hospitals. Medical and technological advances have increased survival rates, but these advances have meant that more survivors are confronted with the long term prospect of physical and psychological recovery. Appropriate early assessment and treatment of the psychological consequences of being a road trauma casualty can significantly reduce stress and sometimes hasten a return to a more meaningful and productive life. However, the legacy of loss and grief owing to an altered sense of self through damage to one's body, mind, spirit and/or relationships can be profound.

During 2001 in the state of Victoria, Australia, 407 people died as a result of road accidents, an increase of 9% on the previous year. As a comparison, this is equivalent to the same number of people killed if a full jumbo jet load was to crash. In the same period, 8942 people received major or serious injuries, resulting in medical treatment and/or hospitalisation. (TAC Road Safety Monthly Summary, January 2002 Issue). The ongoing implications of bereavement and serious injury and the emotional, physical and financial costs to individuals and their families cannot be underestimated. "When it comes to the road toll, all they ever talk about is death. They never tell you about the people who get left behind, the effect it has on their lives." (Denise and Peter Kulk, talking in *Life and Death in the Fast Lane* by Garry Linnell, Good Weekend, January 19, 2002)

A TIME TO REMEMBER

It is within this context that a Memorial Service, entitled 'A Time to Remember' was first organised in 2001, under the auspices of the Road Trauma Support Team, a community based counselling service. The strong sense of appreciation for the Service has seen similar events also occur in 2002 and 2003. A partnership approach has been adopted in which the Support Team jointly planned the occasion with the Uniting Church, the Epworth Hospital and the Transport Accident Commission.

The first Service was held on Palm Sunday 2001, and took place in two locations: in the Melbourne City Square and St. Paul's Cathedral, which is close by. Its purpose was to provide a public opportunity for people affected by road trauma to gather and express their grief and sorrow. It was also an occasion in which media and public attention was drawn towards the need for care and vigilance over the impending Easter holiday period, a time when high numbers of road deaths and injuries are prevalent.

At the first location, the City Square, a personal story of a mother's loss of her daughter was shared, followed by plea*s* of concern about the road toll, as demonstrated by public figures. These were from the Minister of Transport, the Chief Executive Officer of the Transport Accident Commission, and a Commissioner of the Victoria Police. A candle was then lit as a symbol of universal grief, followed by some multi-faith prayers held to honour the diversity of religious backgrounds in the Victorian community.

As a point of transition between this multi-faith context and a distinctively ecumenical Christian Service at St Paul's, the candle-bearer and the Moderator of the Uniting Church lead all those in attendance into the closed-off intersection of Collins and Swanston Streets for a brief prayer and time of silence. This act was to symbolise a 'reclaiming of the roads' from the horror and trauma that people have suffered. With trams and traffic brought to a standstill, and surrounded by emergency service's personnel and police, it was a poignant moment providing an opportunity for many expressions of tears and sadness. Driver (1991) notes that "the liminality of ritual can be used by God to weaken the grip of oppressive powers, and that in fact God has no other use for it". In the tears and symbolism of standing together in that usually busiest of intersections, I believe that for those present such powers were weakened. This ordinary place was transformed into a holy one.

A procession to the Cathedral then took place, filing behind the candle and a cross assembled from smashed car panels. Following introductory prayers, scriptural readings and a reflection from the Moderator, a series of prayers were offered with a symbol being placed at the foot of the cross prior to each petition. These petitions and symbols were as follows:

- for people bereaved by road accidents *(photo of a loved one)*
- for people injured, and their carers *(a prosthetic)*
- for those who administer emergency services *(fireman's helmet)*
- for those who provide health services in hospitals and other settings *(1st Aid Kit)*

• for those who witness road accidents	*(spectacles)*
• for those who make and administer our laws	*(legal documents)*
• for our community at large	*(a wreath of flowers)*

At the conclusion of these petitions the Lord's Prayer was shared together.

Whilst 'Amazing Grace' was sung by a soloist, members of the congregation were invited to come forward and light a candle for their own personal remembrance or grief. Then at the conclusion a blessing was offered by the Moderator prior to people returning to their everyday lives. The range of reactions after the Service was broad: from personal expressions of grief, groups holding and comforting each other and the exchange of stories, whilst some chose to leave hurriedly.

In planning for the Service there was a consciousness in the minds of the planners to ensure the location had access for people with mobility difficulties, and the sand trays were placed at an appropriate height. The huge Cathedral was half full and my recollection was that every person there went forward to light a candle – the timing of which created some logistical hiccups for the groups who had bookings after us! But this time could not be hurried, having a life and depth in need of respect and honour. This was the 'kairos time where God can find us sitting still; that time which is the dwelling place of the eternal God we serve' (Fulghum, 1995).

HEALING AND RECONCILIATION

Mention of reconciliation was made earlier. What of reconciliation at this significant occasion? Reconciliation, broadly speaking, is 'the establishment of harmony with one's world, one's destiny, or oneself'. (Hunter, 1990). For Clebsch and Jaekle (1967), reconciliation is that function of pastoral theology which "seeks to re-establish broken relationships". They also contend that "ritual acts are powerful means of healing, guiding, sustaining and reconciling troubled persons" (Clebsch & Jaekle, 1967). If I could presume to speak on behalf of any person present about how they might have been reconciled with God or others as a result of this occasion, my task would be that much easier. I can but broadly speculate.

I believe acts of healing, and of reconciliation, are closely linked. This event provided an opportunity for both private and public prayer in the company of others, in both secular and sacred spaces. People were free to choose to be present at either or both settings. Reconciliation, in speaking of 'broken relationships', may mean for one person the seeking of God's forgiveness for an action that lead to the suffering of another. For another, it may mean the offering of prayers for personal solace over the anguish of losing a loved one. In the very company of others who have suffered similar unbearable burdens of grief, such solidarity and togetherness may be profoundly comforting. In the words of Turner (1995), it is to be hoped that a ritual of reconciliation such as this one did indeed provide a space where "identities are challenged, reshaped, reframed and social status is temporarily suspended until we re-enter society in new ways, transformed by our encounter with the living God".

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Christian Ministries With Disabled Trust

Presented by Di Willis, Evan Clulee and Debbie Mudgway

This workshop looked at the Christian Ministries with Disabled Trust whose aims are to evangelize, equip and educate. They have 5 main Ministries:
C.F.F.D., or Christian Fellowship for the Disabled, is mainly for those with physical disabilities. It is run all over New Zealand, in the Philippines and in Fiji (where it is called Disabled Outreach for Christ). CFFD has meetings, camps etc.
Joy Ministries, mainly for Intellectually Disabled, is in Auckland and 3 other centres but not in Christchurch. We heard about other ministries in Christchurch. Joy Ministries have a newsletter, meetings, annual national camp, day camps in Auckland etc.
Emmanuel, for families with children with disabilities, is in Auckland. They have activities for mothers, fathers and the whole family, camps, and newsletters etc**.**
Torch for Blind and Visually Impaired is in Auckland and Bay of Plenty, with meetings and bi-annual camps.
Carers meet in Auckland once or twice year and put out a newsletter.

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The workshop talked about the Centre which is in Auckland (2 other areas have once a week or two weekly,) all the different programmes, visitors, messages given by visiting ministers, home school children, ladies groups, Korean groups to do a programme etc

Other aspects of CWMDT were discussed, including

- The magazine, now named 'The Encourager' which is sent all over N.Z. and overseas with 5,500 copies published. Information and centre leaflets are also published and were available to participants.
- Disability Awareness Sunday which involves people doing things in their church on the 3rd Sunday in June or at some other time
- Camps held round the country, especially the big one every Labour weekend at Matamata, with people coming from all round N.Z. and overseas. This camp involves recruiting many new helpers as "buddies" - about 100 each time.
- The taking of church services and the different people involved. Several individuals who have specific ministries were mentioned. At this time various difficulties were discussed, such as people dying, moving away, and a shortage of helpers, transport etc.
- Finally Margie Willer's book, 'Awaiting the Healer', was discussed, along with various aspects of healing, as well as the range of acceptance by different churches - some excellent but some sadly lacking.

Christian Ministries with Disabled Trust: Di Willis is the Ministries Director of Christian Ministries with Disabled Trust and Evan Clulee and Debbie Mudgway are both trustees. Combined they have nearly 30 years of ministering with and to people with disabilities through this nationwide ministry. Evan and Debbie both have personal experience with disability.
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A Healthy Spirituality

Church Mental Health Lobby – presented by Michael Watson and Brenda Cheyne

What is Spirituality ?

- Can mean many things - is hard to define
- Spirituality here is taken to mean the **depth dimension of existence** - not a separate (religious) compartment or part of life

Something greater than self

- Takes me into a larger picture: out of my own limited world into the world of loved ones, of those I have dealings with
- May put things in a longer time-frame and a wider perspective
- May involve a connection to the natural world and may connect with the universe
- Humility - living close to the earth, knowing my place in the universe

A place to stand

- A rock, something steady, reliable, trustworthy
- "Being on my own ground"
- A central truth on which you can rely
- A home within, a sense of home-coming, of being at one, being grounded

Stillness

May include elements of:

- Silence
- Solitude
- Inner stillness
- Being centered
- Meditation
- Contemplation

Forgiveness

- Receiving forgiveness - release from guilt, shame, sense of failure: setting free from limitations and negativities of the past
- Forgiving others: letting go of "my rights" and of hurt, anger, resentment, bitterness

Healing

- May include physical and emotional healing
- May involve **acceptance** of physical or other limitations
- May include the **courage** to face pain and loss and to live through them
- May include a healing from crippling anxiety, fear and loneliness (the burden of living, existential angst)
- Helps us to **live well** and to **die well**

Newness, Renewal

- Seeing the world with fresh eyes or through the eyes of a child
- Releasing creativity - opening up new possibilities
- Elements of joy, of humour and of not taking self too seriously
- Sense that there is something to live for, that there is a future that is worthwhile

In for the long haul

> *"This is not a spiritual quick fix.*
> *It is a way of life and it takes a*
> *lifetime to absorb.*
> *Nothing important, nothing life-altering,*
> *nothing that demands total commitment*
> *can be tried on lightly and easily*
> *discarded.*
> *It is the work of a lifetime*
> *that takes a lifetime*
> *to leaven us*
> *until, imperceptibly,*
> *we find ourselves changed*
> *into what we sought."* *Joan Chittister (Order of St Benedict)*

"Life is only for love …
… time is only
that we may find God"
(St Bernard)

Church Mental Health Lobby is a group represented by Michael Watson, an Anglican Priest working in the mental health area, and Brenda Cheyne, a mother and gardener who has journeyed through depression and Post Traumatic Stress Disorder.
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Christians Coping with Chronic Debilitating Illness

Dennis Clow

INTRODUCTION

“I think you may have Parkinson’s Disease.” These words uttered by my psychiatrist in 1998 opened a new phase of my life, a phase where I have to live with the fact that I have a chronic debilitating illness, an incurable illness that nobody can tell me just how quickly it will progress. I was seeing the psychiatrist because of depression which I’d suffered from for years. He referred me to a neurologist who confirmed the diagnosis and informed me my depression was a precursor to Parkinson’s. The physical effects of Parkinson’s (PD) involve a blank look on the face (this is what made my psychiatrist think that I had it), a stiffening of the body, slowness of movement, stumbling, a lack of dexterity of the hands, a shaking movement of the hands and head, to mention but a few. Loss of short term memory and early dementia can also be part of PD. PD affects everyone differently, some are only slightly affected yet, at the other end of the scale some end up in a wheelchair, completely reliant and not recognising their loved ones.

Already I have had to take early retirement from the parish ministry, have given up handwriting (I now do all written work on the computer), find it difficult to do up buttons or tie a tie, cannot dress or change my grandchildren, get absolutely exhausted daily, can no longer drive any distance, have poor short-term memory, and so on.

That’s enough about me. What I want to do this morning is to ask how Christians cope with such chronic debilitating illness?

HEALING AND WHOLENESS

Some Christians would say if one went to a healing service and had enough faith then God would heal and you would be well again. I don’t know about you but I’ve lost count of the number of times I have been anointed with oil and prayed over for depression and PD. Yet I’m still on anti-depressants and I still have PD. But the irony is that I have been a participant in the healing ministry for years. I have been instrumental in commencing healing services in the last three parishes I’ve ministered in. You might well say, “Physician heal yourself”. You’ve been a help to others why aren’t you healed?”

Well, I’m not cured but I still believe that healing is real at a Healing Service. Such services are a powerful reminder to everyone that God’s in the pain and despair. Through the service the ill person is reminded, in a hands-on way, that they are in the presence of God. The anointing with oil, the touch of the person praying and the faith of those present all combine to give the person prayed for a sense of the divine, that there is more to life than the pain of the moment. If there is no cure the person has still been touched and blessed by God. They have been reminded they can never be taken out of the presence and love of God. A healing service can bring about the miracle of spiritual healing which, in the last analysis, is the most important healing of all.

PAIN, FRUSTRATION AND DESPAIR

Nevertheless you and I are still left with our disabilities, and with all the pain, frustration and despair that can go with them. Surely we have a right to bring before God the rottenness of how we feel. The 16th century Protestant reformer John Calvin assures us that we have permission, and freedom is granted us to lay open before God our infirmities, even those which we would be ashamed to confess before others. Christians, he says, are not free of vexations, anxieties, and huge torments, and their prayers should not pretend they are. Like the psalmist, Christians know what it means to cry to the Lord from the deep abyss. And so Calvin encourages us to be real in our prayers, to avoid pious clichés and platitudes. Let us come before God, he says, with our vexations, anxieties and huge torments.

Much popular contemporary Christian piety doesn't take seriously the hard and difficult moments of life. There are too many services of worship, sermons, songs and popular Christian literature that give the impression that Christian life is a breeze. There's a tendency to skip over Good Friday and concentrate on Easter Day. It's almost as if Christians can't cope with the reality that Jesus suffered, that he was literally tortured to death. This is in spite of the fact that the gospels themselves give more space to the crucifixion of Jesus than the resurrection. Sermons and services which ignore the pain of life have little to say to those of us are facing progressive, chronic illness.

FREEDOM TO LAMENT

Many Christians feel uncomfortable when it's suggested that we should have the freedom to lament and complain to God. They prefer to dwell on the uplifting parts of scripture and to proclaim the wonderful salvation from sin and despair we're offered in Jesus. After all there are many passages which describe the rich life Christ calls us to. For example Paul writes the fruits of God's spirit are love, joy, peace, patience, kindness, generosity, faithfulness, gentleness and self control (Galatians 5:22). According to passages like these, one would think that the Christian life would be a trouble-free experience, full of light and super-abundant living. Yet, in spite of such passages, hurting Christians do have the right to lament, for prayers and passages of lament are a very important, although an often overlooked, part of the Bible.

The same Paul, who wrote about the fruits of the spirit, tells of the terrible sufferings and hardships he had gone through because of the Christian faith (2 Corinthians11:21-29). Other New Testament writers refer to the great sufferings endured by Christians, such as 1 Peter, Revelation and the Hebrew scriptures. There are also many psalms where the psalmists tell us they are at the end of their tether and see nothing but darkness and despair (read Psalm 88:13-18), while Jeremiah knows moments of such wretchedness that he curses the day he was born (Jeremiah 20:14.)

The book that has helped me in coming to terms with my illness and the negative feelings that came with it is “Rachel’s Cry” by Billman and Migliore. They say, “Without the resistance and protest that are expressed in the prayer of lament, Christian life, worship, and ministry can quickly become shallow and evasive.” (p.vii).

Men and women, it’s that shallowness and evasiveness that my very being cries out against. I put it to you that we need a spirituality that will take seriously the pain and hurt which sometimes rages within us. We need a faith that will not only cope with, but also articulate the grief and sense of loss that disability can bring about. I believe that the Christian Church is called by the scriptures to both hear and give voice to pain and not to attempt to paper over the cracks with a glib and trite piety that pretends as long as we have faith enough to praise God then God will somehow magic all the pain away.

The title of this book, “Rachel’s Cry”, is taken from Jeremiah 31:15 where Jeremiah describes Rachel’s inconsolable grief because her children have been slain or carried into exile. “A voice is heard in Ramah, lamentation and bitter weeping. Rachel is weeping for her children; she refuses to be comforted for her children, because they are no more.” As we know, the writer of Matthew quotes this verse when he tells of the grief of the mothers of Bethlehem after Herod’s troops slaughtered all the small children in a vain attempt to snuff out the life of the Messiah.

Rachel refuses comfort because of her rage at the senseless slaughter of her children. They are no more and therefore there are no words of comfort which, however well meant and however pious, can bring her out of the pain of grief. As Billman and Migliore say, “Her resistance to all easy comfort registers a powerful protest to outrageous suffering and injustice.” The book goes on to say that her resistance is both a protest to and a waiting on God, for in her own way, Rachel holds open the possibility of again praising the God of justice and new life. The fact is that the prayers of lament in the scriptures, however bleak, anguished and despairing are not the words of atheists. Behind them all is the conviction that God can act if God chooses to. The laments stem from the fact that God appears not to have acted and the result is great suffering.

A CHURCH IGNORES SUCH CRIES AT ITS PERIL

The church ignores such cries in the scriptures at its peril. Whether we like it or not the Bible reflects life as it really is. In every part of history and most certainly today in places like Iraq there are countless Rachels crying out in the face of appalling suffering. To in any way ignore or overlook the pain of the world is to turn away from the example of Jesus, whom Christians believe is God incarnate. Certainly Jesus could never be accused of taking no notice of the cries of the poor, the sick and the oppressed. He was ever to be found among such people.

Jesus himself suffered, especially in the Garden of Gethsemane, in his trial, and the crucifixion itself. Knowing what hideous pain was in store for him, Luke tells us that in the Garden Jesus prayed for release from betrayal and death so intensely that his sweat became like great drops of blood falling down on the ground (Luke 22:44). It’s Mark’s

Gospel that tells us that just before he died on the cross Jesus cried out, “My God, my God, why have you forsaken me?” (Mark 15:34 - a quote from Psalm 22:1). Here Jesus plummeted the depths of human misery, pain, and loneliness. Billman and Migliore are right to say,

> Among the profound meanings of the suffering and death of Christ ‘for us’ is his awful lament to God as representative of all who suffer and are crushed by the forces of this world. The cry of Rachel and all other cries of the distressed are present in the cry of Jesus (p. 39).

Given that lament is part of the scriptures, and that the depths of lament can be found on the Saviour’s lips, how can the church give permission to lament? Some find the expression of deep grief or heart-felt lament embarrassing. This fact itself inhibits many from in any way giving full expression to the depth of emotional pain within them. Certainly to do so within the context of a Christian Church needs “permission” from the minister and congregation. If either, implicitly or explicitly give the message that lament is inappropriate for a person of strong faith, then the response is usually to bottle up the deepest grief and put on a sunny disposition, or reject the Christian faith altogether, for failing to meet one’s deepest needs.

The style of services usually held in a church can give or withhold permission to lament. Churches known for highly joyous praise-type worship at all their services, including funerals, declare their unwillingness to permit an honest expression of loss, sorrow and anger in the face of suffering and death. Such churches would be most unlikely to use biblical prayers of lament.

PSALMS OF LAMENT

On the other hand Billman and Migliore suggest psalms that sensitive churches can use to encourage people to express their hurt and grief:

- Psalm 88, a description of the clinical condition of a person in profound depression who feels trapped in a darkness that is inescapable, abandoned by friend and lover. It is a psalm that could be used in the tragedy of a funeral of a suicide victim.
- Psalm 109 is a healthy rage at enemies which would have therapeutic value for someone who needs to get anger out of their system. It may help them break out of their rage by expressing it directly to God. This psalm is hardly an expression Jesus’ teaching to love your enemies. Nevertheless there are times when it’s important to express anger. Who better to express it to than God?
- Psalm 22 could speak for and to those who feel that they are abandoned by friends and even by God. It is a psalm that begins with that most terrible of all cries, the cry of dereliction, but ends in praise.
- Psalm 38 may be for those who are ravaged by illness and/or old age. It’s a psalm which would certainly ring bells for someone who’s suffering a long lingering death.

- Psalm 69 could be a psalm that would mean much to someone in public office or in leadership in the church who's facing a great deal of unjust criticism.
- Psalm 55 could speak very powerfully to those who've been sexually abused.

It's important to be able to give free and full expression of what we feel so that we can come to terms with what is or what has happened to us. Yet with the exception of Psalm 88 all psalms of lament have words of praise and hope as well as lament. This provides an important balance for there is no gain in staying with words of bitterness, grief and anger. Such words by themselves may only remind us of pain and injustices of the past and as such keep bitterness and hatred alive. The lament passages are, I repeat, a vital part of scripture, but along with words of praise and thanksgiving, as is the good news about Jesus who both died and rose again for us.

The scriptures proclaim a God who hears our cries, even when we think we're not heard. The scriptures show us a God whose heart breaks for us, his daughters and sons, as he shares our grief and hurt, our bewilderment and loss. The scriptures show a God who in Jesus gave himself to the worst that this world's evil could do - that was to torture him to death. The scriptures tell us that even that horrific pain and cruelty could not defeat God's love, for Jesus rose from the dead. We proclaim a divine love which nothing in this world or the next can take away (Romans 8:37-39).

To be able to explore and express what's going on for us enables us to name our cross and pain. In so naming that which hurts so much we then are open to God's renewing grace and healing power which we supremely see in the dying and rising of Jesus. The process of naming our pain's never easy, but it's the risen Jesus who, baring his scars, comes to us in our naming and says, "Peace be with you." His risen presence is ours.

IS LAMENT RESIGNATION?

Lament is not resignation. Resignation is to take to one's bed, so to speak, and resign oneself to the ravages of one's affliction. To lament however is to express rage and anger at what has happened, and having done this, to affirm hope and to fight against the spirit of resignation. As Billman and Migliore say, "By refusing to concede that the present state of affairs is the last word, and by recalling the mighty acts of God in the past, those who lament prepare the way for new hope and new praise" (p.125).

I want to end on a positive note. Paul wrote, "We know all things work together for good for those who love God, who are called according to his purpose" (Romans 8:28). This verse is a life-line, it brings me hope. It tells me that in the midst of the frustration and pain that my illness brings me, God is working through me and for me. Yes, and good will come about in spite of the loss of my vocation and so many plans and dreams.

Those of us who are disabled should make the apostle St Paul our patron saint. He began his life as a Christian by becoming disabled - he was struck blind (Acts 9:8). He had poor eyesight from then on (Galatians 6:11). Three times he asks for a thorn in the flesh (an illness, perhaps epilepsy, or perhaps his poor eyesight) to be removed, but God said, “My grace is sufficient for you, for power is made perfect in weakness.” Paul’s response to this ‘no’ from God was to write,

> So, I will boast the more gladly of my weaknesses, so that the power of Christ may dwell in me. Therefore I am content with weaknesses, insults, hardships, persecutions, and calamities for the sake of Christ; for whenever I am weak, then I am strong (2 Corinthians 12:9-10).

I don’t pretend to have the great intellect or the impressive courage and tenacity of St Paul, but like him I do have a thorn in the flesh that will not go away. May God give us all the faith to lay our weakness before him and let him use that disability whatever it is.

LET US COMMIT OUR FUTURE TO THE ETERNAL ONE

Dennis Clow is a Presbyterian Minister who has had to retire from Parish Ministry because of Parkinson’s Disease. However he is still able, with the help of his wife Margaret, to carry on with being the Presbytery Clerk of the Presbytery of Waikato. He is the doting grandfather of his five grandchildren and, before the onset of Parkinson’s, was active in amateur dramatics.
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Healing Touch

Peggy Dawson

Editor's note: This was very much a "hands on" demonstration given by Peggy and as such, this is a summary only of what occurred. Please contact Peggy for further information.

The aim of Peggy's workshop was to present to parents, caregivers and their children, ways to deepen their bonds of love and communication through the non-verbal language of nurturing touch. She was able to show "fun" ways of working with children with multiple disabilities. Peggy also explained ways of working with babies and children who suffer birth trauma, believing that every cell of the body has a memory, and the emotions from birth trauma become "held" in the cellular memory of the body, and produce "holding patterns". These can be released through loving touch, supported by loving affirmations, and compassionate eye contact. Parents need to also be supported throughout this process.

Peggy Dawson trained in the San Francisco School of Massage as a massage therapist, and also received a professional diploma for working with people with life-threatening illnesses. At the same time she worked in the "Coming Home" Hospice, the Plane Tree Unit of the Pacific Presbyterian Medical Centre, and in the Day Care Centre of Mother Teresa's Home for people living with AIDS, - all in San Francisco. Since then she has created her own training programme called, "Service Through Nurturing Touch", which she teaches in New Zealand and throughout the world. This training allows chaplains, clergy, and caregivers to learn appropriate ways of touching people who are suffering life threatening illnesses, and also gives them appropriate ways of receiving good, nurturing touch. Peggy feels that the church is being "called" to face the "body issues" which have been denied and neglected for centuries, because this is the work Jesus demonstrated so beautifully, compassionately, and very clearly to us, his love through touch.

Peggy is also an international trainer with the International Association of Infant Massage, working with babies and children. This work took her into an Orphanage in China, which brought her into touch with children and adults suffering from the emotional trauma of abandonment and rejection, as well as with children suffering multiple disabilities.

Peggy is deeply committed to the integration of massage therapy, Healing Touch Ministries, and Spiritual Direction. In July 2001 she completed the Internship in the Art of Spiritual Direction at Mercy Centre, Burlingame, San Francisco. She is also licensed as a Diocese Lay Minister, authorised as Pastor, with permission to anoint, by the Bishop of Auckland.
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Through the Whirlwind: Mental Illness and Spirituality

Heidi Dragicevich

Editor's Note: This paper was unable to be delivered due to unforeseen circumstances. It is presented here however as it is both complete in itself and very interesting. "I hope this exploratory essay raises discussion about the issues relating to mental health and spirituality. This is a complex area yet I hope this sheds some light upon the key aspects of it" (Heidi).

When people say words like schizophrenia, manic-depression and psychosis, what is the first thing that pops into your head? Does it have anything to do with knives, axes, murder, violence, demon possession, unpredictability or dangerousness? The reason these images have such prominence in our minds as being connected with mental illness is that generally the only time we hear information about mental illness is when a violent event happens. We may learn about this through television and newspapers or we may see movies or read thrillers about the "psychotic murderer" which also plays into our fears. These sources create a picture about mental illness for us. Most people do not have other information with which to balance these events in order to create a more realistic portrayal of people with mental illness. We often rely completely on the media for information, and this is often not a reliable predictor of the truth.

Truth is often complex, and simplistic black or white images do not adequately explain it. Most people with experience of living with mental illness are no more likely to commit a violent crime than people without a mental illness. A statistic of one in five people in New Zealand will have experience of mental illness within their lifetime.

WHAT IS MENTAL ILLNESS?

There seem to be four common views about what mental illness is, as mentioned by Mary O'Hagan (2000):

- Biological – essentially it is about chemicals in the brain.
- Psychological – lack of ability to deal with stressors
- Social deprivation / environmental causes – poverty, sexual abuse, unemployment, cultural dislocation
- Spiritual vulnerability - generally seen as punishment

These views may seem simplistic by themselves, however together I think they create a more realistic picture about what actually causes mental illness if there is balance. It appears that the social deprivation model causes less negative discrimination than does the biological model. This is possibly because if someone has a brain disease they are perceived to be less able to control their behaviour and hence may be unpredictable.

There is an emerging view coming from many people with experience of living with mental illness that child sexual abuse and trauma can later cause psychosis and other forms of mental illness. This has been largely ignored by the psychiatric profession. This also contributes to the lack of research in this area compared to biological and genetic causation (Read, Perry, Moskowitz, Connolly, 2001). So there seems to be a lack of balanced information in this profession also. However, every person with mental illness has a unique story to tell, and it can be difficult to make a rule that is true for everyone about the causes. Environmental causes certainly require greater emphasis than they are currently given.

THE EFFECT OF PRAYER AND MEDITATION

Scientific research is showing the positive effects of prayer and meditation on the brain structure. The University of Wisconsin-Madison reports sustained changes in brain and immune functions after meditation. I would suggest that prayer has similar effects. Even though this is new research it could show some of the linkages between spirituality and mental illness which affects the functioning of the brain

In a report by a Mark Ragins in the report “Changing from a Medical Model to a Psychosocial Rehabilitation Model” it is said:

> Schizophrenics in third world countries are regularly reported to have better outcomes than here. Also schizophrenics who explain their conditions spiritually instead of medically apparently fare better.

This information is quite surprising to a western culture that prides itself on advanced scientific development of pharmaceuticals. (Note: it is more appropriate to say a person who experiences schizophrenia rather than a schizophrenic in order not to label the person as their illness).

THE MEDICAL VIEW OF MENTAL ILLNESS AND SPIRITUALITY

John Raeburn from the University of Auckland, Department of Community Health reports in the International Journal of Mental Health Promotion (2000) that:

> Our history in the mental health professions of rational science is one reason that religion does not get proper attention, even though science is now also convincingly demonstrating a number of benefits of, say, ‘church attendance’. However, most research studies emphasise the secular aspects of belonging to a faith community (social support, having a coherent belief system, etc) rather than the ‘spiritual’, subjective or ‘deep meaning’ aspects.

Scott Peck, psychiatrist and author of “The Road Less Travelled and Beyond” states that psychiatry does not attempt to address spirituality and steers well clear of it. He considers that even elementary expertise in dealing with spiritual issues would significantly help the profession deal with a significant amount of difficult cases.

A client of psychiatric institutions, Peter Campbell, in an article written for Open Mind Magazine, February 1993 says:

> Belief is a sensitive subject and I am not arguing for the invasion of private worlds. But respecting something doesn't mean never touching it. I have twice run away from psychiatric hospitals and sought asylum in churches. On one occasion, I got involved in two or three days of religious conversations with a fellow patient which ended in his attempt to exorcize me in the ward quiet room. Nursing staff were aware of all these events. They even brought me back from one of the churches. Yet there was never any attempt to discover what all this meant for me. I often wonder if the rituals, the atmosphere, the day-to-day practice of in-patient care might not be very different if the caring team believed something spiritually important was going on.

There seems to be a tolerance for minority groups' religious beliefs and practices from the mental health profession generally, however not for mainstream service users. I say this from personal experience. Either way, the regard seems patronising. No doubt, this is in the process of changing as more holistic models of mental health emerge to incorporate mind, body, spirit and relationships within the community.

THE CHURCHES VIEW OF PEOPLE WITH MENTAL ILLNESS

While there has been no formal research that I am aware of about 'the churches' view of mental illness, it is generally regarded that punishment and condemnation from God is upon such people. I have experienced this and have also heard many reports from others. There have also been many good experiences reported from mental health consumers in the light of Christian faith communities. Raeburn (2000) mentions that while faith communities can be helpful and health promoting, they can equally be quite damaging if they label mental illness explicitly as demon possession.

In the Bible, 2 Corinthians 12:7 the apostle Paul states:

> To keep me from becoming conceited because of these surpassingly great revelations, there was given me a thorn in my flesh, a messenger of Satan, to torment me. Three times I pleaded with the Lord to take it away from me. But he said to me, "My Grace is sufficient for you, for my power is made perfect in weakness".

Whether or not his thorn was mental illness or not is not clarified. However, the key point was made – he had a disability in order to remain reliant upon God. This could give a disability or an experience of mental illness a positive experience with value and meaning for the person. The powerful effect of spirituality is that it can enable you to see yourself differently in a society that often views the mentally ill as the lowest of the low. It can enable you to transform your spiritual crises into spiritual enlightenment and new birth, and give hope to the hopeless.

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The Role of the Spiritual Dimension of the Self as the Prime Determinant of Health

K. Faull & M. D. Hills

HEALTH DESPITE IMPAIRMENT

Health is defined by the World Health Organisation (1997) as not just the absence of disease, but as a state of optimal physical, mental and social well being. Illness can be defined as the subjective experience of dysfunction; the perception of being unwell (Broderick, 2000). Therefore the opposing concept of health is the experience of meaningful function and the perception of wellness. In essence, health is a state of overall wellness in which the individual perceives their self as whole and functional, regardless of the level of physical, social or mental functionality observable. This paper offers an explanation of the difference between health as experienced and the health observed. Furthermore, we propose a model of self that identifies the spiritual core as the component that determines the constancy and continuity of self necessary for health.

Health is achieved when an individual perceives the core components of self (their sense of 'I') as constant and continuing to exist. Trauma occurs when a person perceives part of that self as having been violated or lost. Such trauma is commonly described as a loss of well-being. Therefore well-being can only be restored when the individual once again perceives the core of self as constant and continuing. Perception of such loss or violation is usually triggered by a bodily, relational or psychological impairment. The degree of observable impairment is therefore only a partial indicator of the level of violation or loss causing diminished well-being (Fitzgerald, 1997; Fuhrer, 1994). Consequently, interventions that repair, compensate or stabilise observable impairment deal only partially with the sense of loss or violation of self that is affecting the health those interventions aim to restore.

The human experience is one of continual change, including loss of cognitive, physical and social aspects that were previously perceived as key components of self. Nevertheless such change provides an opportunity for growth and development of the more intrinsic aspects of self (Fuhrer, 1994). For those with physical disabilities, definition of health has been found to centre on acquiring a resilient self-identity that reflects an open system concept of self (Faull, Hills, Cochrane, Hunt, McKenzie & Winter, 2002; Kluckhohn & Strodtbeck, 1961; Moustakas, 1956; Webster, 2001). Optimal wellbeing is achieved when self is experienced as a component of a larger system rather than as an autonomous, self-sustaining closed system. Despite the changing nature of the objective aspects of self, the subjective ‘I’ has permanence, continuity and potential for growth (Faull, et al., 2002). Healthy individuals focus on ‘being', orientated towards 'becoming' in contrast to 'retaining', so seeking the inherent potential of the self.

The process of 'being' and 'becoming' involves interaction with others, with nature and with the supernatural (the wider system), which is then integrated into a self-system through contemplative reflection. Such reflection culminates in deeper, more meaningful relationships and an expanded self-knowledge (Faull, et al. 2002), based on a comprehension of one's identity, place, meaning and purpose in life. Self-understanding is thus achieved by restructuring one's worldview to include attitudes focused on nurturing a wider system, while accepting the limitations of any one individual's control and knowledge.

Similar processes have been identified for those recovering from mental ill-health (Lapsley, Nikora & Black, 2002) and from trauma caused by natural disasters, war and other similar events (Beardslee, 1989;Tedeschi, Park & Calhoun, 1998). Consequently the ability to recover well-being irrespective of the cause of trauma, described as resilient self-identity by Tedeschi, Park & Calhoun, (1998), depends on an understanding of self as an integral and resilient part of a larger whole.

STRENGTH OF IDENTITY

Cognitive-behavioural self theory suggests that strength of identity is constructed through a learning process of interaction and identification with others, which is perceived and cognitively processed in an individually unique manner (Beardslee, 1989).

Evidence and logic partially support such a view but such models do not fully encompass the reality of human experience. Although interaction with others is essential for learning about self, a strong resilient identity cannot logically be developed by clipping on experiences, social resources and roles if one is not aware of, or does not understand, the innate core of self to which they are to be added.

In this social learning model the self is portrayed as a complete autonomous whole, comprised of individual tangible acquisitions (for example, greater physical and financial independence, friendships, people focused support systems and schemata) that facilitate the aims of stability, constancy, independence and self-determination. This implies not only that the individual is the architect of self but also that he/she has access to the knowledge and power necessary to design the self. It assumes that with the right resources the individual will not only be able to determine the events confronted in his or her life but will have full control over them. The individual will perceive anything less as a failure of self, resulting in ill-health.

STRATEGIES FOR MAINTAINING IDENTITY STRENGTH

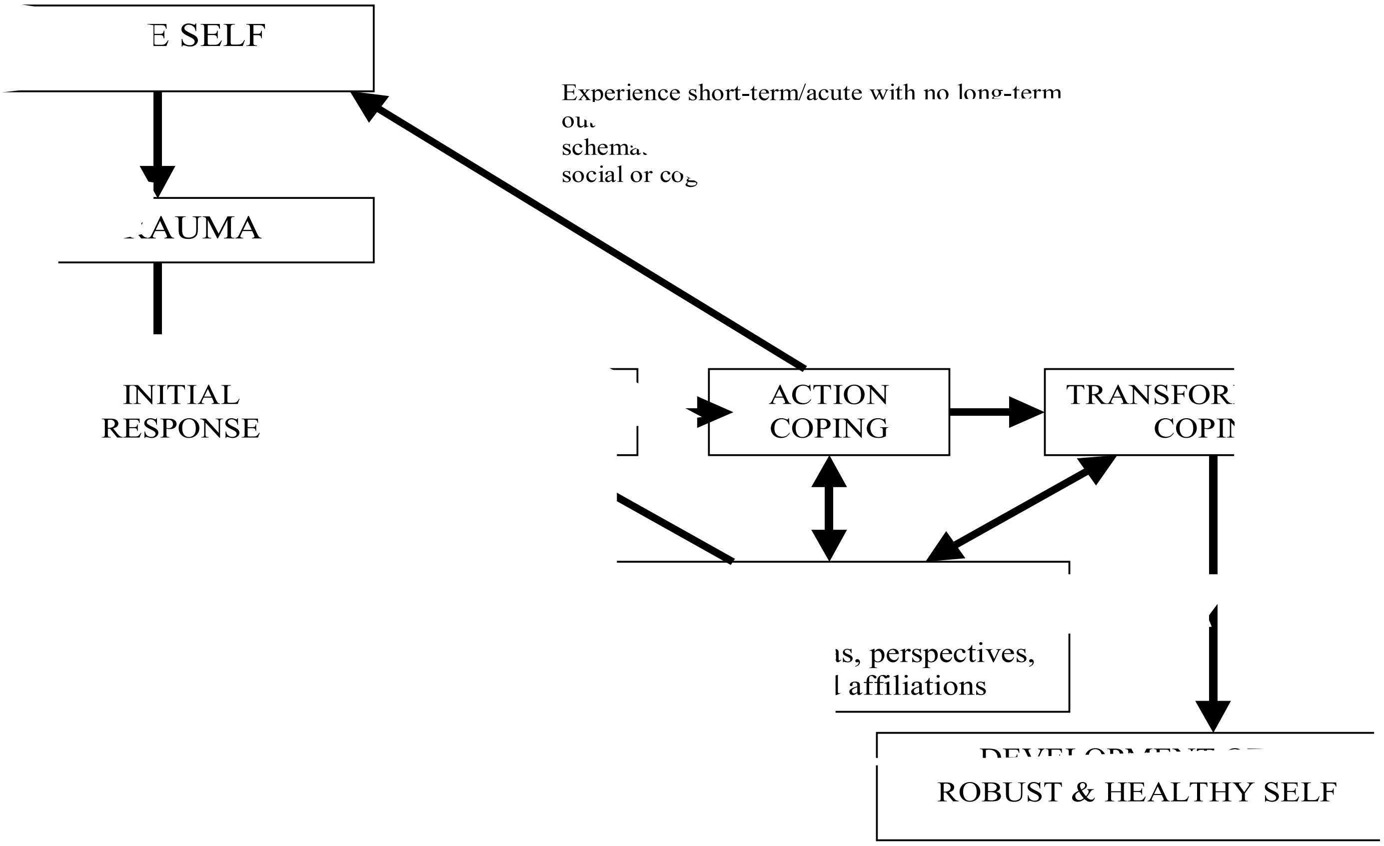
This theory of the self architect supports two coping strategies which aim to retain our perception of self as knower and controller. The first, Inertia Coping, requires us to do nothing when faced with challenges to the self, in the belief that the challenge will simply disappear or resolve itself. The second, Action Coping, involves the individual doing something to address the challenge to self and regain control (Breakwell, 1983). For example, a person with a disability may seek knowledge of the disease/dysfunction, focus on a return of physical flexibility and fitness, experiment with various medications and supplements, seek and use functional aids, examine and change attitudes and lifestyles, or pray for a cure. Pargament (1997) refers to these two options as the Conservation of Ends whereby the individual attempts to preserve who they perceive themselves to be (Inertia) or reconstruct and regain their pre-threat identity (Action).

While these are credible and usually partially successful strategies for coping with acute ill-health, they imply that health requires a return to the former levels of functioning and control. The reality of many experiences, for example disability, is that they are traumatic learning experiences which changes one's perceptions of power, control, infallibility and knowing to the extent that a return to the same pre-trauma state is impossible. Changes to the core self - the “I” - occur that are not only irreversible, but ongoing.

Spiritual theory of self acknowledges that many life experiences challenge the assumption of self-mastery and resumption of a pre-trauma state. It supports a third view of coping, known as Transformation (Breakwell, 1983; Pargament, 1997). Transformation allows the retention of well-being by acknowledging disability as a challenge which offers an opportunity for self-growth. The model developed by Tedeschi and Calhoun (1995) to depict posttraumatic growth has been adapted for those with disabilities and illustrates the three coping strategies (figure 2).

Realising that personal control and individual knowing are incomplete leads to acceptance of the limits of self. This increased self-understanding in turn results in a radical change to a worldview in which self is perceived as a subsystem of a larger system. Such identity growth requires not only interaction with others but also time spent alone. Interaction results in experience and knowledge of the commonalities and contrasts between our own and others’ realities. Time spent alone enables identification and understanding of both the universality and uniqueness of human existence. Awareness of the ways in which we are connected with, or separate from, the world allows understanding of the self as a unique individual within a wider system (Weber, 2000). In summary, understanding of self, meaning of life and consequent successful management of life experiences is central to health. Awareness and understanding of the essence of self as a spiritual being connected to all other life is argued as essential for the self to reach its full health-giving potential (Faull, 2000; Faull & Kalliath, 2001).

Figure 2



State of shock and loss, lack of life manageability – life out of control.

Role behaviours and perspectives of self no longer appropriate nor offer adequate explanation of experience

Emotional overload and accompanying stress and fatique.
Goal: To return life and self to how it was
Method: Personal reflection interspersed by sharing feelings/self-state with others and seeking their support to achieve goal

Perception of control and manageability returns, belief that the individual can regain old self if he/she tries hard enough – hope rekindled
Goal: To return life and self to how it was
Method: Interaction and schemata

take responsibility for self and health

Return to old self not possible

Awareness and experience of self as constant and continuous
Awareness and experience of the limits and responsibilities for self control and knowledge
Goal: To explore and develop towards one's potential

CONSTANCY AND CONTINUITY OF SELF

To maintain a strong identity, the individual must perceive their core self as constant and continuing, although the social and physical environment, as well as personal roles, abilities, physique, and relationships relentlessly change.

Objectively, a continuous self results from awareness of the continuation or connection across time of physical and social aspects of self, such as one’s genealogy, surname, ethnic and cultural identity, accomplishments, and eventually estate and memorial. Spiritually, however, a sense of continuity results from a belief that the self is an enduring part of a greater whole in some way that may or may not be similar to the self's present objective form. The self is perceived as eternal, being part of a greater, meaningful, everlasting system. Power, knowledge and ultimate control of life are perceived to reside outside the individual, who is a small component of a wider system.

Objectively, a constant self results from experiencing oneself as consistent, in that one’s family role, given name, social identity, education and skills, possessions and status are assumed to be unchanging. Spiritually, however, constancy is achieved by awareness of the self as a specific part of the greater whole. “I” always has been and always will be a particular element of the wider system.

To achieve a resilient continuity and constancy of self, the individual needs to acknowledge, relate and experience connection with the wider system. Spiritual models of self propose that all people have a spiritual core to their being that provide people with the resources for strong interconnection, sense of place and purpose (Vash, 1981; Do Rozario, 1997; Matthews, 2000). All dimensions of self are perceived as affecting one another but as the other dimensions of the self function, they either promote or impede growth of the spiritual core of the self. For many in our individualistic society, this core may be relatively inactive and unacknowledged and therefore access to greater self-understanding is denied (Do Rozario, 1997; Fitzgerald, 1997). In this case the universal human need for constancy and continuity of self is met by a focus on the objective rather than the spiritual self. (Weber, 2000). In summary, it is proposed that the objective self cannot fully explain how people manage to retain the resilient perception of self required for health when adversity causes permanent loss of objective aspects of self. Only a spiritually orientated concept of self enables the development of a self sufficiently resilient to remain healthy through all life's experiences. Central to this reasoning is the concept of spirituality, which will be discussed next.

THE CONCEPT OF SPIRITUALITY

Four broad literary themes encapsulate the concept of spirituality (Baldacchino, 2001; Do Rozario, 1997; Dyson, Cobb & Forman, 1997; Fitzgerald, 1997; Selway & Ashman, 1998; Strang & Strang, 2001; Tedeschi, Park & Calhoun, 1998; Tuck, McCain & Elswick, 2001; Vash, 1981; Weaver, Flannelly, Flannelly, Koenig & Larson, 1998; Walton, 1999). The themes assume that there is a supernatural creative force from which all has been formed. They are:

1. **Relationships**: The strongest theme is the existence of meaningful relationships within the self, and between the self and others, external spiritual forces and the natural world. In other words, the self is perceived as an inherent part of a greater whole.
2. **Connectedness**: This theme is intrinsically interwoven with relationships. Not only must a relationship be acknowledged, but its nature must be experienced and acknowledged as an essential component of self. Health is dependent on the degree of connection with self, others, the natural world and external spiritual forces as well as on the level of health of those things to which one is connected.
3. **Meaning**: The characteristics of the individual's relationships and connections determine individual interpretation of the purpose of life. Included is the concept of hope, which is an assurance that all will work for the betterment of the system, including the individual, even though objective evidence may suggest otherwise. The opposing construct to hope is fear, which is the conviction that there is no certainty that outcomes will be positive for the self.
4. **Beliefs/Clarity of Principles**: The preceding three themes enable the development of a personal belief system that is clear, strong and rigorously upheld, and which provides a structure for rationalisation of life purpose and experience. The strength of this belief system depends on the clarity of individual values, life meaning and of the concept of 'I'. It is the means by which the individual comprehends, interprets and reacts to experiences.

These themes are reflected in New Zealand Maori models of health such as Whare Tapa Wha (Durie, 1994) and Te Wheke (Pere, 1997). Both models emphasise the central influence of spirituality over all dimensions of the self system. Relationships that are perceived as inherently connected to the individual self system are forwarded as determiners of one's perception, behaviour and interpretation of experience in line with the individual's unique life meaning and beliefs. Health (ie a resilient self) is determined by the degree of wholeness or interconnection of the dimensions of self with the wider system.

However, spirituality/health research has been impeded by the assumption that religious behaviours such as church attendance, altruistic behaviour and praying are always sufficient indicators of spirituality, rather than of religion (Sloan, Bagiella and Powell, 1999). Other researchers such as Vash (1981), Do Rozario(1997) or Matthews (2000) have focused on individual experiences of the phenomenon of spirituality. However increasing our understanding of the relationship between spirituality and health requires understanding the universal principles involved in incorporating spirituality into the self to achieve health.

A SPIRITUAL THEORY OF SELF

Traditional models of self propose that the 'I' is constructed from social, cognitive and physical dimensions. On the other hand, the spiritual model claims that as the 'I' is an intrinsic part of a greater whole, it is constant and continuous, and thus determines how the physical, cognitive and social dimensions of self are constructed.

Within the spiritual model of self (figure 3) the physical dimension consists of the physical body and external physical entities such as home, the natural world and other people; the social dimension consists of relationships and roles, and the cognitive dimension is one's view of the world and the self. These aspects of self, often observable to others, are subject to continual irreversible change and are depicted in figure 3 as fluid, opaque and porous. In contrast, the essential characteristics of the spiritual core or 'I' of self remain constant and continuous. Retention and continued growth of self requires that the cognitive, physical and social qualities attributed to the self match the unique and essential characteristics that are the spiritual core. In other words, each of these dimensions must 'fit' or affirm the values and beliefs that form the spiritual core. A spiritual concept of self means that the spiritual core must be perceived as the fundamental component of self which must influence other more external aspects of self if one is to be healthy. Consequently, perception of the spiritual core of the self as constant and continuous is necessary for wellbeing. On the other hand, the self as a whole is an open and permeable system in which there is dynamic interchange between its physical, cognitive and social dimensions and the environment.

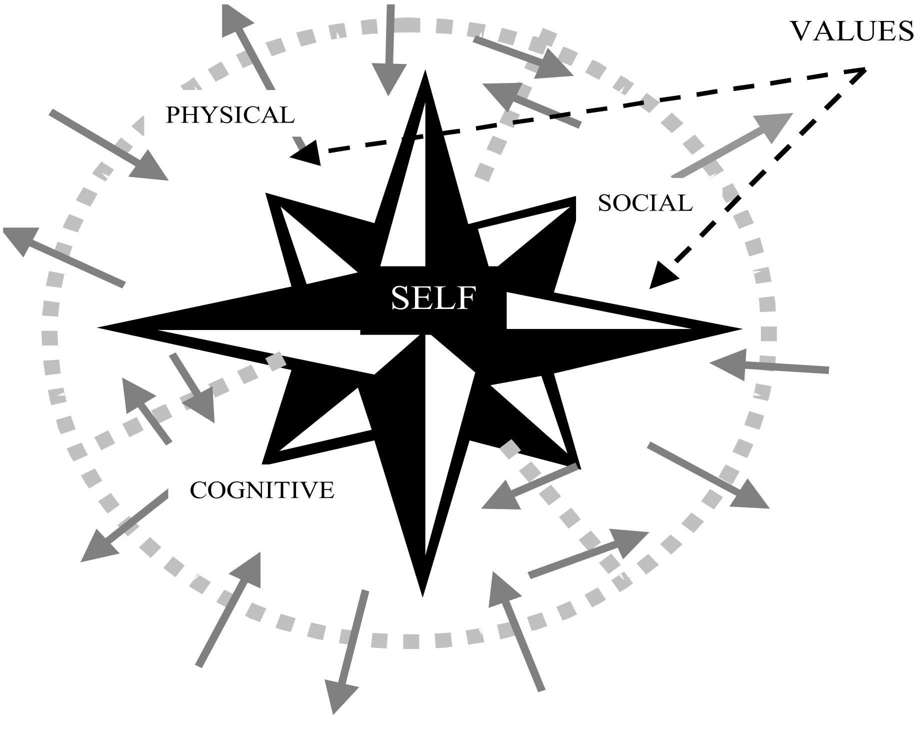
Figure 3: The Spiritual Model of Self

Arrows represent the dynamic interrelationships between the physical, cognitive and social dimensions of self. The dashed lines illustrate that the self-system is open and that there are no impermeable barriers between these dimensions of self or between the self and other selves, nature or the supernatural.
The 'star' represents the spiritual self. It is depicted as solid as it is constant and continuous. It protrudes into all other dimensions. Therefore, when developed, its influence is observable in other dimensions. Individual values determine the 'shape' of the star and therefore what physical, social and cognitive characteristics 'fit' the spiritual self.

The essence of Self is spiritual. It is sourced from and connected to an external spiritual source.

Awareness of the connectedness of the dimensions of the self and of the self and the external world, results in the development of self-understanding. The outcome is clarity of beliefs and life meaning, which is exhibited as personal values.

As values develop and strengthen, social connections, cognitive schemata and physical priorities become increasingly aligned with the spiritual self. Such reconfiguration enables continuity and constancy of identity, which results in a stronger, more resilient self.



To sum up, wellbeing and therefore health cannot be achieved without a strong self-identity, that is, the perception of self as not only unique, but part of a wider system. A spiritually centred identity provides access to coping resources that are essential for achievement of a resilient identity. An open system of self provides a belief system that widens comprehension of experience, allowing greater self-understanding. The person who embraces an open system is able to see their life as a continuum between past, present and future, in contrast with a closed system of self, which encompasses only one time frame (either past, present or future).

Self-transformation is the ultimate strategy for coping with significant life change (Breakwell, 1983; Pargament, 1997). A closed self-system denies an individual access to the Transformation coping strategy, whereas an open self-system facilitates access to it. As outlined above, such an open system requires a spiritually centred identity. Therefore a spiritually centred identity is necessary if healthy coping with significant life-change is to be achieved.

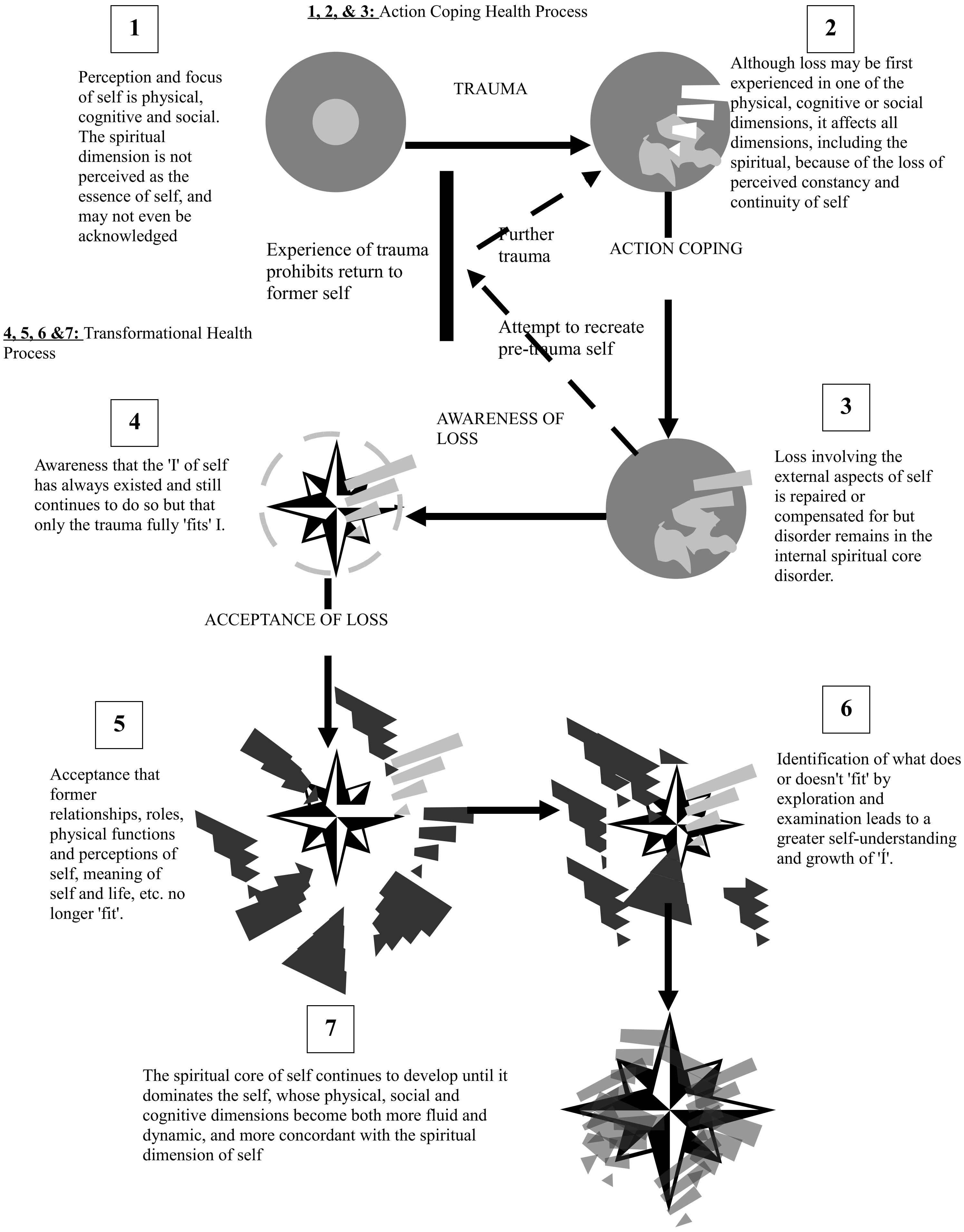
To put it another way, an identity whose strength is based on no more than physical, social and cognitive resources is not sustainable when the self-system is challenged significantly. An apparently strong identity that lacks a spiritual world view of self will result in low resilience and a loss of health when significant challenges are experienced. Resilience implies that the identity is not brittle but can bend, absorb and change. Thus transformational coping with major challenges to the self results in growth and a stronger, more resilient identity (figure 4).

The fundamental need is to be able to perceive life experiences as manageable, comprehensible and meaningful (Antonovsky, 1987) and essential for this to occur is the perception of self as constant and continuous. Resilient identity requires self-understanding, which is a product of the schemata or perception of self that one has. For those who view self as a closed, autonomous and exclusive state of being, the concept of self-identity will assume that strength is achieved by adding external resources to the individual. In contrast, self-identity for those with a spiritual world view of self will entail nurturing or adding to the whole system in a manner that reflects and is congruent with the spiritual core. Doing so allows perception of the self as constant and continuous, despite external assaults on it.

This implies that acknowledgement and development of the spiritual dimension of self is the key to maintaining health in the face of threatening challenge.

Understanding one’s self relies on both cognitive awareness and experiential development. For example, awareness and acknowledgement of the concept of love is not the same as understanding love. One has to love and be loved to fully understand it. Similarly, one cannot fully understand the meaning and impact of the spiritual self without experience of externally orientated spiritual relationships and connections. Therefore the experience of loss of physical, social or cognitive dimensions of self can promote stimulate understanding of the permanence and resilience of the essence of self, the spiritual core.

Figure 4: Process of Healthy Adaptation to Trauma



1, 2, & 3: Action Coping Health Process

4, 5, 6 &7: Transformational Health Process

1 Perception and focus of self is physical, cognitive and social. The spiritual dimension is not perceived as the essence of self, and may not even be acknowledged

2 Although loss may be first experienced in one of the physical, cognitive or social dimensions, it affects all dimensions, including the spiritual, because of the loss of perceived constancy and continuity of self

Experience of trauma prohibits return to former self

3 Loss involving the external aspects of self is repaired or compensated for but disorder remains in the internal spiritual core disorder.

4 Awareness that the 'I' of self has always existed and still continues to do so but that only the trauma fully 'fits' I.

5 Acceptance that former relationships, roles, physical functions and perceptions of self, meaning of self and life, etc. no longer 'fit'.

6 Identification of what does or doesn't 'fit' by exploration and examination leads to a greater self-understanding and growth of 'Í'.

7 The spiritual core of self continues to develop until it dominates the self, whose physical, social and cognitive dimensions become both more fluid and dynamic, and more concordant with the spiritual dimension of self

Spirituality or the acceptance of self as a subsystem that is externally orientated, inclusive, interdependent and predominantly subjective is the resource for accessing a self that is constant and continuous, which will result in a strong, healthy self-identity.

That is: **Self-understanding = function** (Awareness x Experience)
Health = function (Self-understanding x Spirituality)

A self based on understanding and spirituality can develop a sense of control, knowledge and living in the present (being) but with an optimistic focus on the future. Such a worldview allows appreciation and celebration of present experiences and a view of the future with hope rather than fear.

The Acute/Objective Action Coping Health Process (Figure 4) is an objectively oriented component of the health process, which aims to conserve pre-threat self. In contrast, the Chronic Transformational Health Process requires radical perceptual change in thought and behaviour, rather than relying on inertia or action coping to retain pre-threat identity. Transformation reflects the spiritual model of self and provides a health-giving process for healthy change. Acute health intervention may be adequate to reduce or eliminate physical, social or cognitive dysfunction but such a process cannot be guaranteed to result in health. Whether or not dysfunction is removed, one cannot remove an experience that has violated an individual's concept of who they are, their beliefs in self-control and self-determination. Living can be seen as a chronic disease. Consequently, only a health process that incorporates the chronic model of health can hope to facilitate health.

Interventions aiming to promote health thus must accept that the physical, mental and social selves are reliant upon the spiritual self for the perception of the constancy and continuity necessary to construct, maintain and develop a self-identity sufficiently healthy and resilient to deal with significant change. For intervention to be successful in promoting health, it must focus on the spiritual self, rather than just the physical, social and cognitive selves. Returning to the definition of spirituality, such interventions must therefore aim at improving relationships, connectedness, meaning and clarity of principles. By doing so, the intervention will strengthen the spiritual self and increase the identity resilience necessary for the successful adaptive functioning reflected in well-being, the basic measure of health.

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AVOIDING MIS-DIRECTED PASTORAL MISSILES – THE SYNDROME AND THE SOLUTION.

Janine Gibson

INTRODUCTION

Someone comes to you in an emotional mess - they want you to help them, to care for them, and all too often solve their problems for them. So off you go solving their issues, providing for their needs, looking after them, giving your love to them. But it seems like a bottomless pit that you keep throwing your love into with little result and exhaustion sets in place. You ask yourself "Isn't this what Jesus did, healing the sick, feeding the poor?. Didn't he also say that after loving God the next priority is to love our neighbours? What about the Good Samaritan who stopped and helped the man left for dead by others on the side of the road?"

Yes he did say and demonstrate this to us. But he also demonstrated having a passion to care and support balanced with the wisdom to do it effectively. So frequently those involved in professions related to helping people find themselves in holes themselves after a period of time. They get exhausted, lose their passion for ministry, and they burnout. After rushing into help they are the ones who need the help.

There are key elements that we need to be aware of when we are helping others, to give support professionally and in a way that leads people to Christ. We should know what we are doing...and why we are doing it. (Barry Pearman, 2002, *The Power of Vision*).

Mis-directed Pastoral Missile Number One:
THE SELF EXPLODING BOMB

In helping Anna, a patient with border-line personality disorder, her support worker and her chaplain asked those involved to limit the times we took her to a physiotherapist off the bus route. Previously we had been taking her daily at some inconvenience to ourselves. But our question was this: "Why, what's wrong with helping her?".

Anna had made a choice to take this physiotherapist rather than an easily accessible one. Instead of taking responsibility for herself and catching the bus she was now getting people to take her every day. To be functioning in society she needed to be making decisions that did not rely on others – therefore part of supporting Anna to get better was not to do things for her that she could do for herself.

One lady could not understand this and carried on taking her to physiotherapy. Anna was pleased and the lady was happy to take her. Or was she? Two moths later this lady was nowhere to be seen - burnt out by a regime of helping Anna on demand. So the question is, "Did this help Anna?" No, well intentioned ministry resulted in:

- Rejection for Anna
- Burn-out for the helper
- Anna does not learn to take responsibility.

Yet once again someone gives up and walks out of her life. Good intentioned, but not thought through ministry, in this case was damaging to the helper who burnt out, and to Anna who was rejected. Anna was still not learning to take responsibility for her actions. It is the other people who put in boundaries with Anna that have stayed for a longer haul and ultimately have been more helpful.

Mis-directed Pastoral Missile Number Two:
THE TAKE-OVER ARTIST

"Here, let me do the telephone banking for you…..". This is in response to a 30 year old woman, Laura, who needs help with setting up telephone banking. She wants you to do it for her. She is quite clever but lacks confidence when tackling new things. It can be so tempting to get on the phone and do it all for her, i.e. The Take-over Artist Syndrome**.**

The alternative is to let her do it for herself and to show her what to do when (and if) she gets stuck. This can be a bit frustrating but rewarding when she has learnt a new skill and does not have to rely on you for the future.

Mis-directed Pastoral Missile Number Three:
LET US PROVIDE A SERVICE FOR YOU

Doing a service *for* people instead of involving them *in it* is not a good idea. There is a better way and this is seen at "Living Room" (*editor's note: see "Ah, Hmm and Whoopee" for explanations about this programme)* when we include the community in the service by such things as:

- Interviewing people who are likely to come before starting a service
- Leadership meetings
- Brainstorming sessions
- Involving people in using their gifts to lead worship and/ or the service
- Giving message
- Interactive plays
- Sharing times
- Shared prayer times-10-15 minutes every service
- Freedom to ask questions during the message
- Everyone helps set up and pack up
- Supporting each other
- Able bodied volunteers supporting people as they seek to know Jesus

Mis-directed Pastoral Missile Number Four:
I MUST DO MY BIT FOR THE POOR UNDERPRIVELEGED
....AND GRIT MY TEETH WHILE I DO IT

Our philosophy is if you don’t enjoy helping please don’t - we want our support chaplains to enjoy their work. Some of the support chaplains have come from difficult backgrounds. Some have been supported by other support chaplains and are now in a position to support someone else. We like being part of this community and that's why we do what we do.

The Living Room support chaplains – volunteers who work with the Living Room

The purpose of a support chaplain is to:

- provide ongoing pastoral support (listening, teaching, praying) for people living in our community with a disability
- provide feedback for future planning

The support chaplain does a range of activities such as going for a coffee, a walk on the beach, spending time studying the Bible, praying together or simply having a chat. It's really up to the individuals to decide on what's most appropriate. Support chaplains receive regular support, training and supervision. Underlying the practical side of support chaplaincy is a need to understand how to give this support.

Windsor Park Baptist Church –Vision and Values for the Support Chaplaincy

The Living Room motto is “Where everybody is someone and Jesus Christ is Lord”. This to me is a key to everything we do. Jesus must be Lord in all we do. Everyone is important. We all have different gifts that we can offer each other.

Support chaplaincy’s integral values:

- Our support must be both compassionate and professional
- The person giving support is in need of support also - monthly chaplaincy support meetings, supervision, training
- To maintain ministry in the long term we all need support and encouragement
- Our focus is to point people to Christ and being a disciple of His
- The power of vision

The power of vision

One key philosophy behind the Support Chaplaincy is the concept of soul care and the power of vision. A compelling vision is a

> belief of understanding of what could possibly happen in a person's life, not in terms of occupation or skills but rather in terms of maturity of themselves and their character becoming like Christ, e.g. someone who finds making friends really difficult, becoming a person who is warm, generous, comfortable with themselves and is outgoing. Is this possible? Could this really occur? (Barry Pearman, 2000, *The Power of Vision*).

SO HOW DOES THIS WORK IN PRACTICE? A CASE STUDY

This is illustrated by our support of Tina, an attractive women in her 30's. She is an interesting person, very intelligent and a person of strong feelings, but these are hidden behind a flat voice, a symptom of her mental illness. When Tina becomes unwell it can be hard relating to her - she can be quite abrupt and not easy to get along with. Twice I have been told to get out of the unit by Tina. I look back to the day she gave her heart to Jesus and it seems an age ago. Her life at this point in time is a mess. Yet the vision God has given me is of Tina being well, not being stuck in a lifestyle of mental illness.

At times like this you wonder about the point of visiting. It's one thing being Jesus with skin on but you don't necessarily know how to relate. Then just when you least expect it you get some small acknowledgement that they want you to be there. You see a small glimpse of what this person can be. Today I visited her and she is out of the Unit. She has a long road to go and we are praying that God will touch her life. She knows God but has yet to place her full trust in him. Yet most Tuesday nights she will make it to the Living Room. People are praying for her and amazingly out of her own weakness she touches the lives of others. She relates very well to Anna the lady who burns out unwary Pastoral Missiles. They understand each other well and minister to each other. Tina faithfully visits Anna who at present is in a home. Anna in her turn has a lot of phone contact with Tina and despite her own problems has some good listening skills. Anna introduced Tina to the Living Room and has shared a lot of her faith with Tina. Tina knows how to put boundaries in place with Anna and Anna knows when she is out of her depth and gets help if she thinks Tina needs help.

Even when Tina is really unwell, in the midst of her pain she will think of others and I see Jesus working in her life. It's then that I see the vision I have been given for her, and incidentally see the power of community at work. Soul care does not just come from support chaplains but from within the group and we encourage our people to support each other, not just turn to their support chaplains for support.

BOUNDARIES

Boundaries are essential to enjoying and being a good support chaplain. This means taking time out for yourself and having times when you don't answer the phone. For example Friday is my day off from work, my sabbath.

After one stressful session with Tina when I was yelled out of the hospital, I gave myself a break for a couple of weeks from visits. I could feel myself burning out and I took the time out. As a result I was able to offer effective long term support through a difficult period in Tina's life.

What are Boundaries?

Boundaries define us. They define what is me, and what is not me. A boundary shows where I end and someone else ends, they lead to a sense of ownership.

With boundaries we need to look at who we are and what values and guiding principles we hold to. What are we looking to achieve in our ministry (or other areas of our lives)? One thing we can do is have a personal mission statement and ministry statement to help us define who we are. In support chaplaincy think about what you are trying to achieve. What is God trying to achieve. How can I best achieve this? How much time can I realistically put in?

Tina now has two support chaplains involved with her and we both deeply care about her and want to see her grow to know Jesus more and become whole. But I have to be aware of my boundaries so that other people including myself don't get neglected. Ultimately we are God's servants and can do nothing without God. He does not want Tina reliant on either of us, but on Him. We also have to be aware that as Tina has gotten better we don't want to disempower her. This woman is smart and intelligent and runs her own flat. Yet when she is in hospital without responsibility she reaches a point where she does not get any better. To regain her mental health she needs to be able to make decisions herself.

Boundaries also work the other way. I know one mistake I used to make was over-encouraging someone to go to the Tuesday night service. Laura would go if I pushed her. I had to learn to step back and let her make the decision whether to go or not. Otherwise I am taking away her free will. Because Laura is gentle it's easy to be bossy.

CONCLUSION

I hope this has given you a small taste of what it means to be a support chaplain. The examples I have used have been people with Mental Health Disabilities and have been female. We have support chaplains who work with people who have other disabilities and men who get alongside other men. The main thing is to point people to Christ and being a disciple of His.

I will finish with a short description of where the Living Room and Support Chaplaincy has made a real difference in the life of one young man. Four years ago a young man named Geoff came to the Living Room. He was not a Christian - he was an agnostic. Geoff had a negative affect which meant that he had a very expressionless face. Over time he opened up a bit, came to camps and came to the services. One night he asked whether an agnostic could become a Christian. He gave his heart to Jesus and started doing bible studies with a support chaplain. One day we looked at photos of Geoff.

There was one taken where he had what I would have called a smile at that stage. In current photos he has a beam on his face.

He now works with our Work team on Mondays and Fridays and has gone from strength to strength. He is part of our leadership team and now leads at the front. He has a terrific sense of humour. He is alive and mentally stable. While he had the best treatment available before becoming a Christian, this has given him hope and a future. He knows Jesus and he is learning to put His trust in Him. He both gives and receives love.

This is what the Living Room is about.

"Where everyone is someone and Jesus Christ is Lord."

I would like to acknowledge the work Barry Pearman put into the original presentation of this paper last year. I have followed very closely Barry's original paper with his permission and added in my own observations and comments. Barry Pearman's papers are available through "Community Ministries, Windsor Park Baptist Church, P.O. Box 65 385, Mairangi Bay, Auckland 10New Zealand"

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Ah and Hmm and Whoopee

Janine Gibson

INTRODUCTION TO THE LIVING ROOM

I am involved with a group called the Living Room which meets on Tuesday nights at Windsor Park Baptist on the North Shore of Auckland. The Living Room is under the Community Chaplaincy based at our church.

On Tuesday nights we spend time in Worship, Sharing, Learning from the Bible and praying for each other. We also have a time where we can develop new relationships over a cup of coffee. Once every two months we have a community sharing night where we have a shared dinner and a time where people can contribute items such as a good joke, story, song etc. We are not a large group. People come from all sorts of backgrounds - builders, retirees, people on a benefit. The service is suitable for people with disabilities, including mental health disabilities.

What we are attempting to achieve is safe community: “Where everybody is somebody and Jesus Christ is Lord.” This means:

- Safety
- Discipleship
- Comfort and relaxation
- Room to practice spiritual gifts
- Prayer, fun and fellowship
- Worship
- Acceptance.
- Clear, understandable teaching
- Laughter
- Encouraging a faith that impacts all our lives, not just Tuesday night
- A place where God is present through His Holy Spirit
- Changing lives

Our values could be summed up as:

- **Ah**-Rest Reconciliation with God
- **Hmm**-Reconciliation with God
- **Whoopee**-rejoicing.

If we don’t have these values we are not Jesus with skin on. In the story of the Prodigal Son when the Father welcomed home the wayward son we see all three elements

- **Rest**: Where there is 'ah' - space for rest. Imagine the prodigal son collapsing in the father's arms, exhausted from the journey. We have had people come to the Living Room and promptly go to sleep as it’s so relaxing. Isn't that what a Living Room is all about, a place to rest and restore? Our places need to have elements that are restful, safe and secure. Busyness is banned. Connecting people with a restful Father.

Part of the Living Room community involves having a safe place, a place where people can be shown the love of a Christian community through activities that are safe and fun. Part of this comes from activities such as camps and movie nights. From this people come to know of the love of Jesus through community and begin coming to our meetings and learn about the gospel.

- **Reconciliation:** Where there is 'hmm' - space for reconciliation. The prodigal son came home and was reconciled with his father. So we need space for reconciliation with our God - a growing sense of God’s love, forgiveness, grace, and mercy. Telling people about the Good News of Jesus Christ to others - growing together as a community. Learning to accept our humanity, our baggage, stepping out of victim-hood into self-responsibility. In the story of the prodigal son, when the son came to the father in humility, the father forgave and the relationship was restored. The Living Room is a place where people can come to know and give their lives to God - evangelical, telling the hurt about the love offered freely by Jesus, bringing truth where there are lies, connecting people with a forgiving Father.

- **Rejoicing:** Where there is ‘whoopee’ - space for rejoicing. The prodigal son and his father had a great party. Here we are not talking purely about worship. At the Living Room we make space for fun, enjoying God and each other, having parties, telling jokes, making sure that life doesn't get too serious in contrast to what someone once said “I don't know how to have fun”. Yes, there are times for seriousness but please more fun!!! Connecting people with a fun loving Father.

COMING TO BE INVOLVED WITH THE LIVING ROOM

My twenties were spent under the motto: ‘work hard and play hard’. I accumulated two degrees, a banking history and an intimate knowledge of many pubs in Auckland. After 10 years of working hard and drinking hard I spent five years trying to get myself right with the help of 12 step programmes. And to some extent I did. But there was still a hole in my soul which was not filled. I still felt very empty.

I came back to church in 1996 during a period of ill health and a relationship breakdown. After reaching a decision to recommit my life to Jesus I realized one day that the hole in my soul had gone. As a bonus my physical health also improved due, I believe, to the prayers of my sister and excellent medical treatment.

This was the beginning of my Christian journey. It's not been easy, I have had a lot of emotional issues I have had to work through, but for me becoming a Christian was literally the start of a whole new life. I now laugh easily and have joy in my life - things that were absent before. The joy of the Lord is my strength.

Four years ago I became involved in the Living Room at Windsor Park Baptist Church. I wanted to study theology and an internship was suggested to me by church leadership. After my interview and expressing an interest in recovery from alcoholism and an interest in mental health issues I came under the supervision of Barry Pearman as an intern at Community Ministries. I have loved being a part of the Living Room ever since. The Living Room represents many things that were missing in my life and its neat seeing the smile on people's faces as they come to know Jesus better.

So why am I explaining this? Well, for me I have found the truth that you can only go so far without Jesus. In 1990 before I stopped drinking it was fairly obvious that things were not right. In 1996 things superficially looked fairly good. I had treated many of the symptoms of a wrong lifestyle but inside I was depressed. Many of the things I did were good and worthwhile but to me the central thing of my life was missing, and that was my relationship with God. I got to the point of thinking, "I'm doing the right things and I'm still empty - where to now?" To me the answer was surrendering to God - and that was the beginning of real life for me.

WHY THE NEED FOR PLACES LIKE THE LIVING ROOM?

Spirituality and its place in Mental Health.

We see life as a holistic model including spirituality. The biopyschosocial model is widely endorsed in the secular community as the way of the future and this model looks at the person in three areas – the biological, the psychological and the social. While it does have flaws but I believe it's the best model that we have at the moment and a model that we endorse at the Living Room.

However we believe that spirituality should encompass biological, psychological and sociological areas of our lives whereas the biopyschosocial model tends to compartmentalize people's lives into three different areas and treat each one separately.

When someone is unwell they often get the medical treatment first, which is often appropriate but not always. Then they might get some psychological help. Then if you actually are able to access it, you might be able to get some help with your social skills and problems. This I believe is the reality of the system we are burdened with. It's like a stack of plates added on top of each other. If you are a Christian it can mean one more plate added to the top. In our culture, where we love to compartmentalize, we generally go to the plate system and view our spirituality as another plate.

However for us there is a key element missing for the whole spiritual aspect of the person - their relationship with God should encompass everything. The other three elements of mental health should intertwine and spirituality should surround and permeate all areas of life so that:

- Spirituality connects all parts of us
- Spirituality encompasses all
- God is interested in all

The spiritual component of one's mental wellness is probably the most overlooked aspect. Yet everything relies upon it. Every area of one's life will be dependent upon the spiritual life, and the relationship one has with God.

The Living Room is a safe place where people can come to explore spirituality and come to know Jesus in a safe environment. Many people want to be able to learn about Jesus but in a safe way.

- Will Jesus abuse me?
- Is the church a safe place?
- Is it okay to be honest before God?
- Does God love me when I am sick or only when I am well?
- Why am I sick if I am a Christian?
- Who is Jesus- what's he like? When things aren't going well is it because God has abandoned me?

HOW SPIRITUALITY AND MENTAL WELLNESS INTERRELATE

Good spirituality is essential to mental and emotional wellness for all of us. Here are some of the ways this works:

1. Our concept of who we are in relation to God:

We often base our feelings of self esteem on what we do or what other people think of us. The bible tells us otherwise. We need to know who we are in relation to God and to base our self-esteem on our worth to God. “By faith we have been made acceptable to God, and now, because of our Lord Jesus Christ, we live at peace with God” (Romans 5:1). We are encouraged in society to base our feelings of self-esteem on what we do and how busy we are and what we earn.

So what happens when we become unwell either mentally or physically? One thing I realize with some of the people I support is that they get frustrated because they would like to do more. One girl tried for ages to maintain a 3 day a week job but eventually could not cope simply because of tiredness. It's important that we realize that we are human beings, not doings. The question to ask is what would God say? Does he love us for who we are or what we do? I believe it's for who we are. Yes it's great if we can do lots but that is not what should give us our sense of self-worth. Having a spiritual understanding of God's acceptance and love of us dramatically affects our view on life and activity. I am called to be more than to do.

2. Our concept of what God is like:

Our view of God and the values and beliefs that we have about God has a marked effect on our mental wellbeing. As adults we carry through from our childhood the views of God that we have learnt from looking at our earthly parents. None of our parents are perfect and we may transfer on to God some of their not so perfect attributes, e.g. an idea of God being harsh and judgmental. We must talk about what our heavenly Father is like, as seen in the story of the Prodigal Son which shows the total love of God.

3. The truth that will set you free:

The power of the word of God. Jesus said, “You will know the truth, and the truth will set you free” (John 8:32). One thing that helps faith is regular Bible reading, and by reading the Bible we come to understand what God is like. John 1:14 tells us “the Word (Logos) became flesh and lived with us”. When we see Jesus we see the Father as Jesus lived exactly as the Scriptures would have had God live.

The use of Scriptures is fundamental to mental health. By regular Bible reading, God's truth can be stored in our heart. In the weekly Living Room service scripture is presented in a way that people can relate to and apply to their lives. Bible reading can also help our mental health by giving us the tools to cope with issues such as anxiety.

4. Yokes to be broken, yokes to be put on:

The yoke is a large collar that fits over the shoulders of an animal. Ropes or poles were attached to the yoke and attached to a farm implement like a plough, cart etc. Often the animal would be yoked to another animal to get more pull. We all have yokes around us in a metaphorical sense. We can be yoked or joined to something or someone else. We are yoked to our past, the things that have happened to us.

Yokes to be broken- We are yoked to the burdens we carry. Some of these yokes need to be taken off our shoulders, as they are too much to bear. The yoke will be broken because of fatness (Isaiah 10:27). Being fat here refers to the neck of the animal getting so big and swollen that the yoke can't fit any more and is broken. So how does one get so fat spiritually that the yoke of the past is smashed off? It's the Holy Spirit and in particular the anointing of the Holy Spirit. In some versions of this verse instead of fatness it uses the word anointing. Anointing was done in the Old Testament to endorse the new king. Oil was poured over his head. In the same way we need the Holy Spirit to be poured out over us and into us if the burdens and the yoke we pull with are to be broken. We are to be living a spirit filled life.

Yokes are important but we need to have the right yoke. Jesus said “If you are tired from carrying heavy burdens, come to me and I will give you rest. Take the yoke I give you. Put it on your shoulders and learn from me. I am gentle and humble, and you will find rest. This yoke is easy to bear and this burden is light” (Matthew 11: 28 -30). Instead of carrying our burdens for ourselves we can learn to turn to Jesus and gain some acceptance of where we are and healing. Personally, by learning to rest in Jesus and spend time with Him I have started to re-gain a sense of hope and joy. The yoke I think Jesus would give to me is to trust Him with my dreams rather than insist on them being fulfilled at this minute. Also to let Him lead me rather than insist that to be happy I have to have my timetable followed.

THE DILEMMA FOR US

So what is God calling us to do? We have a mental health service/ structure that does not readily embrace the role of God and spirituality. We can do two things. Firstly to begin with working on ourselves, and secondly make safe ‘third places’ (see overleaf) where spirituality can be safely explored and encountered.

Working on ourselves -the I, the We, and the Work

If we help with the Living Room we need to be learning to be healthy ourselves in all areas of our lives. We need an understanding of who we are and our relationship with God. Who am I, what I am here for? What is God’s purpose for me? The original giver of the “Ah Hmm Whoopee message” was Barry Pearman and his answer to this was as follows:

> I believe that my sole purpose in life is to bring glory to God. I want to fit into the very purpose he has for me, therefore I want to be close to God and living in his very presence. It is up to me how much I acknowledge it, give credence to it, submit to it and live within its power and love. The more I acknowledge the presence of God in my life the more I will abide with God. The ultimate example of this living in God's presence is Jesus. In his incarnate state he only did what he saw the father doing. “I tell you for certain that the Son cannot do anything on his own. He can only do what he sees the Father doing, and he does exactly what he sees the Father do” (John 5:19). Is this redundant? So where does all this fit into caring for ourselves. To best understand this I would like you to consider a picture of Jesus and the little children.

Imagine yourself as being one of those children cradled in Jesus' arms. What would he say to you? What would he say to show his love and undeserved kindness to you? This is an image I use to stimulate me to think about my life and how mentally well I am. I climb into Jesus’ arms and let him minister to me. I look for his leading in three areas of who I am. The “I”, the “We”, and the “Work”.

The I, the We, and the Work-A model that can help us.

The **“I”** refers to who you are. You as a separate identity to everyone else. What makes you unique, special and distinctive? The **“We”** refers to the key relationships that you have. This might be with your spouse, family, friends etc. The **“Work”** refers to the activities that you are involved in. It may be paid employment, or unpaid activities. It's what you spend a lot of your time doing. In caring for ourselves we need to recognize each of these areas and attend to the needs of each.

God plays a central position in all of this as God holds all of it together. God wants to be involved in who I am, in my key relationships and in my work. So if we look at self-

care and preventing burnout we need to look at each of these areas to see how we are doing in them and set goals in each of these areas.
We also need to make safe third places where spirituality can be safely explored and encountered. What is a third place? This is a term that describes a place where people meet and have fellowship and relationship for no other reason than that they want to. A first place might be the family, we all have one of those, all the relatives etc. A second place is the workplace. It's a place where you have to go to. A third place maybe a club, a sports team, a small group/ cell group. Looking at a TV example, the show 'Cheers' is a typical example with its theme song having this line “where every one knows your name” -a third place is a place where everyone knows your name. You feel connected and loved.

We need to have more third places in our society that are safe for people to come and experience God. A safe place for some people does not initially mean church as many people have the perception that church is not a safe place as a result of a background where they have experienced abuse. The allegations and admissions of sexual abuse among the clergy does not make church seem a safe place to these people. We have to earn the reputation as a safe place. We try and keep the Living Room as safe and fun a place as possible, and also have third places which are lower key, (for example two fun camps a year, card making and movie nights). The title of this article is ‘Ah and hmm and whoopee’. For us a spiritual third place has to have in it the values of Rest - Ah, Reconciliation with God - hmm, and rejoicing - whoopee. If we don't have these values we are not ‘Jesus with skin on’.

CONCLUSION

At the Living Room we have tried to create an environment where people can learn about God in a safe environment. We have started a new group in Ponsonby over the last year and while using a different format of a Bible study we have found that the values of **Ah**-Rest, **Hmm**-Reconciliation with God and **Whoopee**–Rejoicing, work well here as well. We want to keep an environment where our faith in Jesus is taught in such a way it transforms our whole lives and our hope and vision for the future is that other people will join us and other people in providing safe spiritual third

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Drawing Near and Risking Embrace: Telling Stories, Sustaining Life

Lorna Hallahan and Trevor Whitney

ABSTRACT

Participants are invited to reflect on times of risk and embrace to identify what can sustain those who dare to move beyond doubt and despair into closer connection with others. To conclude, participants are invited to reflect on transformation in the church as more people with impairments take their place at the table.

INTRODUCTION

Beyond the Ramp: The Work of Embrace seeks to express God's concern for justice and full participation for all people with impairments in the faith community of their choice.

The Work of Embrace applies an action-research model that uses the strengths of the faith community as the major resource, to form a bridge into identified areas of concern. It is not an external-expert driven approach, but one which prefers to see that those who live within a community are best equipped to clarify their vision, identify strengths and resources and truthfully name points where the community falls short of its best intentions. This implies initial attention to relationships, not structures. Therefore, the Work of Embrace builds on the assumption that the congregation is committed to the fullest possible inclusion of people with impairments. We assume that the congregation has the ideas, the people resources, the capacity and the energy to embrace people with impairments. The Work of Embrace aims to assist the congregation to:

- **Continue** to probe and develop a critical and honest understanding of their congregational life with people with impairments,
- **Articulate** their own vision of embrace,
- **Identify** bridges and barriers to full inclusion,
- **Carry out** conscious, manageable strategies aimed at bringing people with impairments to the heart of their faith community.

SOME BRIEF POINTS ABOUT THE RESEARCH SO FAR

The research into relationships within church and community has explored existing relationships with people with impairments; and looked into congregational structures, attitudes and practices that inhibit or facilitate embrace. So far the research has revealed a fairly consistent pattern of relationships - consistent across these congregations and consistent with other, non-religious community organizations.

Looking generally across the three congregations, people with impairments fall into three categories:

- First, a number of people with impairments, often age related but not always, truly belong within the life and work of the congregation
- There is a second, larger group of people with whom the relationships could only be described as 'instrumental' or functional. These are people not bound by affection but by the desire to do something worthwhile in their lives
- The final grouping is those who are not currently participating but are identified as targets of outreach and mission.

The research into theology, community development and disability studies shows that people will not be embraced simply because they are physically present. Embrace requires an act of the will. It is not an organic process when we look to people who, through a combination of their condition and their life experiences are unlikely to fare well in the 'relationship market'. Furthermore, their location within the human service world (which is a major contributor to the social construction of disability as undesirable, requiring remedying or segregation) creates access and attitude barriers that are often invisible but unyielding.

The drama of embrace (presented by M. Volf in 'Exclusion and Embrace') provides analytical insight about stances and actions to promote the move to knowing persons with impairments as those who require love not just services. The focus on love - let's call it creating affinity between people - alters the power dynamic. As service modeled relationships are shaped by professionalism (what I can offer you in your plight) they generally lack mutuality. They are low on the affective scale. They can also contribute to the 'wound of rejection' by reducing the person's roles to client, patient, resident, not friend, family member, colleague etc. The person is known through their deficits not through their gifts and passions. Services bring many needed resources and skills but they do not bring belonging.

Assuming that the church (as the Body of Christ) offers to know people as deeply as possible – as fellow not as other, as vital to community life, not as social burden – it makes sense for us to focus on building affinity. Affinity relies on a deep understanding between people as important in forging closeness...

In the long term a different church may evolve. It may resemble more the beloved community and less a socially sanctioned institution. This may be a welcome change for some and a distressing change for others. Some may see this as a victory in affinity, others as a crisis of influence and power. Are we ready for this debate?

CONCLUSIONS

Impact on Church... the emerging church

For those who are like reindeers this is an exercise not of trying to solve the problem but to dislodge it by opening a different perspective that makes it look less important.

Dorethee Soelle:

> The strongest witnesses of liberation theology are prayers, liturgies, worship plans, in which the Christian myth, especially the exodus and the resurrection is dramatised. That can only happen in groups that are dedicated to changing the world and who do not distance themselves from such an enterprise by withdrawing into academic resignation. They need God, because the interpretation of this world which controls them, is a death sentence for the poor; they must become poorer so that the rich can become richer. It is an illusion to suppose that we live in a world that can be understood and controlled by science and that can do without such interpretive categories as a god who is justice. Only the rich can conveniently live without god.....from the poor we learn the contrast language of hope.

'From the disabled we learn the contrast language of hope.' The church needs people who understand what it is to live through movements - this is not inclusion, it is calling the church to conversion. People of disability offer the church hope. Without this and the voices of hope of other excluded peoples the church cannot survive. Despite the persistence of the idea that people of disability need the welcoming of the church and all that company of well meaning people, the real truth is that the church needs us, more desperately than ever. But it doesn't only need us as individuals, adding to the grand story of the church our vital intimate stories - the secrets of our hearts, our lamenting liturgies - the church needs us a movement. In our number we count those who have survived the asylum era, we count those who have been leaders in moral thought, we count those who have known loneliness and can still talk of the justice that connection brings, we count those who know that the importance of being shaken is to know that a god that is love and justice is a god who shakes.

Reference

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Story-telling in and through the Whirlwind

Trish Harris

Editor's note: As this workshop involved a variety of activities, including discussion, this is an outline only of what occurred.

> "Stories move in circles. They don't move in straight lines. So it helps if you listen in circles. There are stories inside stories and stories between stories, and finding your way through them is as easy and as hard as finding your way home. And part of the finding is the getting lost. And when you're lost, you start to look around and to listen."* (*Corey Fischer, Albert Greenberg and Naomi Newman of a Travelling Jewish Theatre)*

This was a workshop in the true sense of the word – participants had to *work*! It was also a workshop in the creative sense i.e. people discovered new things through playing with words, colour and images. This is a brief outline of hand-outs and the process we used.

SOME KEY QUESTIONS WHEN IT COMES TO STORY TELLING:

- **What** story do I want to tell?
  Our lives are made up of many stories. Each story tells of a different aspect of ourselves. e.g. the story of my family, the story of my gender, the story of my work, the story of my faith/spirituality, the story of my disability, the story of my ethnicity.

- **Who** do I want to tell it to?
  First and foremost I think we need to tell our stories to ourselves. You may also want to tell close friends, family (or maybe not!), your faith or other community.

  > What is the source of our first suffering? It lies in the fact that we hesitated to speak. It was born in the moment when we accumulated silent things within us.
  > Gaston Bachelard*

- **How** do I want to tell it?
  There are many ways we can do it - verbally, through music, through movement/ dance, through the written word, through art. Creative ways allow us so much possibility!

Participants then looked at a painting of a whirlwind. They split into four groups:

- one group wrote **statements** about the painting,
- one group wrote **questions** about the painting

- one group wrote **exclamations** about the painting
- one group wrote **commands** about the painting

This was an opportunity to let the imagination have a work-out, and we were all surprised and delighted at the results.

Participants were then asked to take the image of the whirlwind closer to home, and choosing a favourite colour, they were asked to 'doodle' round the shape of the whirlwind. On one page they were asked to write a statement, question, exclamation and command, about their **disability journey** at the moment. On the other page they were asked to write a statement, question, exclamation and command about their **spirituality journey** at the moment. We finished with people sharing a little of what had emerged for them in the exercises.

More questions about story-telling:

- Where and how does transformation happen with story-telling?
- Is the teller transformed?
- Is the listener transformed?
- Is the incident transformed?

Consider also - what are the stories we **don't** tell?

** Both quotes can be found in:
Metzger, Deena (1992) *Writing for your life - a guide and companion for the inner worlds.* San Francisco: Harper.

Trish Harris is passionate about the voice of disability being heard, especially through creative means. She developed arthritis at age six, grew up in a Catholic family, and now works as a writer/editor. Trish has been very active in the conference organization and believes when such core strands as disability and spirituality come together, powerful things emerge!
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Shaping Life Attitudes: Transition of Spirituality and Faith Through Disability Dynamics

Merima Isakovic

WHAT IS SPIRITUALITY?

Spiritual and mental growth involve the same processes. In his book ‘The road less traveled’, Scott Peck (1978), emphasized that there is no real distinction between consciousness and spirituality. If this is to be the case, the process regarding spiritual and mental growth and development should be the same. This spiritual and mental growth is an extremely complex process that lasts for life. The path of one's spiritual growth is very long and unique and should not be analyzed from any kind of 'single exclusive' and therefore narrow theoretical perspective.

SCIENCE AND SPIRITUALITY

Brian Vandenberg (1991, cited in Vash, 1994) pointed out that psychology was born at the moment when Nietzsche, in 1982, said: 'God is dead'. Since then, psychology has recognized many issues, such as metaphysics, ontology and existential aspects. Science seemed to be seeking for a fragmented truth, supported only with quantitative, tangible, material facts/data.

Unfortunately, the scientific 'window' was narrowing issues related to philosophy and the practice of human life. This has had a great impact on rehabilitation practice.

Carolyn Vash (1994) in her book ‘Personality and adversity: Psychospiritual aspects of rehabilitation’, describes hospitals as ‘body shops’, emphasizing that in the post-injury hospital environment and practice, there is not much attention given to spiritual issues. Could medicine help people experiencing major life changes, due to severe disability, if that help does not take into account the uniqueness of people’s values and beliefs that are the core principle of their existence? Vash asked the question throughout her work: ‘how do you re-spirit medicine?’

Science is awakening out of its rigid frame, seeking for more qualitative approaches, focusing more on cultural and spiritual values of the ‘unique’ people concerned. Rehabilitation neuropsychology is on the path of redesigning rehabilitation’s approach, hoping to bring more benefit to people.

PERSONAL POWER

There are two basic types of disability and these will influence the various types of existential concepts involved:

1. disability which is acquired at birth

2. disability which is acquired as a sudden change through injury or illness

People having a disability of either type, often ask themselves similar questions:

- Who or what am I?;
- How could I fit into the societal milieu?;
- What 1 am supposed to be doing as a part of that milieu?
- and actually, what is that vague picture, called the 'societal milieu'?

CHALLENGING OUR OWN AND OTHERS PEOPLE'S PRECONCEPTION

Louise Hay (1987) emphasizes that agreement is not necessary at all, but that 'open mind' and patience certainly are. Is it possible to love our difficulties (Peck, 1978)? Yes it is: to be able to live through them and overcome their physical, social, psychological and, in particular, their spiritual properties. Louise Hay (1987) also emphasized that psychospiritual benefits, in the presence of severe disability, are often difficult to understand and apply.

If you love yourself and your difficulties, you will be able to understand and support yourself better. We should not forget that those who do not have any disability also need help to understand, and therefore accept, and support it. People are afraid of anything 'unknown' and bitter. If they are given love and patience from people with a disability they will find their own way of responding with love.

After saying "God is dead", before he died, Nietzsche said, "I am sorry I haven't met him myself."

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Intellectual Disability and the Beatitudes

Robin List

INTRODUCTION

'Circles within circles; wheels within wheels.' The old saying is anchored in the first chapter of the prophet Ezekiel where his astonishing vision of creatures sent from God is described. The spirit of the creatures is in the wheels. I don't want to dump that part of Ezekiel's vision into my own descriptions and claim it in some direct, literalist fashion, but there is a representation worth holding onto. It seems reasonable to assume that if a wheel in Ezekiel's vision had been outside the others, then the spirit of the creature would not have been in it. The moment we start to draw the circle representing disabled people outside all other circles which represent the parts or whole of society, we are moving onto the very dangerous ground of taking upon ourselves the ability and power to decide just who is a human being and consequently, just whom we may exclude from that status, e.g. the Nazi killing of disabled people because they were considered less than human.

There are well-intentioned people who are dangerous to the health of disabled people and their families. If these are our friends, what might our enemies do to us? As we are working from a Christian base perhaps it would be best to avoid all the medical and educational stuff and just do things the Christian way? Fine! But before I rush out to do it I have three questions:

THREE KEY QUESTIONS

- **What is the Christian approach to disability?**
- **Who says Christians are less dangerous company?**
- **What does the Bible say about this?**

Returning to our picture of society as 'circles within circles, wheels within wheels', the part of life which we call intellectual disability does not appear in the Bible in words or ideas, or not that we would recognise as our present Western words and thoughts on this subject. This may simply indicate that the biblical writers held a view of society as being more unified; where the wheels stay inside the wheels. The Bible describes a mainly rural society with a less complicated structure, where everyone could be fitted in to some role and be a useful part of the whole. That sort of society is more interested in what people can do than what they can't. For all that, note the exclusion of 'defective' people from liturgical duties in Leviticus 21:17 - 23.

Physical disabilities were seen as making a man fall below the standard of holiness required for the priesthood and even women were not seen as having any relevance to the issue. (See 2 Chronicles 8:11 where Solomon brought Pharaoh's daughter from the Citadel of David up to the house he had built for her. "It is not for me," he said, "to let a woman live in the palace of David king of Israel; these are holy places, where the ark of Yahweh has been.")

The priests as well as the animals they sacrificed were both to be without blemish. But the wellbeing of the priests' minds is not mentioned. Were intellectually disabled or psychiatrically ill priests in or out? Part of the rule for the community at Qumran suggests an answer; "No madman, or lunatic, or simpleton, or fool, no blind man, or maimed, or lame, or deaf man, and no minor, shall enter into the Community, for the Angels of Holiness are with them" (Rule of the Qumran Community of Essenes).

By the time of the prophet Isaiah, people with physical disabilities were offered the hope that if they lived to see the messianic kingdom they would be freed from their troubles: "Then will the eyes of the blind be opened and the ears of the deaf unstopped. Then will the lame leap like a deer, and the mute tongue shout for joy." (Isaiah 35:5-6a)

Insanity usually described a person driven that way by fear, as in Zechariah 12:4, or else one in the full flight of prophetic utterance (2 Kings 9:5-11). The variety and subtlety of our understanding of mental health cannot be found in the Bible. The simple fact is this, the categories which gave shape to ancient Israelite society do not map neatly onto the way our world operates and we are left with a great deal that we cannot know. Labelling our assumptions and prejudices about the unknown as inspired or as biblical revelation is pathetic and often harmful. I have been told by the mother of an extremely dysfunctional family that my daughter is disabled because I don't have the right sort of faith. What a mercy she didn't offer to loan me some of hers!

CONSTRUCTIVE CHRISTIAN THOUGHT

The most constructive Christian thought has developed out of the compassion of Christ. Think of the man with the shrivelled hand in the story in Mark 3. Jesus smashed through age old barriers of law, custom and superstition when he acted. Consider too the man born blind in John's Gospel. Jesus again breaks new ground.

In Jesus, the compassionate urge to bring things to wholeness triumphs over legalism and blame fixing. Sadly the hostility that Jesus met and the slurs that were levelled at those he helped are still around today. Tragically we find them at work in churches. We need to regain that humble but salty awareness of 1 Corinthians 1:27-29: "God chose what is foolish in the world to shame the wise, God chose what is weak in the world to shame the strong, God chose what is low and despised in the world...so that no human being might boast in the presence of God".

The Church is adept at noting that God has always chosen to work through the least likely people, but more adept still at speaking with her fingers in her ears. Ever since the Emperor Constantine adopted Christianity as an official religion of the Roman empire the Church has had its love-hate affair with the trappings of worldly power. How easy and sensible it seems to move the rich and powerful to the front of the queue. Vested (and vestmented) interests are still threatened by the radical world view that

Jesus proposed. What do ordinary people think?

Abuse and neglect have often been the lot of the disabled in the past. That is such a simple, true sentence, yet it stands for horrors that we would like to think were unspeakable. They can be spoken about and they must be told if there is to be change for the good. Then, swinging to the other extreme, another historical trend cannot be said to be truly positive either, but at least it intended no harm. I am referring to the notion of 'holy innocents', 'les enfants du bon Dieu'. Christians may have less of this attitude than some other religions, but I remain to be convinced. More historically, the study and treatment of cretinism in European alpine areas met real opposition because the villagers saw their cretins as blessings from God. A superstitious awe of any person is to be avoided and it is still necessary today to overcome the attitude that the disabled cannot sin, or have a ticket to heaven somehow more graciously given than to others.

> The theory that unusual virtues spring by a direct consequence out of personal disadvantages, as animals get thicker wool in severe climates, is perhaps a little overstrained (Eliot, 1917, p.390).

'Holy innocence', however, cannot be totally written off as superstition; it prompts questions. To what extent are the intellectually disabled people 'innocent' by virtue of their ignorance? What binds and limits them? What is it that gives them freedom? What did those villagers know? Did they see assets where we see deficiencies? I wonder, is our error in moving from 'knowing' to 'knowing about'? Have disabled people become objects of study to the extent that along the way we have lost sight of the fact that they are people? Compared with the villagers who revered their cretins we now know more in part, but do we understand the whole person (and God) less?

How do theologians see intellectual disability? Theologians apply their minds and skills to systematically thinking about the Christian faith and the issues which confront it. How do they cope with intellectual disability? With a few exceptions, not very well. Sometimes I wonder; if God in Christ came offering salvation and wholeness to all, why do most theologians settle for 97%? Out of necessity theologians work in fairly general terms, and that is reasonable, but it tends to exclude some areas of difficult questions. Unfortunately there is a general ineptitude amongst most theologians when they do make reference to intellectual disability. Too often it comes as an after-thought, using old-fashioned language and revealing an ignorance of not only the realities of disability, but also an ignorance of the huge fund of academic work in this subject area. A curious intellectual narrowness shows up in the choice of ground upon which intellectual disability is discussed by theologians.

Two areas keep cropping up:

> **Suffering:** Where a disabled person is actually involved in suffering as a result of their disability most theologians offer useful thoughts. It is usual for them to write of innocent suffering being transfigured by union with Christ's suffering. A less acceptable idea, though not without merit, is that such sufferings bring blessings

because they enable growth of compassion and other virtues in care-givers (the positive end of the view expressed by the villagers concerning cretinism). Let me suggest that using the "suffering" label is simply stretching an existing category to include those seen as being outside "normality".

Intellectual Measurement: It is really disquieting that some theologians are so bound up in academic and intellectual issues that they present a case based on their own preferences, failing to see that their argument condemns itself and falls to pieces in a ridiculous fashion. When, into the bargain, a writer does not feel the need to gain any information about the subject before holding forth, we are treated to something pathetic. On the positive side, Baillie (1939) in his book "Our knowledge of God" explained that a child or an intellectually disabled person could have an awareness of God and have faith without a self-conscious working out of what that meant. He also rejected the idea of revelation being simply information communicated by God. Baillie had the wit to see that while being aware of our own faith is necessary to growth, that is not necessarily an intellectual activity. Now Baillie's book might seem rather elderly, but I would leap much further back and quote St Thomas Aquinas: "We shall know God the more perfectly in this life in so far as we understand more and more how He surpasses everything the intellect can comprehend" (cited in Vann, 1945, p.155). To add to the distinguished line-up, in John Calvin's "Short Treatise on the Lord's Supper" (1541), he is far more humane and realistic than many modern theologians, declaring instead everyone accessible by Christ. He takes the example of deafness and freely allows for the input of other senses and feelings.

We must all accept honestly that we each have our disabilities, yet despite them every one of us, every tiny wheel within a wheel, is a bearer of precious gifts from God. We like to say these things, we acknowledge that they are biblically founded, but they are so often said with glib sentimentality. Do we really believe the words of our own mouths? Let's move away from the negatives of suffering and the put-down of intellectualism and visit some new, positive and potentially upsetting territory.

DEFICITS OR ASSETS?

Not only the Church, but also the more immediately relevant academic disciplines have spent most of their energy for at least 100 years trying to grapple with what is perceived to be wrong with disabled people - understanding and putting right. This is justifiable activity, for we must not use a variant of the 'holy innocent' idea to neglect the growth of a part of humanity. The point which has been missed, however, is that rectification, as far as it can be taken, does not embrace the whole of our relationship with disabled or other people and it of course presupposes that people want to and should be like their therapist. We need to stop trying to bring disabled people into 'our' circle and realize that the circle of humanity is bigger than we may wish to realize - in that it already contains the disabled. This carries the unsettling idea that 'we' might have something serious to learn from 'them', and might in fact be better for developing some of the attributes of the intellectually disabled!

At one of the hinge points of the book, ‘Riding the bus with my sister’ (Simon 2002), Beth, who is intellectually disabled, challenges Rachel, “You worry too much,” she says, turning towards the approaching bus. “I don’t worry. You should try being more like me.” The reader needs to take that aboard their own bus. Might our lives be improved by embracing attitudes and behaviours of people we usually consider inferior to us? That word ‘some’ is important. Beth has qualities that are most undesirable and the book hits strongly at sentimental views of disability. It is an ironic touch that the National Library of Australia cataloguing details list this book’s content as relating to mental illness. That’s fair to no one and shows how much still has to be done.

Having our being in the image of God involves owning the paradox of the hiddenness and powerlessness of God. We must recognize that human existence is unfinished, open, “...moving into possibilities that have still to be unfolded” (Macquarrie, 1977, p. 62). The fragility and vulnerability of disabled people is a witness to the limitless power of the incarnation of our Lord. Disabled people are a constant reminder of the openness of God, of the risk that leads to glory, not failure, despite the opinions of the world. Broken people have or leave more room for the power of God to move, and perhaps no one has expressed this so refreshingly as Jean Vanier in his many books and by the living out of his faith and love with disabled people.

We must be alert to the spirituality of the disabled. God has a flair for choosing the least probable way of working and we often acknowledge this, but with our heads rather than our hearts, without humility and so without vision and insight. I have gathered anecdotes from the parents of intellectually disabled people; specifically anecdotes which, to them, reveal a spiritual life at work. Two themes emerge from the hours of sharing - delight in worship, and ability in relating to the natural world, particularly animals, which is perceived as having a spiritual quality. The recurring words are ‘simplicity’ and ‘directness’. These are not words of wishful thinking or a hope that someone is human after all. These are words about deeply desirable spiritual qualities, however clumsily they are expressed.

Kung (1974) has called for a consciousness of transcendence in our technological society, and it is intriguing to find a professor of special education and rehabilitation describing the necessary qualities in the group usually accorded the least likelihood of success or relevance in such a society. Wolfensberger (1988) is an unlikely source for inspiration, but he prompted me to read the beatitudes in a new light. He is careful to stress that all assets do not occur in one disabled person and that a sentimental over-generalized stereotype must not be grown out of what he has observed to be true of a ‘goodly proportion’ of what he chooses to call ‘retarded’ people. Whatever we might make of Wolfensberger generally, he has raised some ideas which we might strive to avoid, but they will not go away, taking disquieting questions with them. Take time to re-read the Beatitudes in the light of the lives most people with intellectual disability are obliged to live.

QUESTIONS TO THE LEADERSHIP:

- To what extent do intellectually disabled people have a leadership which we do not wish to acknowledge?
- To what extent are they the meek who shall inherit the earth because they have kept the beatitudes for us all?
- What must we do to bring about the communion which overcomes the inherent resistance of intellectual disability in itself and so achieve authentic existence for us all?
- Can the disabled inform us about human spiritual experience?

At the very least, the baptized person belongs fully to the Church and requires an environment in which mission and vocation can be exercised. The faith and understanding of the community must be prepared to act for, and/or with the disabled person. Then that person becomes the centre of an outward spreading action which speaks new words of faith. The question is not what does God want us to do to/for, or even with, intellectually disabled people? But rather, what is God saying to us through them? What qualities of theirs must we develop in our lives in order to hear them, and thus God, better?

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Spirituality and Disability – A Deaf Perspective

David Loving-Molloy

INTRODUCTION

The first thing that will strike many people who encounter Deaf people is that they do not consider their deafness to be a disability. That is probably the single most telling reason there are a lack of Deaf people at this conference. It is not that Deaf people don't like disabled people or that they can't get on well together. Rather, most Deaf people simply do not identify with the disabled 'label'. There are many reasons for this but that is another story and a separate topic. However as an example, one part of the Deaf community would see themselves in terms of a cultural or linguistic minority as opposed to accepting a medical definition of one's condition.

It is perhaps unfortunate in some ways that Deaf people and disabled people do not mix more, at least as far as spiritual needs go, because it would appear that both groups have similar experiences when it comes to church life. It is specifically this similarity of experience and its consequences for churches which I wish to address in my presentation today. To do that I will ask a number of key questions but I will need your help as we enter into the very real barriers we face in open discussion. Luckily we have interpreters with us who can bridge our distance. So to make it work we will need to slow down a little with one person responding at a time.

QUESTION 1: 'Do you find yourself actively involved and accepted in your local church?'

The Public Picture of Churches

If you have answered this question in the affirmative then you are one of the lucky few. It has been my consistent experience growing up as a Deaf person that most Deaf and disabled people are INVISIBLE in the church. This is an astonishing thing but it is true. If you go into any big Church gathering on a Sunday –

- you will NOT find any Deaf people leading the readings;
- you will not find any blind people leading the choir or music;
- you will not find any wheelchair people giving out communion;
- you will not find any schizophrenic people preaching;
- you will not find any cerebral palsy people helping with the collection.

Instead we tend to have our own gatherings or we allow hearing Church groups to lead the service while we struggle in a secondary role. Take for example a typical service where there are readings from the Bible. When Deaf people are involved what usually happens is that the Deaf person signs from the text alongside a hearing person who is voicing it. This has the effect of looking like a bi-lingual presentation in which neither the Deaf nor the hearing person are leading. When a service relies heavily on a Sign

Language interpreter Deaf people themselves are relegated to spectator roles. What would it look like to have a Deaf person actually leading the reading of God's word? Probably the best way to handle this would be to have the Deaf person signing the text at their own pace while an interpreter sitting among the congregation voices over a translation of the sign language used. In this way the Deaf person is clearly leading alone without any confused bi-lingual appearance.

Church ministries such as reading God's word involve leadership, and what is lacking in our churches is the visible witness of disabled people leading in our services. We disabled people have to take some responsibility for this lack of visible witness. Church leadership teams are also responsible in ensuring that the diversity of God's people is represented in their Sunday celebrations. Sunday celebrations are the public face of our churches and they need to ask themselves exactly what sort of face they are presenting.

One of the major difficulties about typical urban church communities is their size. Large congregations have become impersonal gatherings where members can come and go without being noticed. So unless the local church leadership team is a well organized group they will not even be aware of disabled people within their church community. But in Christianity such neglect goes against explicit examples found in the gospels where disabled people are welcomed by Jesus and bear witness to the power of Jesus' healing in their lives.

QUESTION 2: 'Do you know of any examples of this in the gospels?'

Perhaps one of the most interesting examples recorded in all four gospels is the account of the blind man (or in some accounts two blind men). We find this episode in the following passages:
Matthew 9:27–31
Mark 10:46–52
Luke 18:35–43
John 9
What is interesting in the first three gospels is that the blind man (or men) comes after Jesus, whereas in John's Gospel Jesus approaches the blind man. This shows the two-way responsibility of personal spirituality. Individually we are all responsible to make our own efforts to meet Jesus or God or the Spirit in our lives. At the same time, if we belong to a church community then that community is also responsible to 'be Jesus' and approach us as well.

The key point is that once we have had this experience of Jesus, once the Holy Spirit really means something in our lives, then we will become a visible witness and our local church community will not be able to ignore us. This is something I have found particularly true in the Deaf community. Deaf people are very visual people and also very experiential people. What I mean by this is that reality for Deaf people is something they have to experience in a personal way. It can be compared in a certain way to the famous gospel story of Thomas (John 20:24–29). The disciples had an experience of the risen Christ but Thomas was not with them at the time so he refused to believe. Thomas needed a concrete experience which he eventually received. In the same way Deaf people need an experience of the Spirit to be able to appreciate spiritual life. Of course I think that is the same for most people.

QUESTION 3: 'What experiences of the Spirit have you had and how have they changed your life?'

With our local Deaf church group we have had 'Life in the Spirit Seminars (LISS).' These are 8-week spiritual programmes which can lead a Deaf person to experience God's power in their lives. Because it is the power of God working in us which will enable us to be effective witnesses to God's people in our local church and in the wider community. We need this power. If we return to the stories of the blind men we can see this new power of God at work in their lives.

In Matthew's account the power of God impelled the men to witness publicly even though Jesus cautioned them not to (Matthew 9:30–31). The experience of Jesus was something they could not hold to themselves – it was Good News and everyone should learn about it. In Mark's story of Bartimaeus we see that not only was his life physically changed but also his circumstances changed too – he became a disciple and followed Jesus along the road (Mark 10:52.). So here is an example of commitment to follow Jesus which was a big change when we consider that as a blind man Bartimaeus was "scolded" – put down – by the people. Having experienced the power of Jesus in his life he became determined to follow him. Luke's account is more explicit in the response of the blind man: "…he followed him praising God, and all the people who saw it gave praise to God." (Luke 18:43).

QUESTION 4: 'How do we praise God in our lives?'

In many ways this is an important question for us disabled and Deaf people. Are we happy to be separate and have our own groups meeting at different times from the bigger Church communities? I have seen this happen in Deaf communities and I would not be surprised if it happened in disabled communities also. But I would like to suggest that segregating groups within Church communities is not the Christian way to do things. I would like to challenge Deaf and disabled groups:

- Don't stay comfortable in your own group but be leaders of diversity
- Don't give up because of the prejudice and put down of ignorant people
- Don't set your sights lower than leadership in your Church and community

Don't get me wrong, I am not suggesting that we don't have our own times together. Disabled and Deaf people need times by themselves to strengthen their members. In my own Deaf church group we have Prayer and Praise evenings by ourselves so that we can practice the gifts the Holy Spirit has given us and nourish our souls with good teachings. We also have our own Bible study times together. But on a Sunday at public worship, we mix with local hearing Church communities. That is our witness to them. We haven't got an even share of the leadership yet but are working towards it.

Jesus touched our lives and we have experienced the power of God. Therefore we believe we should take our rightful place among God's people, not just among disabled or Deaf people, but among the whole Church. That is where we belong and is where we have our battles to fight and witness with our testimony. But before we can do that we need the power of God in our lives, we need baptism in the Holy Spirit, and we need to make a commitment to prayer and each other. This is what happens to all of God's people as it happened to the first Christians in the Acts of the Apostles (Acts 2).

Our challenge is to get first things first with God. How strong is my relationship with God? How strong is my prayer life? How do we get stronger? We may need to do this in our own group with people who share our own experience of disability or deafness. That way we can be a support for each other. But the power that is going to transform us from being merely interested in God and spirituality, the power that is going to transform us from being afraid to witness, the power that is going to transform us into evangelizers – is the power of the Holy Spirit. The Holy Spirit will transform not only our spiritual lives but our whole life – we will be like different people.

In the story of Pentecost some of those who witnessed the events thought the disciples were drunk! Something had taken hold of them. They had changed from people who were afraid (John 20: 20), apart, isolated: "They were all filled with the Holy Spirit and began to speak different languages as the Spirit gave them power to express themselves". (Acts 2:4). And this is our challenge. This is the sort of transformation which will empower the disabled and Deaf communities to witness to God in their lives. This is the confidence which will enable us to speak out at our local Church communities, to become leaders, to evangelize those who do not appreciate disabled and Deaf people in their midst as their brothers and sisters. But unless we have received the power from on high it will not happen. Unless we make the commitment to God and nourish ourselves with solid spiritual food, preparing our hearts for the Holy Spirit, it will not happen. In the gospels there are many examples which show that God touches lives if people have faith and that is something we will get through a relationship with God. But if we don't make the commitment then we won't receive the benefits and we will be continually frustrated by the lack of acceptance for disabled and Deaf people in our local Church groups and the wider community.

I want to challenge churches today. I hope some church leaders are here. I want to say: have a good look around your congregations at the main service on Sunday or Saturday.

- How many disabled people and Deaf people do you have leading the service?
- Is your congregation truly diverse, truly universal?
- Who is missing?

Jesus Christ reached out to everyone, and we should too. You might say there are no disabled or Deaf people in your area, and I would say: there are there, it is just that you are not aware of it. Perhaps these people do not feel welcome at your church. But there are always friends of friends who know someone who is disabled or Deaf.

Yes, there are many challenges facing churches today – and dwindling numbers could be one of them. This reminds me of the famous gospel story about the great banquet. Luke's account is very telling (Luke 14:15–24). What we find here is that because the average Christian Church community and its leaders did not come to the party with God, "…the poor, the crippled, the blind and the lame…" enjoyed the feast instead! They accepted God's invitation. So for the disabled and Deaf people here today, that is our challenge – to accept God's invitation into our lives. This will require commitment and faith and the power of the Holy Spirit. It won't be easy.

But the wider Church and its leaders have an equally difficult challenge.

- Is your church a true witness to the diversity of people in your midst?
- Have you come to the party with God and accepted responsibility to include disabled and Deaf people?

This is an integral part of your service, mission, what it means to be Christian. If churches struggle for membership – I say: 'where are your disabled and Deaf people?' We will fill your churches. It will be no problem, there are plenty of us. If you reach out and invite us we will come but it will change your service and ministry completely.

- You may need to widen the wheelchair ramp which had hardly ever been used.
- You may need to find out about Sign Language Interpreters and how to use them.
- You may need to accept blind dogs and hearing dogs right up the front of your services.
- You may need to hold an annual mental health workshop for your Church Leadership Team.
- You may need to educate your whole Church community on the equal place disabled and Deaf people have in the community of believers.

QUESTION 5: 'What adjustments need to be made to accommodate disabled and Deaf people at your Church?'

We find in the gospels that people were always bringing disabled and disadvantaged people to Jesus and in Mark's account of the story about the paralytic they even lifted the roof to get a paralyzed man to him. Jesus did not turn them away (Mark 2: 1 – 12). Our churches should be a witness to this, a welcoming place for disabled people. We don't want people in the church to solely see us as an opportunity for healing. No, we are here to participate and lead services. We are here to evangelize you and show you how you too can effectively evangelize us. In John's gospel Jesus prayed for unity and I think that is something that is lacking a lot in disabled and Deaf communities today. In most Deaf communities Deaf people are content to separate themselves from hearing groups. We have Deaf clubs, Deaf sports, Deaf social groups, and Deaf churches. But Christ's vision of communities was much bigger.

QUESTION 6: 'What is your vision of spirituality among people?'

If we are united in the expression of our spirituality whether it is as disabled Christians, Muslims, or of other faiths, then we are going to be effective witnesses and ambassadors to the wider Church communities. This conference can be a watershed in the process towards greater effectiveness and unity among disabled groups. It also challenges church communities to discover whether or not they are truly representative of God's people? In general our gathering here is another invitation by God. It is a further call to conversion along the way of our faith journeys.

As Deaf and disabled people we have a crucial role to play in the growth and life of God's people. We are called to witness, to testify, to be visible models of the power of the Spirit at work in our lives. In many ways it is a prophetic call and like the blind man Bartimaeus in Mark's gospel (Mark 10: 48) we have to be prepared to be ridiculed and scoffed at. But once we have experienced the power of God in our lives, no ridicule or scorn will deter us again. Yet to maintain, strengthen and become even more effective we will need to commit ourselves to spiritual growth. Without commitment our efforts will be impeded and we will not have the conviction to be convincing witnesses. The challenges I leave you with today are twofold:

Firstly to the disabled and Deaf communities – commit yourselves to spiritual conversion. You will need a group to pray with regularly. Don't judge other churches but look at ways you can work together. United we stand, divided we fall. Our biggest challenge is to be integrated into the local church community – not become our own separate disabled or Deaf church. We are part of God's people just as much as anyone else, but we need to get out of our comfort zone and challenge the wider community.

Secondly to church leaders and church communities – you need to take a long hard look at who comes to your services and who leads your services? Which sections of society are absent in your congregations? Are your ministers and leaders in a service truly representative of the community? How challenged are you by disabled and Deaf people? Are there any unconscious, unintended discriminations in your approach to selecting people to minister in your services and witness to the community?

At the end of the day Jesus always had time for people, and this is what church communities are all about. But when we become so comfortable that we lack the time to integrate disabled and Deaf people into our church we will end up in danger of……..
MISSING OUT ON THE PARTY WITH GOD!

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Whirled Around: Depression, Families and Faith

Mary Peterson

Editor's note: As this workshop involved a variety of activities, including discussion, this is an outline only of what occurred. For further details please contact the author.

For Elijah God was not in the earthquake, the fire, the storm and wind … but in the still small voice beyond all that.

•Where is God when the storm is raging?
•How do families cope when someone they love is suddenly a very different person, when their personality changes because of their disability?
•How can faith communities best support the disabled individual and those around them?
•What are the effects of depression on the faith of the individual?
•What are the effects on families?

S tress
E mbarrassment
L oneliness
F rustration

I solation
M isfit
A nxiety
G rumpy
E scape

•" I see myself as a misfit with other people."
•" … very individualised faith now, narrowed, increasing focus on life after death, … form of escapism"
•"Conversation: I open it, I finish it. – I put a time limit on it so I can escape."
•"I don't want to visit people from my past…… I prefer people to know me as I was, not as I am."
•"My faith is as strong as it always was…….God will bring peace to my soul."
•"I want to remain useful. I'm frustrated that I can't do what I used to do."
•"Unpredictability……" "I worry about what she will do next, her attempts to help cause more problems."
•"Dad's depression creates anxiety in himself and all around him."
•"His disability restricts the whole family in what we can do or plan … in everyday life things as well as holidays and outings. We have to pussyfoot around him."
•"I worry that we can't be honest with him anymore because of his anxiety and depression……He couldn't deal with it."
•"He's my father but is it like having a new baby in the house - there is stress on

everyone: 'Has he eaten and taken his medication?' But for Dad the last bit of control he has over his body is when he eats and takes the pills, so he does it when he wants to."
•"Role reversal of parent and child is sometimes really hard to take."
•"… embarrassment keeps me from finding friends. Searching for reality and something to hang onto makes me rely more on God the immoveable."

Recommended resources:

Nash, M. and Stewart, B. (eds.) (2002). *Spirituality and Social Care: Contributing to personal and community wellbeing.* Jessica Kingsley Publishers
Ralph, Kenneth F. (1996). *Yes, I get depressed,* Joint Board of Christian Education: Melbourne.

A selection of resources for use with children:
Children's Bible Ministries (2000). *Special to God,* - a teaching resource with flashcards for 5 – 6 year olds. ("Aims to help children accept people who have disabilities, and to see every person is precious to God; to help children handle disappointments in life.")
Duffield, Nora (1996). *Talking to kids about…* (A series of books including trouble, divorce etc). Random House: Auckland, .
Fox, Mem (1984). *Wilfrid Gordon McDonald Partridge*, Omnibus Books:Sydney, (About caring for others : how a small boy helps a very elderly woman)
Millman, Dan (1991). S*ecret of the Peaceful Warrior : a story about courage and love,* California: H J Kramer Inc
Tiller, Steve (2002). *Boat and Wind* , Michaelsmind: Atlanta, (Explores how friendship changes the way we view life)
Varley, Susan (1984). *Badger's Parting Gifts,* Random Century: London , (An animal story about how special memories help people cope with death)
Wheatley, Nadia & Ottley, Matt (2001) *Luke's Way of Looking,* Hodder: Sydney, (About a boy learning to believe in his own special individuality)

Recommended resource organisation:
Skylight: *helping children and young people deal with change , loss and grief* - offers a range of resources, training programmes, support and counselling
Phone: 0800 299 100 Fax: 04 939 4759
Email: info@skylight-trust.org.nz
143-145 Riddiford Street, Newtown, Wellington

Mary Peterson is the National Coordinator of Ministry with Children and Families for the Presbyterian Church of Aotearoa New Zealand. She was formerly the General Secretary of the Churches Education Commission for ten years and before that Mary was a teacher. She teaches courses for Massey University and the Ecumenical Institute of Distance Theological Studies. Her mother lives with the effects of a brain hemorrhage and her husband has Parkinson's disease.
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Healing from Hardship - Growth from Grief

Dr Nancy Reeves

As a clinical psychologist and psychotherapist, I have worked with adults and children in the area of trauma, grief and loss for the past 26 years. Although my University degrees are useful, most of the important skills I use to help people heal the losses in their lives, I have learned from the grieving people who shared their pain with me. I would like to tell you some of the things I have learned. Let's start with some definitions:

Loss

A loss is any experience that restricts us in some way, and if we do not make some change in attitude, behaviour or life-style after a loss, the restriction will stay and burden us. For example, if the family member who usually handles the household finances experiences a head injury in an accident, he or she will find that the resulting poor concentration and short term memory difficulties will have a severe impact on the ability to balance the books. If the family is willing to acknowledge and talk about this aspect of the loss, the issue can be dealt with, probably by another family member taking on that role. If the reality of the head injury is denied or ignored the books will not be done well, adding financial loss to the other restrictions already present because of the accident. Loss can be as concrete as a chronic illness or bereavement or as nebulous as the shattering of a dream or expectation.

Grief

Grief hurts! It is a holistic process, involving emotional, physical, mental and spiritual dimensions. Pain is felt in all these areas. The purpose of grief is to heal, and the pain, strange as it may sound, is helpful in that healing. We grieve, to some extent, for any loss. The grieving process helps us adjust to a loss by showing what the loss means to us. We can then decide what we need to do in order to heal. The pain of the grieving process is present in each of the four dimensions listed above, and keeps us focused on our loss so we will do the ‘work’ necessary for our healing.

Because we grieve for the implications and meaning of a loss, not only for the 'fact' of a loss, the grief may last a few weeks or many years. The following implications are examples of a few that may be present in your grieving process:

- Intrapersonal (how the loss affects self-esteem and self-image)
- Interpersonal (how it affects relationships)
- Financial roles and status (how does position in family, job, and wider community change because now you are a person with MS or a paraplegic)

The number and difficulty of the implications determines the length, depth, and difficulty of our grief. None of us can know how long our grief will last.

The grieving process is like a spider web. Every strand is connected, yet we can't tell beforehand which strand will be more appropriate to travel on at any one time. One implication may not be grieved for years. For example, the parent of a child with special needs will likely have a surge of grief with each developmental stage or life ‘milestone’, such as starting school, which their child misses or does differently from other children. Yet, it would not be helpful for them to grieve the future losses while their child is still a baby.

The goal of grief is not to reach a point where we feel nothing about the person or thing we have lost. Healing involves four points:

- **A shift of energy -** energy that had been used to assist your adjustment to the loss is now freed for survival and life-enhancement needs
- **Being able to think about the loss** without having to 'sit' on emotions to keep them from becoming overwhelming
- **Feeling able to live**, not just exist
- **A change of focus -** the loss leaves the centre of your awareness or life. Although, at times, some aspects of the loss will need time and energy, most of the time it feels integrated in your life

The grieving process naturally comes and goes in waves. We move in and out of various implications and symptoms as they become relevant. Sometimes we feel overwhelmed and in the 'depths' of grief. At other moments we may experience a sense of peace or just a soft, light sadness. Family members will have different grief experiences. A child's relationship with a mother is very different from the connection between a mother and father and so will experience different feelings and issues.

By riding the waves, we do not usually stay long in very intense grief. We will, though, revisit the depths a number of times. Some people have a problem feeling deeply and try to keep busy or to otherwise divert themselves from the emotions. Others feel guilty about the normal ‘respite’ periods when they feel little grief, and so they think or feel themselves back to a deep level of pain. Interfering with the natural process by trying to control the depth of grief is exhausting and slows healing.

Some normal symptoms of grief, include:

- **Emotional** - sadness, anger, longing, depression, anxiety or fear, apathy or resignation
- **Mental** - poor concentration, poor memory, difficulty making decisions
- **Physical** - tears, sleep disturbance and/or fatigue, restlessness, weight change, diarrhoea or constipation, cardiovascular disturbance, nausea, sexual disturbance
- **Spiritual** - doubting or examining beliefs, sense of distance from God, difficulty praying or meditating

Spirituality

We all have a spirituality - a personal response to life's mysteries and questions. Whenever we ask “Why did this happen?” “Is life worth continuing?” “Can I ever be happy again?” we are in the spiritual realm, examining the values and beliefs that guide our way of being in the world. Some people find their spirituality is supported by religion, a structure of clarified beliefs, laws and rituals. Others walk a spiritual path outside of organized religion.

Because we don't just grieve for the fact of a loss, but for the meanings and implications of that loss, spiritual issues always arise in grief. It is normal and healthy to question and explore our beliefs. Prior to experiencing deep grief, we may not realize how a belief such as ‘Bad things don't happen to good people’, or ‘A person of faith should be able to accept all loss without pain’ can restrict our healing.

Just as our interests, abilities and bodies change and mature during our lifetime, so do our beliefs. As a child, we may believe ‘Love is all I need to make a relationship work’. As an adult the belief changes to ‘Growing relationships need time, energy and qualities such as patience and compassion.’ If our earlier belief does not mature, a separation or divorce may trigger deep feelings of shame as we view ourselves as failures in love.

A conscious, examined spirituality will similarly mature as we live through life's ups and downs. It will then reflect our true values and provide solace.

All faith traditions speak of the importance of a refuge to support us on our path. Those people who believe in a Creator, turn to their image of this Being for support, healing and guidance. Those who do not believe in a divinity seek solace and guidance in their source of refuge, such as in Buddhism: Buddha, the Dharma (Way) and the Sangha (the spiritual community).

Why does God allow pain and suffering?

Grievers frequently ask this question. Most faith traditions that speak of a Creator, describe that Being as loving and compassionate. The divine does not want us to suffer, yet the only way to prevent suffering is to intervene directly. This would destroy our free will and make us little more than puppets. There would always be the question of how much our lives were being controlled

Birth and death, growth and decay, loss and gain, health and illness are all aspects of the life cycle. Hurricanes and droughts are consequences of natural forces, although with our human history of plundering the earth, we contribute to a number of “natural disasters.”

My friend cannot take away my pain, but knowing she is willing to stand beside me in love and acceptance makes it easier for me to bear my burden. If we change our image of a punitive, judging God to one of a friend who suffers with us and wants us to live happy, fulfilled lives, we can feel comfort and gain courage to meet life's losses.

Spiritual practices change

Spiritual practices such as prayer, meditation, attending worship services, and reading inspirational texts may need modification during the grieving process. As our healing needs change some of these practices may take on more or less importance in our lives. Some grievers feel so vulnerable in public for a time, that attending group worship is a chore rather than a source of comfort. Honouring these changing needs, makes us more flexible and effective in meeting them.

One man spoke to his minister about his discomfort in the large service. The pastor suggested a smaller prayer service during the week that became a lifeline for him. Another person spent a few Sunday mornings walking in the woods, “hearing” the divine speak through nature. As the rain and her tears mingled she felt cleansed of some of her pain.

Some people find their usual way of praying or meditating becomes arid and God seems very far away. If we are receptive, we will often be guided to the type of prayer or meditation we need. One woman, whose prayer had always been very structured and full of words found that she kept forgetting what she was saying. When she became more present to her experience, she realized sitting in silence gave the sense of being held in a loving parent's arms. She didn't need to talk about her pain

Spiritual directors and pastoral counsellors meet with people whose spirituality is within or outside a faith tradition. They are trained to help grieving people find the spiritual path and practices that are right for them, not to impose their own. Individual sessions, ongoing groups or one time workshops or retreats at spirituality centres are all available to support the healing process.

Tools to encourage healing

One of the spiritual tools I teach involves finding a life-affirming symbol for the grieving process. A symbol is an object, word, place vision etc. that stands for a meaning other than its obvious or usual one. Symbols can change in meaning. For example, most times I associate a heart shape with love. If a loved one is booked for open heart surgery though, the heart shape may speak to me of pain and worry instead of love.

Tara came to me for counselling with a symbol for her grieving process: “Beating my head against a brick wall!” We looked at how life-denying that image was, and how it caused her to retreat from her grief. Tara became open to looking for a new symbol. In our next session she said, “The grieving process is like a path through dark woods. The love and support of my family and friends, of my faith, of my inner resources are like clothing that protects me from being hurt too deeply by the brambles, the stones and the cold. And I am moving towards the light.” I liked that image so much I used it for the cover of my book ‘A Path Through Loss’.

Another tool that many people tell me is useful for their healing is writing or drawing in a journal. Keeping track of our grieving process allows us to see how far we have come, clarify issues that seem confusing, and provides a way to ‘let off steam’. If you are experiencing normal symptoms such as poor concentration or difficulty with memory, it may be helpful to create a journal with sections, such as ‘helping tools’ ‘affirmations’ and ‘new awareness’. My book ‘A Path Through Loss’ includes such a journal and people often tell me how much easier it is to find the material they want to re-read when it is in sections.

There are many good books on grief and healing that will provide guidance and support. My books are now available in New Zealand. These include: ‘A Path Through Loss’. ‘Found Through Loss: Healing stories from Scripture and Everyday Sacredness’, ‘I'd Say Yes God, If I Knew What You Wanted’, and ‘The Midwife's Story: Meditations for Advent Times’ which asks the question ‘What does God want to bring to birth in me?’ By being ‘informed consumers’ of the grieving process, I believe we will discover the unique path to healing and growth that fits for us. May you find your path.

Dr. Nancy Reeves is a clinical psychologist from Canada. She has specialized in trauma, grief and loss for 26 years. She is a psychotherapist, spiritual director, published author and poet, wife and mother. She teaches graduate courses at the University of Victoria and the Vancouver School of Theology. Nancy conducts workshops in New Zealand, Australia and North America in the areas of grief, transformation, healing, spiritual discernment, and ritual.
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Editor’s note: *We are pleased to advise that Nancy's books, ‘A Path Through Loss’, ‘Found Through Loss’, and ‘I'd Say Yes, God if I Knew what You Wanted’ are all available or can be ordered through any bookshop in New Zealand. They are also able to be supplied direct, freight free through:*

Tony Tizzard
Nationwide Book Distributors Ltd
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Well Connected – Journey to Mental Health

Suzanne Tocher/Ryan

Editor's note: For further details of this workshop please contact the author or refer to her book "Well Connected" (see note at end of outline).

This workshop told the story of Suzanne's mental illness, hospital treatment and later rehabilitation.

- "Traumatised by experiences in World War 11 my father ran our post-war household like a military camp. As a result I developed severe psychological problems".
- "As a patient at two New Zealand mental hospitals in the 1970's and 1980's, the treatment I received was not helpful. My Christian faith, long term therapy with a skilled psychotherapist, writing and painting have been the key to my journey to mental health".
- During the workshop she shared that "without a connection to the 'Well' (God) true deep inner healing is not possible - that a holistic approach to healing is necessary - drawing on the emotional, spiritual and psychological. I have come to this realization through an amazing spiritual encounter that I experienced when I was in the deepest darkest place I had ever been in".

They think I should stay in the Mental Hospital.
They have examined my head,
but I am leaving.
I stagger down the hall with my suitcase.
My hair is brittle and falling out,
my lips are split open,
my clothes crumpled and shambolic.

A taxi driver is waiting at the entrance
to take me to the airport.
He says "It's good you are coming out of there".
As I sit in the back of the taxi,
the driver turns and gently says,
"Have you examined your heart with God?"
The first rays of dawn light cut through the dark.

At the airport desk I pick up my prearranged ticket.
There is a tap on my shoulder.
I turn around and see the taxi driver.
He places a coin in my hand,
the change I'd left behind.
I feel as though I have received a spiritual gift.
Dawn has broken.

Suzanne Tocher/Ryan is the author of a book "Well Connected" in which she tells the story of her mental illness, hospital treatment and later rehabilitation. She says that her Christian faith, long term therapy, writing and painting have been the key to her journey to mental health. This book was published by Philip Garside Publishing Ltd, October 2001, and can be obtained through the website - www.pgpl.co.nz, or at places like Whitcoulls and Paper Plus where it can be ordered.
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I remember my father's words
As he was dying,
"Give us a kiss, Suzie."
Reaching out,
making his peace with me.

I take in his words and am at peace.
Now I reach back to him with love.
(Suzanne, p.57)

How Parish Nursing may Address the Needs of Those with Mental Health Problems and their Caregivers

Elaine Tyrrell

Editor's Note: This is a descriptive framework of this workshop as it also involved a great deal of discussion. Please contact the author for further information.

What is a Parish Nurse (faith community nurse):

- Is a registered nurse
- Has a current practising certificate
- Is a committed Christian*
- Works in a community of faith
- Is involved with primary health care: health promotion and education; health counselling; advocacy; referral and possibly care management*
- Seeks to link faith and health, viewing the person holistically
- Is a member of the ministry team
- Uses trained volunteers to support their work
- Is accountable for their own practice and to God but works within the legal and ethical guidelines of the nursing profession

(* may be of another faith and may choose not to do 'hands on' care management)

Addressing Mental Health Needs

Reflect upon how society tends to look upon those with mental health problems – think of two concentric circles, one within the other. One circle represents a person. The other represents that person's mental illness.

Which way do you perceive someone living with a mental health problem? Some would contend that mental health professionals see the big circle as the mental illness and inside is the person. Can we see the person as the big circle and reduce their mental illness to a small part of them?

Just a Band -Aid? (Discuss present mental health provision and list responses)

What can the health system offer those with a mental health problem?

- Link with GP – DHB's changing care so GP is monitor rather than psychiatrists
- Link with specialists as referred – psychologists, counsellors, psychiatrists, early intervention nurses, crisis teams
- Medications
- Support agencies e.g. Schizophrenia Fellowship

- Inpatient care – long and short term
- Education and training
- Respite care
- Other – e.g. electro convulsive therapy (ECT)

What can the health system offer their families and caregivers?

- Issues of Privacy Act
- Funding focus on clients rather than their families

What is lacking in the provision for those living with a mental health issue and their families?

- The medical model addresses mostly the mental and physical needs
- Spiritual issues can be thought to be counterproductive e.g. religious delusions
- Chaplaincy are stretched and often focus on acute needs whilst many mental health needs are chronic
- Some hospital chaplains are not comfortable or trained to cope with mental health issues
- Other

What does a faith community provide? (Discuss and elicit responses)

- Love
- Worship
- Spiritual healing - wholeness, shalom (include ideas of anointing, prayers for healing)
- Communion with God and others
- A place in society - being needed
- Support of a parish nurse

Model of how Parish Nursing may look at the health of an individual:

Physical, mental, social and family or whanau health are all interlinked. Furthermore each of these impinges on spiritual health and vice versa (see figure 1).

Share the story of a young woman who was diagnosed with postnatal depression who is still living with the consequences 9 years after the birth of her second child. The impact on her immediate and extended family: the impact on their finances, their neighbours, and her and her husband's struggle to maintain their faith and feel accepted within a faith community. As a Parish Nurse I have been involved with advocating and supporting this family as well as the whole faith community.

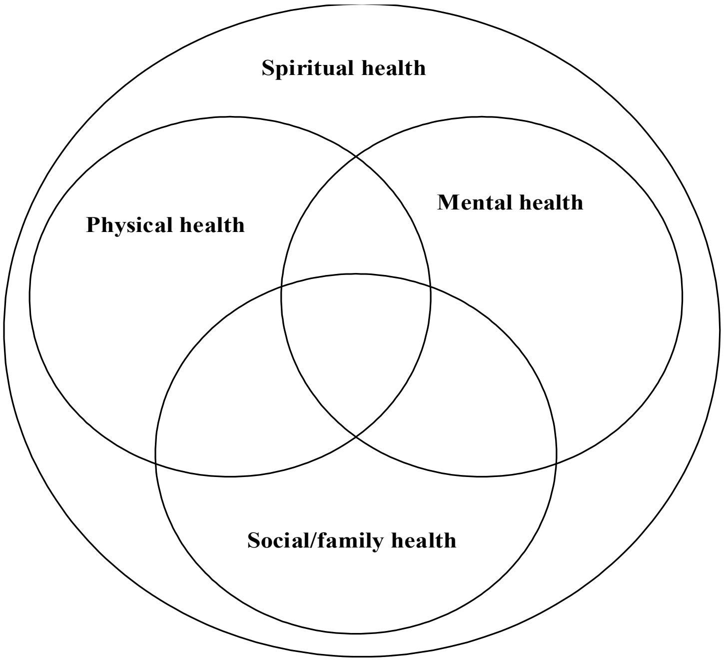
Discussing with a colleague, Mike Lynch, who is the Field Officer for SF Nelson, (Supporting Families) we agreed that many with mental health issues often need someone to accept them, support them non-judgementally and also be willing to be with them for the long haul. He suggested that faith communities often could be the ones to provide this role. They see the person and not their problem. Indeed one of their leaflets states:

"Select someone—a spouse, a friend, a clergyman, a support group, a relative— who will listen without passing judgement."

"Spend time with people who are positive, affirming and fun!"

("Support, Hope and Recovery" pamphlet, Schizophrenia Fellowship NZ Incorporated)

I hope that we in the churches might be considered in these categories.



A model of how parish nursing could view the health of a person

Figure 1

The Impact of Dementia on someone and their Family

I work fulltime at a psychogeriatric unit for the local DHB. We assess and treat those aged over 65 with a wide range of mental illness. We often receive those with dementia who, because of their disturbed behaviour, cannot be managed at home or in a rest home. We are specialised in handling physical and verbal aggression and changing doses of medication so that those in our care appear calmer. What we have little time to address are their spiritual needs. Eileen Shamy from Christchurch developed a special ministry to those with dementia and she wrote in her book "More than Body, Brain and Breath"(1997, p16):

> While much time and money, effort and a large measure of social compassion secure adequate physical care for people with a dementia illness, very little is done to nourish the spirit. Yet the most frequent question I am asked by those who have recently received the diagnosis of Alzheimer's Disease and who understand the prognosis of increasing memory loss and confusion is this: 'What will happen to my faith when I can no longer remember?'

She writes of the need to awaken the spiritual within those who apparently cannot express their own spirituality. She advocates the use of the familiar and of rites such as the sacrament of Holy Communion. Colour, music, images, nature and the touch of someone who cares can, I believe, evoke the spiritual within those we care for. This is yet another area where a Parish Nurse can reach out.

Further Examples of how a Parish nurse and team might support those with mental illness:

- Support with presence at home, in the church, in the community e.g. walks for health, beach therapy….. (such are part of our ministry at Nelson Cathedral)
- Be an active listener
- Give them a role in the faith community which uses their gifts without adding to their stress
- Contact mobile community team if person is in an unsafe situation e.g. suicidal
- Provide information about services available in community e.g. budget advice, social activities
- Make referrals to those better skilled in different areas of care e.g. counsellor, minister
- Pray for and with the person
- Keep regular contact or provide network of support with volunteers or church members - e.g. transport to appointments or worship
- Share literature, poetry, prayers and scripture resources in a sensitive manner
- Provide up-to-date information for the faith community to remove the stigma of mental illness
- Provide ongoing training regarding therapies, medications, supports
- Liaise with mental health professionals
- Act as an advocate or refer to mental health advocacy services if necessary
- Learn from the person about their mental illness—they can be experts!
- Give support if required to family members or caregivers of person with mental illness e.g. give them a chance to go out by providing 'sitters'

- Keep in touch when other supports are being reduced or are minimal

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Elaine Tyrrell works in the Anglican Diocese of Nelson as a Parish Nurse Advisor having been parish nursing at Nelson Cathedral since 1998. She was a licensed lay minister in Liverpool and now in Nelson and is married to Charles Tyrrell, the Dean of Nelson Cathedral. Parish nursing has been piloted at the Cathedral and they have since been inundated with requests for help to start up this ministry in many Christian denominations, throughout New Zealand and also in UK and Canada. Elaine is on the Board of the NZ Association of Faith Community Nurses
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From Spiritual Isolation to Inclusion in Faith Communities

Yanny Webb and Anne McCormack

> Spiritual wellbeing is the affirmation of life in a relationship with God, self, community and environment that nurtures and celebrates wholeness. It is the strong sense that I am "kept" and "held" by Someone greater than myself who "keeps" the whole of creation, giving life meaning and purpose. It is the sure knowledge that I am part of that meaning and purpose. (Eileen Shamy)

SOME CAUSES OF ISOLATION

Things that may prevent integration into a faith community for people who suffer chronic health problems or disability are:

- Lack of transport
- Being different, a sense of not fitting in, shame, or guilt
- Lack of understanding of (health) condition, lack of acceptance
- Church services may not meet the needs - i.e. too language orientated, too long
- Physical obstacles, sound system, can't see screen, not wheelchair friendly
- Churches have limited resources
- Lack of awareness of what church has to offer
- Reliance on support people /staff
- Fear of unexpected, unusual
- Fear of strangers

OVERCOMING THE ISOLATION

Finding creative ways to integrate into a faith community may include some of the following:

- Connection and dialogue between disability groups or individuals, and faith communities. A community worker or chaplain may be needed to facilitate this
- Education of church folk regarding the specific needs and presentation of symptoms that accompany particular disabilities
- Teaching of inclusive theology and language
- Adaptation of church services, or maybe some special services to allow for short attention span, or other specific requirements
- Take the church to the people, visiting, offering the sacraments at home, meet, and celebrate in small groups in private homes, or residential facilities
- Education of staff/support people in regards to spiritual support, rituals and celebrations
- The facilities may need to be upgraded to provide a physical environment

suitable for people with disabilities
- Provision of transport
- Demand that staff take residents who want to attend church services, home group or outings, but require support to do so
- Assistance with dealing with grief, feelings of guilt or shame

Henry Nouwen from 'The House of God - Creating true intimacy':

> When Jesus says: 'Make your home in me as I make mine in you' (John 15:4), He offers us an intimate place that we can truly call 'home'. Home is that place or space where we do not have to be afraid, where we can let go of our defenses and be free from worries, free from tensions, free from pressures. Home is where we can laugh and cry, embrace and dance, sleep, watch the fire, listen to music, and be with a friend. Home is where we can rest and be healed. The word "home" gathers a wide range of feelings and emotions up into one image, the image of a house where it is good to be, a house of love.

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Yanny Webb has extensive experience working with people with disabilities and particularly intellectual disabilities. She has been involved in various roles in NZ and elsewhere. Both Yanny and Anne, who work as community liaison chaplains, have successfully linked homes that were set up after the closing of an institution and provide ongoing support and education to enable the church community to offer appropriate support.

Contact: yannywebb@hotmail.com

Anne McCormack has a wide and varied background in social work and disability. She is widely know as an able communicator, professional supervisor and facilitator. Both Yanny and Anne, who work as community liaison chaplains, have successfully linked homes that were set up after the closing of an institution and provide ongoing support and education to enable the church community to offer appropriate support.

APPROACHING THE BELOVED : BEYOND SERVANTHOOD

Rev Trevor Whitney

INTRODUCTION – THE PRISONER

In Florence, Italy, there's a gallery called "The Accademia" that displays some of the sculptures of the sublime renaissance artist Michelangelo. It includes his most memorable work, that of the Old Testament hero and Israelite king, David - a picture of languid, youthful confidence and physical perfection. But juxtaposed against this figure of ancient beauty are a series of four tortured figures that you encounter on your way to viewing 'David'. The series (a further two are displayed elsewhere) is referred to as "The Prisoners"; human figures that Michelangelo never completed. I've viewed these figures first-hand and I've seen each figure struggling for release from the confines of their suffocating environment, limbs and torsos straining to break free. However, ultimately each figure is destined to remain a prisoner of their rigid and unyielding surroundings.

Lizzie too is a prisoner to her surroundings – she lives in an institution for people with disabilities. Her particular impairment leaves her slowly but inexorably losing more and more of her physical and intellectual function. In terms of its outer manifestations I find it a particularly visually grotesque impairment to behold. When I entered her room for the first time I stopped and spent some time with the other residents who shared the room with her. When I had finished visiting these people I glanced at Lizzie from a distance, and I didn't like what I saw. I spied a writhing figure laying inside a padded bed, feet bound to protect her from her own involuntary actions. Like the priest and the Levite from the Biblical parable I chose to pass her by, and I left her room without talking to her.

A couple of weeks later I was on Lizzie's ward again, and this time I was determined that I would try to overcome my fears and introduce myself to her. And so, with some trepidation, I did. Apart from her uncoordinated and bound body I saw a figure whose features, to my eye, bore no relation to the photograph of her above her bed. I saw a gnarled face with a wild-eyed animal-like expression. I introduced myself to Lizzie, and spoke to her concerning her family and other details I could discern from a range of family photos stuck on her wall. She offered some inarticulate sounds I found impossible to interpret. I said good-bye, and left feeling quite frustrated because I felt I had been talking to a brick wall.

Somewhat forlornly I visited Lizzie again a few weeks later, more out of duty than desire. Again I began to talk to her about everyday subjects, but again seemingly to no avail. I felt this was a lost cause. I knew from case notes that she came from a religious background, so I closed the visit by suggesting to her that I might say the Lord's Prayer. In response to my somewhat mechanical and forlorn suggestion Lizzie, to my astonishment, said two words that shone like a beacon through a fog. “I pray”. I could scarcely believe the clarity with which she spoke those words “I pray”. It was like a revelation. It wasn't so much that she wanted to pray that grabbed my attention. The point was that in place of a brick wall, there was communication. In place of this object writhing in bed like an untamed animal, there was a living human being seeking love and relationship, just as I do and need. “I pray”. Two of the most profound words I have ever heard.

Apart from the unrelenting and degenerative nature of her impairments and the restrictive nature of her treatment, exemplified by her padded bed, I was compelled to realise that I was a part of the unsculptured stone that served to imprison Lizzie’s humanity. As I approached and looked upon her I imprisoned her with my superficial judgments and prejudices and shortsighted values. In turn, I became a prisoner to my impaired perception of human worth.

OUR FIELD OF VISION

The problem I had in approaching Lizzie, as with many of us who are considered able bodied and approaching people with a disability, is that we imprison the human being before us by enclosing them within a restrictive and limiting field of vision. This is especially so where their impairment is particularly visual or aural in nature. A wheelchair, crutches, inarticulate speech, no speech, involuntary or aggressive physical or verbal gestures, slowness of movement, childlike intellect, physically distorted facial features, dribbling, walking cane, seeing eye dog - these are just a few of countless images that can severely impede our vision and distort our motives for approaching or not approaching the person before us. We see a few immediate symptoms of their impairment, we hastily make our judgments, we restrict our vision, and we temper our approach accordingly. In so doing we have sorely limited and demeaned the worth of the human being before us. We turn one who, as a unique human being can claim to be beloved, into a prisoner.

What we have managed to do in the process is to imprison so much of that person's identity, so much of what makes them the unique and precious human being they are. Beyond the outer symbols, or manifestations of their impairment, is a multifaceted person crying out for validation, acceptance and freedom of individual expression.

- What of their unique skills, interests and passions?
- What is their desire for loving relationship and community?
- What is their want for some sense of spiritual formation, and validation of their search for meaning and value?
- What is their need for sexual expression and intimacy?
- What is their yearning for physical, intellectual and emotional support?
- What is their right to laugh and rage, love and hate?

By our hasty judgments and blinkered vision we invalidate so much of that which is fundamental to healthy, human identity and expression.

BARRIERS TO AN EMBRACING APPROACH

So what are the barriers that impede our approach and prevent us from fully embracing the other ? The following is a two verse manifesto that formed the raison d'être for a facility that catered for people with intellectual disability nearly a century ago.

> God help the imbecile! More dark their lot than dumb or deaf, the cripple, or the blind; The closed-soul vision theirs, the blighted mind, Babes, though full-grown; the page of life a blot. Yet say, shall their affliction be abhorred? Their need overlooked? shall charity pass by, Leave them to perish with averted eye? Forbid the love that bums to serve her Lord! (Minda Home, 1909).

We may mock the use of what we gauge to be highly offensive language. We may pour ridicule upon what we perceive to be antiquated motives. However I would argue that comparable language, similar equally inappropriate motives, and barriers to embrace, litter our approach to people with disability today. Furthermore, such language and motives cannot be excused in any generation on the premise that that which was done to, or for people with disability, at either an institutional, community or individual level, was done from "good intentions". We may wish to affirm the desire to do good, but we have to account for outcomes that were and are the consequence of inappropriate thinking and strategies or approaches toward those with a disability.

DIFFERENT FORMS OF APPROACH

The Medical or Service Delivery Approach

One of the presuppositions that can underlay our approach to marginalized people, including those with a disability, is that they are principally in need of being cared for, medically, socially, domestically or administratively. We immediately see the graphic consequences of the person's physical, intellectual, mental or sensory impairment, and respond by offering the appropriate professional care. In Oliver's (1993) sociological critique of this approach, aptly titled, Social Work: Disabled People and Disabling Environments, Finkelstein points out that under this model the people with a disability can become objects of service delivery. There is a risk that, whenever care is provided by any professional service provider, unless the person concerned has nurtured a well-developed personal network of friends, they can easily be led to believe that their identity is defined by their impairment and their subsequent disability. That is, they become objects of service delivery.

Whilst we all, in Western society, are heavily dependent upon receiving professional services in order to sustain our personal and professional lifestyles, it is worth raising questions as a consequence:

- How would we who are able-bodied feel if we understood our worth to be defined principally in terms of services received?
- How would we feel if our values, skills, attitudes, beliefs, need for loving relationship, and everything else that may define our whole identity beyond our administrative need, was subsumed by professional service?

And yet, people with a disability can find themselves as those who are 'done unto' on the basis of immediate need, rather than valued and related to as human beings of comparable worth. As Finkelstein graphically indicates, the consequence of this approach can be "social death" (in Oliver, 1993, p.27).

This is also an approach that displays an inequity of the power residing within the service deliverer over that of the service receiver. This inequity in power naturally leads to inequity in the relationship, an impoverishment of the recipient's self-estimation of worth, and a blinkered approach by the service deliverer that can fail to regard the resources the recipient may bring to the relationship.

The Approach of Christian Charity and Evangelism

Still under the broad banner of service delivery we encounter the Western Church's response to the poor and outcast. As with the medical model of service delivery, this approach defines marginalized people, such as those with a disability, as needful recipients. The difference here is that the service deliverer, the Church and its apostles, bear resources that broadly come under the banner of 'the Gospel'. These resources are bundled into packages with accompanying labels such as 'salvation', 'charity', 'protestant work ethic' and 'healing' (meaning 'cure'). Such packages have often accompanied the Church's approach to people with a disability, parcels offered as gifts,

THE BURDEN OF HUMAN FRAILTY AND MORTALITY

I approached Frances for the first time for the purpose of introducing myself to her. I had started working, about three weeks earlier, as an interim chaplain in a facility for people with intellectual and/or physical disability. In terms of experience and understanding people with disability within such a setting I was "wet behind the ears"
It was mid-afternoon and I found Frances lying in her bed, tired and in need of a rest. I introduced myself to her and began my visit with a view to discovering something of her story, both from what she was able to say, and from what I could discern from the photos and furnishings that adorned her portion of this room. She could only talk very slowly and deliberately, the result of a series of strokes she suffered about ten years previously. As we began our conversation I began to discover a person with whom I felt I had much in common.

Apart from being of a similar age to myself I discovered she had achieved two university degrees by about the age of thirty, including one in the area of psychology, and one that related to the field in which I was studying at the time. As she spoke I could discern that she, like me, was a person who valued the use of words, and the meaning they can convey when creatively expressed. As I looked around her room I noticed a small bookcase containing a few select volumes indicating a significant level of intellect. Yet, to my sorrow, particularly as someone who loves to read, she told me she had lost the capacity to read. And as our conversation slowly progressed I found myself being provoked by questions that arose from my subconscious.

- How would I feel if the capacity to advance myself through formal study was snatched from my grasp?
- What would I do if the words in my head could no longer be verbalized in the manner I sought for them?
- What would I do if the words were simply no longer there?
- How would I feel if the mountain of books and journal articles that lay piled up on my bedside cupboard, and in my carefully cultivated personal library, were rendered unreadable?

As these questions uncomfortably arose, and as I continued to focus on this young woman and her struggle for language, I had the somewhat eerie experience of feeling myself trading places with Frances. Momentarily I found myself as the one struggling with words and thoughts so difficult to formulate and articulate. I couldn't and wouldn't dare to deduce from this fleeting sensation a sense of knowing what life was like for Frances, however it did evoke in me momentary feelings of helplessness and vulnerability, frailty and, indeed, mortality. For a moment I was Superman exposed to kryptonite, feeling far weaker, and more human than I wanted to be. It was a feeling from which I wanted to escape. It was a feeling I wanted to deny.

Vanier (2001) addresses such weakness by suggesting that the denial of such human frailty, is to “deny a part of our being” (p.40), that it expresses a need for community, for the humanity we are offered by others.

Scholar and mystic Simone Weil (1952) describes the reasonableness of the burden such human frailty imposes when, in describing those she terms ‘the afflicted’, states,
“Except for those whose whole soul is inhabited by Christ, everybody despises the afflicted to some extent, although practically no one is conscious of it” (p. 817).

Like the moth that ventures too close to the burning light, coming too close to a source of our frailty and mortality can threaten our well being, ego and lifestyle to the point that we may feel our souls being extinguished. Therefore, out of fear our approach may turn to retreat, or denial, or we resume the role of the servant. In thinking of denial and servanthood I think also of that absurd and demeaning Christian saying: “But for the grace of God go I”. Perhaps a part of the falsely sustaining philosophy of those who count themselves religious, is that we can more stoically approach and serve those who are marginalized if we feel less frail, less incarnate and, by inference, more blessed and immortal, than they. We become sustained in the knowledge that we are the ones who are graced and the other is the one in need, to be pitied. Thus our self-centredness and vanity permits us to approach our “victims”.

In seeking to come to terms with the natural desire to retreat from our human frailty through self-centredness, we may at least start by acknowledging the naturalness of wanting to avoid such a burden. Brown (1996) cites Vanier when, in describing burdens, such as human frailty, as our inner 'monsters', states ".. if we accept that monsters are there, we can let them out and learn to tame them. That is the growth towards liberation" (p.5). But what more is involved in overcoming those monsters that both imprison the one I approach, and diminish my value to them?

TOWARDS AN AUTHENTIC APPROACH

Beyond Servanthood

As I take time to further reflect upon "The Prisoners", I naively think in terms of how it would be to see these trapped figures released from their unyielding surroundings. How good it would be to see these figures free to fly and achieve their potential. But then, when I stop fantasizing I realize they wouldn't fly at all. They'd fall flat on their faces, struggling to use their atrophied muscles, fearful of the unknown that accompanies their new-found freedom. Perhaps they would feel like the prisoner who wants to recommit a crime in order to experience again the security and routine, albeit utterly restrictive and imposed, that is the nature of prison life.

So how does the spirit in us engage with the spirit of the captive in a way that overcomes the shackles of debilitating approaches? How do we progress a theology that not only invites freedom but also overcomes service-based approaches, as well as the captive's desire, to retreat again into being an object of servanthood?

In light of this we may be provoked to think in terms of friendship. For example, Mottmann (in Eiesland & Saliers, 1998), in addressing the overcoming of the social disabling of those with disabilities, proposes "friendship as the foundation of all mutual help" (p. 121), or in other words, a friendship that overcomes solicitous care and the desire to help. However I would contend that such friendship alone does not account enough for the required commitment, either of me to the one I approach, nor they to me. Friendship can be too easily muddied by the waters of romanticism, condescension or pity. I would argue that, without being prescriptive, we need to go in search of principles that undergird a theological and philosophical paradigm that seeks to go well beyond friendship, a paradigm in which human integrity and worth are honored as sacred.

Brian was a resident of a facility for people with intellectual impairment. He was living with an advanced level of dementia. I went to visit him the day after he had returned from a rather distressing time in hospital, in which it seemed he did not receive the level of personal care he required. I stood by his bed. As we talked he would occasionally and quietly emit an anguished question such as, "I'm not gonna die, I am 17". I felt I had few words to offer so I just started stroking him on his head. As I did so, and amidst his pain, Brian lifted his emaciated arm from under his bed sheet, raised it towards me, and started patting me on my head - indeed, an enclosed circle of pastoral stroking! It was a truly humbling gesture. My feelings of being the professional servant melted away as in that moment I felt I needed Brian as much, perhaps more, than he needed me. I was reminded that my dependency extends to those who suffer much and who, whilst having many needs of their own, also assume the role of teacher and carer to me.

When we gaze at the other with unconditional acceptance we begin to not only see their worth, but in response to their worth, we see our need, our lack of self-sufficiency. Our need, our suffering comes into sharper focus. This is the point that Henri Nouwen describes in one of his final books, 'Adam', where he speaks of how his life was transformed by a young man with profound intellectual and physical disabilities who relied on the likes of Nouwen for 'around-the-clock' care of a most intimate nature. Nouwen describes how he came to see Adam not as one who was simply there to be cared for, but as one who met him at a profound point of need.

> Here is the man who is more than anyone connected with my inner self, my community and my God. Here is the man I was asked to care for, but who took me into his life and his heart in such an incredibly deep way. Here is my counselor, my teacher, my guide, who could never say a word to me but taught me more than any book, professor or spiritual director (p. 101).

Towards Mutuality - Seeing the Other as The Beloved

We begin to see the value of the one we approach when we see our conceitedness to them, as a member of the human family, to which we all belong. We begin to view them not from a position of power or superiority but as one in whom we truly share love and suffering, one human being to another, eye to eye. We begin to see someone amidst their joy and pain. We see their potential but we also see their prison walls, and we see a need to enter those prison walls even though we can never claim their experience as our own. And in daring to enter that prison we begin to view our pain, our prisons, in sharper focus.

Some of a religious persuasion may speak of such transformation as seeing Christ in the other. After all, does not Christ invite the disciple to find himself through losing himself in the need and suffering of our neighbor (Matthew 10:39), who is seen to be Christ to us (Matthew 25:31-46)?

However I think of one who assumes a preciousness that seeks unconditional embrace. I think of one who is beloved, and who is invited to see the beloved in me. And what we are describing is an approach based upon viewing the one before us as one in whom we can engage in a relationship of mutual worth - two people in need of, and enriched by, the presence and gifts of the other.

Jesus and Mutuality

I am reminded of Jesus. Many of us of Christian persuasion have become accustomed to the Son of God being described in terms that exalt rather than abase. We are more comfortable adoring the one born to a virgin (Luke 2) than embracing the lonely and distressed figure who cries out in abandonment prior to his arrest (Matthew 27:46; Mark 15:34). We marvel at Jesus when he heals, exorcises and walks on water, but we try to rationalise away or ignore the one who can treat the Syro Phoenician woman with contempt by referring to her as a dog (Mark 7:27). We are more comfortable with transcendence than the frailties and flaws of true incarnation.

Whilst Jesus met the needs of those he encountered, as an incarnate being he had his human needs met also. When Jesus encountered the grief of Mary and Martha over the death of their brother Lazarus he responded with tears (John 11:33). It was the women who evoked in Jesus the capacity and need to grieve. When Jesus reached out to the leper to heal him of his impairment (Luke 8:3), not only was the leper's need met but Jesus’ ongoing need for identity and communion with a fellow child of God, a fellow human being, was sustained and nurtured.

Mutuality and Community

So it is that when we are prepared to embrace the incarnate, “emptied” Jesus (Philippians 2:7) we see one who engaged in relationships of mutual caring and need. We see meetings of one frail human being with another. One of Jesus' principle needs, as it is for all of us, was the need for the nurture and support that comes from being a part of his community, which is itself a key outcome of truly mutually caring relationships.

Metaphysical poet and writer John Donne (c. 1572 - 1631) once penned these famous words:

> No man is an island entire of itself. Every man is a piece of the continent, a part of the main. If a clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as if a manor of thy friends or of thine own were. Any mans" death diminishes me, because I am involved in mankind. Therefore never send to know for whom the bell tolls. It tolls for thee.

The approaches I have thus far outlined, through their underlying assumption of superiority, deny the possibility of seeing the person with a disability as a part of a community. They deny the possibility of giving and receiving care on a community level. Donne would no doubt concur that both my community and I are diminished if I retreat to my island of self-sufficiency.

I remember being asked, in my role as chaplain, to visit Malcolm, an elderly resident with an intellectual impairment, who was dying. I found him as he had been for most of the last year of his life, lying in bed peacefully asleep. I sat beside his bed with gentle music playing in the background and occasionally spoke a word to him, and sometimes stroked the soft hair on his head, as I wondered if he was aware of my presence amidst his unconscious state. I spent as much time as I could with him over the next couple of days. It was during this time I became aware of people who were an important part of Malcolm's living and dying, people who cared for him and wanted to be there for him to the point of death. There were those who had prepared a birthday party for him the previous weekend even though he spent much of the occasion apparently unaware of proceedings. There was a fellow resident who came and said good-bye to a mate. There were various staff members who attended to his comfort whilst he lay asleep. There were other staff who took time off from other tasks to simply come and see how he was faring. There were Malcolm's legal guardians who, from his bedside, spoke emotionally of one who over many years had been a dearly loved child. I was a privileged witness to kind words and gentle touches. And so it was that Malcolm died surrounded by love and care from those who clearly received much love from him.

The abiding message that Malcolm left me to understand was that he was someone who drew a small, caring community of people around him largely on the basis of his being, not his doing. If community is to be principally judged on the basis of worldly achievement then Malcolm will inevitably be judged a failure, after all, as a generalisation, people with disability are invariably placed low on the ladder of social contribution. However I am sure it would be fair to say that each member of that community was enriched immeasurably for being welcomed with such acceptance by Malcolm. It was Malcolm's way of embracing them. I am also left with a feeling of gratitude, that a community of people could approach him, not as his superiors, not as those overwhelmed by a sense of burden and duty, but as those who were prepared to open their arms and embrace him as he was.

CONCLUSION – WHAT OF THE PRISONERS?

What of those “Prisoners” and their unyielding environment? I do not pretend that the approach proposed in this paper “proclaims liberty to the captives” (Isaiah 61:1). That may be a tad elitist and pretentious on my part. However it is an approach that places one alongside the prisoner, within his or her walls, even if only as a visitor. A visitor cannot know the pain of the one who is so tightly shackled by prejudice, condescension, outdated values, and patterns of control. However it is a posture that shows a measure of solidarity, care and commitment toward the captive, and thus a sense of integrity.

It may not serve to set the prisoner free but it may serve to loosen the shackles imposed by his or her environment, as well as the shackles that may prevent the visitor looking the other in the eye and seeing one who is beloved, awaiting embrace.

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Whispers from God: We all have our place and part to play within the family of God.

Dot Wilson

GOD MADE US WHAT WE ARE" Ephesians 2:10

The hardest thing that I have ever done is bring up my three children alone through their teenage years. I put this ahead of all the surgeries, many months in traction with a metal skewer through my leg. As part of my journey I have consented to this incarceration on three different occasions, followed by intense months of physio to become mobile again. I did this over the next few years and this resulted in having three lots of lengthy surgery, two years apart.

It was immediately after the first of these experimental procedures that my husband decided to opt out and leave me with the children who at the time were aged 12, 11 and 8. At this time I was totally dependent upon others for basically all my needs. My children were virtually thrown into doing and caring for me as well as trying to come to terms with the fact that their dad had gone to live with someone else. I must say that in all honesty all I wanted to do was end my life, but I could not as that would have meant all I had just been through would have been for nothing. Also I had three children whom I felt so helpless at supporting while being so dependent upon others who needed me!

An unforeseen marriage break-up is devastating in itself, without adding the trauma of long lengthy surgery, incarceration and intense rehabilitation. The weight simply fell off me and I remember my mother taking me to get some new clothes and standing in front of a mirror with a new skirt on saying, "I cannot wear this as it shows my big bottom", and the stunned look upon the face of the assistant. Only then I realised that the person in the mirror was a reflection of me - a someone that I did not yet identify with in my own mind, having lived in a drug-induced haze for a very long time! It was some ten years that we survived on the DPB supplemented by either sewing or looking after other people's children.

My children in time left home as they should but as the last one was nearing this I remember being in the depths of despair wondering how on earth I was going to survive financially when he was gone, even thinking that if I had another baby then I would at least have that security! You see, with each surgery anything gained seemed to have a trade off cost with the development of some very bad variables that saw me unable to bend or sit, meaning I was fast losing my ability to sew. My prayer was a bit like that of Job pleading for God to make things better and thinking that that should happen by my being able to maintain my gift of sewing, as long as I possibly could.

At this point everything in my life seemed at an end, and again opting out seemed like a solution. It was a very bleak time indeed. My car no longer accommodated my needs and aggravated my pain intensely, so I only used it for bare essentials. At this point physio was such a central component of my life that sometimes I would ask myself if hospital was an extension of home, or home an extension of hospital, for my life seemed to revolve around either going to, being there, or coming from it. The car that had once been an aid to my freedom was now seen as being an irresponsible contributor as I struggled to endure the pain and retain my hard-fought independence. What could I do? I had no money and the only way that I could see me making any was being taken away from me. The replacement of my car seemed so impossible. I had been to Social Welfare to see if they could help, only to be put through the most degrading process of ever, moving goal posts of applications and reviews to finally walking away from this all together.

In the midst of this lengthy process of review I met a woman with whom I shed tears and my story of woe. She said to me, “You need an advocate,” and gave me a phone number to ring…… so beginning my walk with disabled people!

Advocacy at work

It was because this organisation, New Zealand CCS, assisted me with an application to Lottery, which resulted in an appropriate car, which in turn opened up my world, that I became interested in matters of inequality, and what followed was a bit like a roller coaster ride to where I am today.

My inability to throw out a CCS newsletter advertising a position on a national committee and a forth-coming conference meant that at the end of one Friday afternoon I contacted the manager of the local CCS branch who faxed the application forms for this national committee. He was willing to send me to the conference in Auckland seeing as I was prepared to serve on the local CCS Board!

Wow! I was so delighted. Here I had just turned 40, was going on my first ever plane ride, and to Auckland, when I had never been any further north than to Christchurch. I reassured myself that this would be OK as I would travel with others from the Southland Branch, but in reality I had to go up a day earlier and so went alone.

My first concern was whether there would be enough leg room between the seats and would I fit given the prone way that I sat at this point in time? But once we had this sussed then all I had to do was get ready for the big trip. The day came and I was both excited and scared - in fact absolutely petrified! On the plane a gentleman sat next to me and chatted, soon realising that this was my first trip by air. He explained the different noises that occur when a plane takes off and makes its descent etc. He even spoke to the flight attendant who asked me up to view the flight deck. This man was wonderful, helped me into the terminal at Christchurch, explained where everything was and then presented me with a card! I looked at the card, wondered what I should do with it and then gave it BACK to him and of course, him being a gentleman, just put it back into his pocket. I was so naive. I hope that one day we meet again so that we can have a laugh and I can offer him my Business Card!

On to the hotel for my first ever stay at such a place. It was a very large establishment and I was very unsure of myself. I had to meet with some people but, feeling so scared, I could not bring myself to pick up the phone and make contact so instead ordered room service and locked myself in my room thinking I'd deal with them tomorrow. Of course they (all 6 of them) thought I had not arrived!

Support was offered to guide me into this committee but, oh horrors, the person who was to support me and phone me up, has cerebral palsy and I couldn't understand a word he said! He did phone me every week and taught me my first basic principle - that I must be honest in my communication with people and say if I do not understand so that a different word or shift in body language can then occur. This friend and I worked together on this committee for the next three years. During this time my eyes were opened to the marginalisation through power and control, poverty, tokenism, inequality, and lack of opportunity due to barriers of ignorance and fear of people with disabilities, and the most significant of all, the disempowerment that prevents people from believing in themselves.

CCS National Office offered me a short-term job to set up a network of disabled people around New Zealand and to co-ordinate some self-advocacy workshops facilitated by Robyn Hunt who took me under her wing, guiding and challenging me not only in my thinking but in my direction and the right people that I should perhaps contact etc. Robyn introduced me to the disability rights movement, and it was as if I was on an apprenticeship to leadership.

I must point out here that my constant prayer was that of asking, "Where is my future?" and I stress the point that it was not until I embraced my own disability, instead of always trying to beat it or deny it, that things began to change. A friend of mine, a Dominican Sister, had pointed it out to me much earlier on that my disability was both my greatest strength and my greatest weakness. I really struggled with this concept for quite some time but now liken it to two sides of the coin. My disability is my greatest asset and I now claim this with absolute pride!

Also by now you should be aware of the fact that a goal setter I am not! For me I stumble through open doors after falling out of the ones that firmly slam shut after me. I have this inner voice guiding me, prompting me as to where to next. It is this same inner voice that discerns when it is time to share with individuals about certain parts of my journey or to encourage them or remind them about their faith in God and to use their secret weapon…prayer!

A part to play…..

At the time where I was rebuilding my life I became involved more within the church. I started out as a reader after a plea from the parish priest of the time. Noticing that those involved seemed to be what I deemed very 'good and proper people' with very few women, my driving force was to represent women, single, separated or divorced and disabled women. I thought I would show them and perhaps motivate acceptance of these women who at the time seemed to be in the minority. I also thought that it might shame others into service, but it did not. Instead it lead to more ministry for me. Currently I read, distribute Holy Communion and share a parish co-ordinating role with another, and together we oversee the six Passionist Family Groups within St Mary's Parish in Invercargill.

The aims of the Passionist Family Groups are:

- To share Christian life together.
- To support each other in time of need.
- To give example to, and involve children in our Christian sharing.
- To live and love like the early Christians …'See how they love one another'.
- To build and promote Community Spirit within the Parish.

The family groups comprise of people who, after showing interest in the concept, were placed into groups by two Passionist Priests from Australia. With no prior knowledge of the people cliques were not created. It is interesting because the friendships that have resulted are with people that perhaps one would not have been drawn too. Yippee, here is a place where diversity is acceptable! In my family group we have a variety of enabling aids from hearing aids, spectacles, walking sticks, and walking frames etc.

Family groups meet monthly and do something that is purely social, depending upon the makeup of each group. Our common bond is our Christianity. It is a great place for non-catholic spouses to attend without feeling 'got at'. Family groups are strong in our parish and our old Basilica Church has recently had a new front entrance added that includes steps and ramps fitting in harmony with the design of the church perfectly. The addition also includes an accessible toilet and hot drink facilities. I was so excited the first time I saw a new parishioner sitting in her wheelchair in the main body of the church and not in the previously designated side chapel where a ramp had been added some years earlier.

With the structure in place, the accessible building and the family groups, all that is needed now is for those attitudinal barriers to be broken down - a societal issue that affects us all. The biggest barrier to participation by disabled people is other people's attitudes more often than not, born out of ignorance and fear. When we break this down within our own networks it spills on out into our communities and the 'yeast principle' is born. I discovered this 'yeast principle' in my work with Robyn Hunt who at the time was facilitating self-advocacy workshops for people with disability. Each workshop seemed to evolve and together we started sharing personal stories that uplifted, encouraged, challenged and inspired people to start to speak out for themselves. I think this was the awakening moment for me realising that the more we do for people under the guise of 'helping', 'looking after' and 'out for' with the intention of keeping them safe, in reality what's actually happening is a smothering, often leading to dependency and disempowerment, apathy, lack of identity, frustration and complacency and with no expectations required from anyone. Nobody was telling these people that “Disability is OK! It is yours and mine and ordinary”. We may do things differently or need a hand or two but on the inside we are the same as everyone else. Difference doesn’t mean we are less-than or more-than… just different.

Within the disability rights movement I have discovered disability pride. This only occurs when we people with impairment know that who we are is OK, and know we have and can exercise the same rights as everyone else. It’s what happens to us that is not. This is the principle of empowerment.

In my journey to personal empowerment and leadership, whether within the disability rights movement or the church, I have learnt that all people are unique and have purpose that only they can fulfil. Our society has spent so much time criticising difference that it fails to see God in diversity. It can only change when we are prepared to bloom where we are planted.

I conclude with ‘The Open Door’ by Joy Cowley, taken from her ‘Psalms For Today’ version three.

The Open Door

Life is just one door after another,
and the thing about doors
is that they don’t compromise.
We all know the slamming door.
Sometimes it shuts so fast
that it almost cuts us in two,
and we are left in a state of grief.
At other times a door closes slowly,
squeezing us out of breath
until we have to step aside
and let others be locked out.
A certain fact about doors
is that when one shuts on us
another one always opens,
but that’s not easy to see.
Often, I’m so busy knocking
on the door that’s solidly shut,
that I’m not aware of the other door
wide open at my back.

Dot Wilson is a disabled woman who works with disabled people teaching self-advocacy and human rights. She is in leadership within the Catholic community of the central parish in Invercargill.
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Looking out after looking within: Spirituality and the Disability Movement

Editor's Note: Sunday morning we aimed at looking at (1) The history of the Spirituality and disability movement worldwide, within Australia and the beginnings of it in Aotearoa/New Zealand; (2) Where to next for the movement; and (3) How to continue to foster links across the Tasman and further afield. Short biographies of the speakers are to be found at the end of the discussion.

The trunk emerging: Disability and Spirituality Movement in Aotearoa/New Zealand

Vicki Terrell: Conference Coordinator

This presentation is about the history and the future of the Disability and Spirituality movement in Aotearoa/New Zealand. As a High Anglican, I love symbolism so have chosen to talk about the movement as a tree. I see this conference as being the public launch of the movement, thus the title "The trunk emerging".

The seeds of this tree were:

- Nancy Eiesland (1994). "The Disabled God : Toward a Liberatory Theology of disability" This really got us thinking!
- "Disability, Religion and Health: Exploring the Spiritual Dimensions of Disability" Conference in Brisbane 1996
- "Beyond the Ramp" Conference in Adelaide 1998
- Disability Policy developed in the Diocese of Wellington-Holy/Wholly Accessible
- Application made to the Futures Group of the Methodist church

The Root system – Preparation

- The accountability group for the Ecumenical Project on Disability Issues was formed in 2001. This later became the conference planning group.
- The visioning day held in January 2002 – where are we going, what do we want to achieve?
- Sub-committees formed and developed over time with much recruitment
- Debate on the name "Through the Whirlwind" – lots of communication and challenge!
- Became an Incorporated Society
- The Pre-conference forums were held regularly where new people came on board and we looked at issues e.g. suitcase people; providing a safe environment; worship/reflection; hospitality

Three goals

- To provide a forum where disabled people and others can talk about spirituality.

•To encourage faith communities to become accessible to all through buildings, attitudes and theology.
•To debate moral and ethical issues in society especially as they affect the lives of disabled people.

Trunk

•The conference
•Public launch of the movement
•Networking - joining together
•The inaugural General Meeting of the Disability, Spirituality and Faith Network Aotearoa/New Zealand

Challenges

•Including faith traditions other than Christian
•Connecting with Pacific Island communities
•More Maori involvement
•Educating both faith and disability communities about what the movement is about

Conference tree

In the management group we had a permanent apology to the trees for paper used in bringing our movement into birth and we said that we would have to plant a tree to replace it so we are planning on:
• Planting tree in a public area accessible to all to celebrate this conference.
•Will be planted on the town belt
•It is a challenge to find site accessible but there is commitment to this.
•Planting will probably take place in June

Totara Tree

•Native to NZ, it is used for building, carving and canoe building
•It has the properties of strength and durability
•These properties are already present in this movement.

And so the seed is planted, the roots and trunk are forming and it is hoped that the branches will bear much fruit in the years ahead in both Aotearoa/New Zealand and the wider world community.

A Global Perspective from EDAN

Ye Ja Lee (Korea)

Ye Ja Lee came to the conference representing EDAN and as the acting co-ordinator for the Pacific Region. She brought us greetings from both EDAN and the World Council of Churches. The following is a summary of her message as an exact transcript is unavailable because of language and technical difficulties.

As described by Ye Ja, EDAN is the Ecumenical Disability Advocates Network, which is a branch of the World Council of Churches. This was set up in 1998 out of a growing concern for disabled people globally, believing that:

> all people with or without disabilities are created in the image of God and called to an inclusive community in which they are empowered to use their gifts. This inclusive community of all the people of God is holy in Christ, irrespective of the physical state of their bodies and level of psychological functioning. Through the Holy Spirit, this inclusive community is called to repentance, transformation and renewal (Genesis 1:27 and II Corinthians: 5:17).

EDAN's mission is to support the work of individuals, churches and non-church organizations concerned with issues affecting disabled people globally, while their purpose is to advocate for a just and inclusive community by creating a network of people with disabilities as a distinctive ecumenical contribution to new models of being a church.

Ye Ja described the work being done throughout the various regions of the world, such as Latin America, the Caribbean, North America, Europe, Middle East, Africa, Asia and the Pacific. Each of these areas have a regional co-ordinator who helps promote and deliver programmes according to regional variations. The Pacific region is the largest region of all. Ye Ja told us she is keen on incorporating the work in New Zealand into the EDAN network and would like to work with us in our various initiatives and support us wherever she and EDAN can. "We would like to find ways to help us walk together in our ecumenical journey".

It was exciting to hear what is happening world-wide and it opened our eyes to some of the wider global issues facing people with disabilities, made us realise that there are many unifying issues we face, and that our movement in Aotearoa/New Zealand does not stand alone.

EDAN has provided both moral and financial support for the conference. We have been delighted to be able to have the Acting Pacific Regional Co-ordinator with us.

For more information on EDAN the following website is available:
http://www.wcc-coe.org/wcc/what/jpc/disabil.html

A Trans-Tasman Perspective

Lorna Hallahan (Australia)

As we meet here, the 60th anniversary of the Warsaw ghetto uprising that lasted for a month from the 19th April to the 16th May 1943, is being celebrated. It reminds us that even in a massive orchestrated campaign of slaughter as in the Holocaust, there are tales of resistance. In fact, there were 100 Jewish resistance groups in Eastern Europe aimed at stopping the transportation of Jews to the death camps. This is a time for the descendants of those people who died defending their people, to claim the dangerous power of their memories.

I like the idea of dangerous memory linked to subjugated voices, a dangerous reminder comprised of the memory of struggle. I think we too can explore our dangerous memories, our own history of the refusal of mistreatment of people with impairments. Yes, there is a link between our individual pain and in a way our pride as well, and the collective action that remains critical for all of us. The scale of our looking back has nowhere near the evocative power of the Warsaw uprising but we too have seen quite a significant shift in whose story is told in places like this.

Sharon Welch describes dangerous memories thus:

> Dangerous memories fund a community sense of dignity. They inspire and empower those who challenge oppression. Dangerous memories are a people's history of resistance and struggle, of dignity and transcendence in the face of oppression. Dangerous memories are stories of defeat and victory, of casting off of the past in terms of a present of joy, hope and struggle. Memories of oppression and defeat become dangerous when they are used as a foundation for a critique of existing institutions and ideologies that blur the recognition and denunciation of injustice.

I have seen a marked shift from the first 'Disability, Religion and Health' conference held in Brisbane 1996. The dominant story of that conference was about the fascination with research that located religious experience and spirituality within the range of the therapeutic needs of ill and disabled people. This was supposedly a new insight and yet understood by all of us who experience impairment, that the life of the spirit is essential to our self-understanding. The submerged story that was told amongst those of us who had brought with us critiques of the three main institutions and ideologies and these are important. We were talking about a critique of health and human services as processes that strip people of disability and their families of power. We came with a critique of Christian theology as complicit in this process. And we also came with a critique of Christian churches (there was no other faith voiced there) as preaching embrace and practising exclusion. We also brought with us the beginnings of our theological explorations that might lead us from being lamenting outsiders to brothers and sisters in all parts of the church and social life. Looking back I can also see that a great little network was emerging there.

The next conference 'Beyond the Ramp', held in Adelaide in 1998, turned that dominant submerged story around. The dominant story told in that conference was by people with impairments, their families, and those who consider themselves in solidarity with us. The change was shaped by an agenda, from the research activities of academics as in Brisbane, to a reading of the major categories of issues confronting people with disabilities, and reflected on by people with an interest in spirituality. This was the first time there had ever been a movement style conference where spirituality was the focus, according to my knowledge anyway. In this way, spirituality is not about a therapeutic need and it becomes a source of energy, strength, wisdom and history that fuels a wider struggle around indecency and exclusion. In this way stories start to become dangerous memories and are no longer the case notes in a therapist's file. It was here that I began to feel that I was part of a distinctive tendency within the wider disability movement. I deliberately do not call it the disability rights movement. Our conversations show that our concerns were much more profound than simply pursuing a rights agenda in a liberal democracy. It was also here that I saw the emerging vigour of our little trans-Tasman network.

'Exclusion and Embrace', held in Melbourne 2001, built on this emerging tradition of placing (and these are Andy Calder's words) "personal accounts at the cornerstone of the conference's content". Here there were also real conversations on the interfaith expressions of spirituality. Sadly, I missed that conference so I can not reflect on the feeling of it but as I read the proceedings I see a tension between lived experience, linked with reflections in anthropology, theology, ecclesiology, and an expanding social agenda around desegregation, antidiscrimination, service policies and reconciliation. Dangerous memories are active here too, critiquing abuse and injustice in all their guises, bringing forth tales of change, offering empowerment and direction. Oddly there seems little attention paid to cure or salvation, the perennial concerns of the health system and the church. Clearly it is here too that all those gathered were able to see that the next step is to hold a conference in Aotearoa.

So here in Wellington, going through the whirlwind, the tireless commitment of Vicki Terrell whom I first met in 1996 bears fruit. It was here that Vicki first said she wanted to do this. In a way it does not surprise me at all about Vicki and her comrades, that a wonderful team has grown here and brought us to this thoughtful, eventful conference that creates yet another solid foundation for the future of our movement. Our collective desire is to keep ourselves associated with the passionate and spiritual realms of life, whilst being focused on the reform agendas in all areas of our lives.

Thank you to all of you who have created this place and this space where our voices and our visions have primacy, and to those who stepped forth and accepted this invitation to communicate your ideas, your reflections and at times your anguish and your hopes from your lives and the lives of those who love and touch you. Hospitality offered is a wonderful thing, hospitality accepted is the living out of dimensions of our beloved community and in all of this we can rejoice. But it also must be a hospitality that can not leave out the voices of those who are silenced, because it only identifies the institutions and ideologies that shape the lives of some of us. The question remains as to who is still outside our gates, not just here but in every gathering we aim to create in the name of caritas. So yes, let rejoicing in the vigour and compassion of our little part of this movement be part of our feast here. But let us also finish on the question of whose story remains outside our conversations. Who else do we need to bring in, to hear their weeping and to receive their wisdom? Let us draw them to us and let us be changed in our dialog with them. There are some who through their impairment or their place within the service system will never make it here, will never be able to accept our offer to listen and to talk. But let those people loom large in all our deliberations.

Our gathering here has another dimension, many, many dimensions, but there is one more. I have talked about the place of dangerous memories and the power of hospitality. That just can't stop here. If we aim to empower more people to join our efforts to live together in justice, solidarity and respectfulness, we must strive to find ways that link our values with our action and in that process to build our movement. So in conclusion I offer you these pointers from the great activist and writer, Alice Walker:

"Freedom and flourishing will win out if we humans perform our earthy and earthly function in what might be summarised in the following imperatives:

1. Learn to survive life's sufferings with spunk and sass
2. Protect ourselves and others from disabling suffering, prevent it where possible, and walk with sufferers when we are powerless to prevent or protect
3. Live lovingly in every moment and revel in earthly delights without abuse or excess
4. Work to transform our environments, shaping our households, relocating our breathing space, simplifying our lifestyles, slowing our pace, adorning our surroundings with beauty, reconfiguring our relationships, always opting for greater health
5. Recognise, eschew, resist the dysfunctional
6. Wait things through until wholeness and integrity prevail
7. Look upon all that lives, all that is, with worshipful gaze

Surely these can be lights to guide us collectively and as individuals as we look out.

Issues to challenge, address and change

Huhana Hickey (New Zealand)

As we stood like the totara tree
Gently swaying in the breeze
I hear the whispers in the air
And I cry

I see my tipuna everywhere
Even next to me
Strong and noble, proud and free and yet still I cry
Strong and noble, proud and free and yet still I cry

There is still so much for us to challenge, address and change. We are proof here today that we are spiritual and all live the essence of that spirit, the Mauri. Who we are is for us to define and celebrate. Our spiritual diversity and our diverse identities are to also be celebrated. So I propose for us to visualise one of my siblings, the totara tree, as we develop and grow together to claim our place within the community, and embrace, awhi and support others into this place of diverse spiritual celebration. That's what I see the future as, what is coming from the conference and what we have seen within the conference.

We have something we can take into our future and if it began in Oz and us Kiwis, we are going to be taking it to another level, as we don't like being beaten by them, maybe we have an opportunity to take it out there globally. Now people with disabilities have so many diverse identities. We don't have to come out with one faith. We can come out with all and show the world that people do not have to fight over religion and difference. Maori and Pakeha, all of us, have not fought in a war since the 1880s against each other. We still have our issues and our battles, but we show it through peace. We are dealing with our issues through peace.

Maybe one way we can show the inner quality of those of us with disabilities, and celebrate our diversity and our spirituality, is we can show the world that it can be done in a very different way and that it does not matter where we celebrate, what we celebrate in many ways, but the fact that we do celebrate.

Lets celebrate the future together.

Striking Sparks: Where to from here?

Richard Miller (Australia)

My name is Richard Miller and let me tell you two things about me. The first is that I live on a small farm on the Adelaide Hills in South Australia, and the second thing I want to tell you is that I am a mechanic. Therefore it should not come as any surprise that I tell you that one day, in the middle of summer a few years ago, I was constructing a fence alongside a creek. My son-in-law was helping and we were cutting through a piece of steel pipe that we wanted for that fence. As a mechanic I have lots of lovely power tools and we were using an angle grinder on the steel. I turned around at one stage and to my absolute horror there was the beginnings of a bush fire. The sparks from the angle grinder had caught in some grass which had set fire to some other clumps. It was the middle of summer, in the driest state in the driest continent in the world and the bush fire just seemed to be growing in front of our eyes. It seemed to be a disaster that was about to take place. Fortunately my son-in-law and I were able to put that out. And I thought, “Well now we have a nice dead black area we can grind some more steel without it being a problem”. This time my son-in-law was grinding away at a bit of steel and when I looked, I noticed his shirt was on fire. The sparks from the grinder had caught in his shirt and were starting to singe his beard and hair, so that for the first time I was able to embrace my son-in-law and really beat him out.

Why I tell you those to stories is that we have spent some time thinking about seeds, about trees, and about life and movement. But I also want to sow another idea and that is about sparks. Because sparks have life, just for a short period but they give life to other things, particularly if you are working in a dry area and manage to start a bush fire.

We have heard a lot about the seeds that have been planted but also the sparks that have flown off from different ideas, from the seeds that have been sown, from this movement that began in Australia. When Vicki Terrell at the Melbourne conference said that she wanted Wellington to hold the next, I thought that would be great but, “Gee, could that happen?”. So I said to Vicki “Go for it!” and look what happened. The spark that was Vicki began to grow and we have celebrated some great things.

But where to from here? I want to spend a few minutes interviewing Terri Feeley.
Terri is from Sydney in NSW and is the ‘Vicki Terrell’ of the next conference.
RM: Terri, the conference in Sydney, is it all organised?
TF: Of course not, otherwise we would be having it now!
RM: So there is still lots of work to do?
TF: Lots of work, but we are certainly well on our way.
RM: Terri, are there any ideas that you can share with us that might start to excite us about where the conference in 2004 is likely to go?
TF: One of the things we were talking about is where to from here. And one of the challenges that Vicki talked about was the engagement of spirituality and disability within other faith contexts. Our whole aim is for it to have interfaith participation and

exchange, sharing of experiences and ideas, challenging and looking at the processes, that our movement moves into an interfaith dimension rather than just a Christian dimension.
RM: Do you think we have things to teach other faiths or do you think they have things to teach us?
TF: I think most definitely that it is a process of exchange. It is about us learning from people of other faiths as well as them learning from us, and for us each to challenge each other
RM: Are there things that other faiths perhaps hold that are in common with the more dominant Christian faith about human beings and disability?
TF: I think there is no doubt that there is a common thread through all faiths and that is a recognition of the value and uniqueness of each person who is part of creation, who is the source of life in this world. Whether the faith talks about that as created by God or whether they talk about life as springing from Mother Earth, the underlying commonality is certainly about the value of every human being.
RM: So there are things we might be able to hear again, say from the Buddhist faith?
TF: Certainly.
RM: One of the things we have heard about here is holding in balance the opportunity to think about the real issues that challenge the disability movement but also being able to listen and share people's stories and so on. Will that be one of the features at Sydney 2004?
TF: Absolutely. We do have a fascinating idea that we are playing with at the moment. That is the idea of having a hypothetical and on our panel we would have a person from each of the different faiths and an opportunity for each to have some fun throwing around some different ideas. Obviously there would be the opportunity for some real depth of reflection as we listen and learn from each other. There are lots of challenges ahead.
RM: The obvious encouragement is for us all to be there in 2004.

We have been challenged also this morning to hear about the work of EDAN and to hear about other movements, in particular that which has arisen in SE Asia, which has made connections with Africa and other places. We have something of a vision that after 2004 we will make a connection between this Australasian area and the Pacific and Asian movement so that together we might be able to meet and celebrate and resource each other. I want to strike that spark and sow that seed so that we can make future connections. This movement has tremendous potential and strength in a whole lot of ways, both individually for people and as we meet together, as we share ideas, as we move forwards, as we engage with people who are gate-keepers and challenge them to think and to look in new ways.

Biographies of Sunday morning contributors

(in order of presentation)

Vicki Terrell

Vicki is the Conference Co-ordinator. She attended all three Australian conferences and has worked on “Holy/Wholly Accessible: Disability Policy of the Anglican Diocese of Wellington”. She has been self employed for six years and starts a position as a field worker for NZCCS in Wellington later this month. Vicki is a follower of Christ in the Anglican tradition and is involved in the Northland Parish. Vicki was born into the Anglican church and into the disability community and finds that the communities do not understand each other. She hopes that through the work of this conference that there might be more understanding between them and that there may be a dialogue around spirituality in the disability community.

Ye Ja Lee

Ye Ja is a disabled woman who at present lives in Seoul Korea. She is the acting Coordinator for the Pacific region and is representing EDAN. Ye Ja Lee was the World Council of Churches Disability Work Consultant based in Geneva between 1994 and 1996. She also works for the Korean Differently Abled Women's United group.

Lorna Hallahan

Lorna is the Coordinator of the Spirituality and Disability project in the Centre for Theology, Science and Culture, Flinders University and the Adelaide College of Divinity. Lorna and Trevor Whitney work together in Beyond the Ramp: The Work of Embrace, a project aimed at enhancing the participation of people with impairments in congregational life.

Huhana Hickey

Huhana is the National Maori Advisor for DPA (NZ) Inc and President of Workbridge (NZ) Ltd. She has been published twice internationally and once nationally. Huhana is currently writing her second book called ‘*Whanau Whanau’* which explores the issues around spirituality, identity and disability for Maori with disabilities who were adopted illegally. Tikanga Maori is a strong focus in her life and something she is learning, experiencing and embracing.

Rev Richard Miller

Richard is the General Manager, Community Services Commission, South Australia Synod of the Uniting Church in Australia. He was the chairperson of the Disability and Spirituality Conference in Adelaide in 1998 and has been actively involved in the spirituality and disability movement.

In Conclusion……

From a visitor (Andy Calder)

From being at the opening ceremony and standing in this place, I now find myself standing here again to say farewell. For me this conference has been an amazing time. I almost hesitate to call it a conference. I have heard it described in so many ways from a convention to friendships, being renewed and refreshed, and I look forward to returning to my family. I have a deep sense of sadness about leaving you and I have, for myself, developed a sense that this is a clan. So as I go back to my family I feel I am leaving my extended clan. It has been a wonderful time to be here from Australia and I look forward to seeing as many as possible over in Sydney. Again I congratulate the planning committee, all the hard work and vision and thinking and long hours that have gone into putting this together. I would like to finish my part with a blessing written for the Australian scene and based on the knowledge of Australia being a vast country with an interior surrounded by water. It is written by Julie Perrin (who is really my wife)

For you deep stillness of the silent inland

For you deep blue of the desert skies

For you flame red of the rocks and stone

For you sweet water from hidden springs

From the edges seek the heartlands

And when you are burned by the journey

May the cool winds of the hovering Spirit

Sooth and replenish you in the name of Christ

Thank you

From the Tangata Whenua (Leo Te Kira)

As at the end of every hui we wish you well on your journey back. We thank you for your sharing and I wish you well as you go back to your mainstream society with so many impediments.

They have so many challenges to face in their attitudes, but sometimes they are really inspiring, those out there in mainstream. Some of their thoughts are so handicapped but they have moments of inspiration as they think their main stream attitudes. And I think one day they will make a brilliant Sunday night movie about how they have overcome their great challenges and their crippled attitudes. So I wish you all well as you go back to your crippled and disabled society. May God go with you and I am sure that some time in the near future, with all their impediments they will be an inspiration to us all as they beat the odds with their mainstream ideas. Let us give mainstream attitudes a clap as they have come on so far in the last few years.

God who challenges us,
God who embraces us.
We thank you that we have known you sitting beside us
as we have gathered together.
We thank you for the challenge we have known amongst each other.
We thank you for the discomfort and
the times of disagreement between each other,
when you have taken us beyond our understanding and our comfort zones.
But beyond this, Oh Gracious One, we thank you for the way
you have brought us together,
for the commonality we have known between each other,
for the warmth and sharing that we have known,
for the insights and revelation.
As we move out to our communities be with us, give us a safe journey home.
Keep us strong in the bonds and ideas we have shared together with each other.
Help us in our various settings and our communities
to live our lives as fully as you have decided we should live.
Gracious one, be also with our community as it struggles to understand,
as it struggles to find peace,
with the gift we have to give everyone.

No reira, e nga manuhiri no nga hau e wha, hoki pai atu ki o koutou kainga. Ma te Atua e tiaki i a tatou katoa - Tena Koutou, Tena Koutou, Tena Koutou Katoa!