Towards Liberation: Pastoral Relationship with People with Intellectual Disabilities Living in Institutions

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Abstract

From a pastoral narrative perspective this extended reflection seeks to describe and understand the lives of people with intellectual disability who live in institutions for people with disability in Adelaide, South Australia. Through the spiral application of a hermeneutical methodology, based upon liberation theology principles, a pastoral model of relationship is sought that offers a measure of liberation to those who experience oppression as an outcome of living in this context.

A model of pastoral relationship will be developed through careful analysis and understanding of a comprehensive range of typological narratives that authentically represent the lived experience common to many who live in this environment.

A key claim undergirding this extended reflection is that those who live in these institutions have their lives principally shaped by a medical model of relationship. This model objectifiably regards those for whom it applies as needful, dependent, medical identities. These people live in a historically and contemporaneously-constructed context that has silenced and continues to silence their identity through this discourse. Pastorally, such a relationship is oppressive because it denies these people their right to be regarded as whole human beings created in the image of God. This oppression is metaphorically expressed by reference to the image of Michelangelo's six unfinished statues referred to as '*The Slaves*.' Here, each statue depicts a human being who, because of his unfinished, 'marbled' state, appears to be utterly contained within their lived context.

Pastorally, the careful articulation of the institutionally-shaped lives of these people affords a measure of vital identity. This is achieved through the thorough and careful narrative detailing of their daily lives, patterns of relationship with staff and others who live in this context, and their relationship with this pastoral carer who is their chaplain.

An alternative model of care is proffered that seeks to give authentic expression to a pastoral, theological mode of liberating relationship. Thus, narrative, theological understanding has been applied to a critique and adaptation of philosopher Martin Buber's concept of 'I and Thou,' that is, the nature of human existence. The model thus conceived is referred to as 'Immanent Thou-ness.'

This model honours the other person with an intellectual disability as the Thou, signifying the other as fully created in the image of God. Such regard is only possible through pastoral commitment to coming near to this person, both theologically and socio-politically. The pastoral carer is deliberately choosing to be set apart from staff who maintain a medically-transcribed distance from those for whom they care.

However, the carer's commitment to coming near is only realized through an ongoing confessing attitude that casts aside professional hubris that prevents them seeing themselves and the other person as both flawed yet completely loved by God. This move from objectified to interpersonal, grace-filled regard defines the pastoral relationship in terms of mutuality, offering a measure of liberation to the other person.

Understanding of those for whom the carer bears responsibility is never fully realized. Their lives can never be completely understood. Therefore, updated narrative-based, theological understanding and modelling are always required. Pastoral commitment to the person with intellectual disability living in the institutional context must be ongoing, as long as there are new stories to be told.

Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made to the text.[1]

J. Trevor R. Whitney

Date

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[1] There has been one peer-reviewed publication arising directly from this thesis, namely, Whitney, Trevor. "Intellectual Disability and Holy Communion: The Peace That Passes Understanding." *Journal of Religion, Disability & Health* 13, no. 3-4 (2009): 247-59. This publication is attached at the end of the thesis.

Acknowledgements

This extended reflection has been made possible through the invaluable contribution of many. Firstly, I owe deep gratitude to those people with intellectual disability living in institutions with whom I engage in pastoral relationship. These people have graciously accepted me into their lives, honouring me with their stories. In doing so they have enabled me to construct collective narratives of which a number have found their way into this thesis. I truly hope that my pastoral analysis and understanding of these stories, too easily hidden from public consideration over generations, afford faithful description and insight.

I also wish to thank my principal supervisor, Dr Lorna Hallahan, who always offered wise and generous critique, encouraging me to find my true pastoral voice, and to conceive of ideas and discourses well beyond initial conceptualisations. Your affirming critical engagement enabled me to stay the course of a both stimulating yet exhausting journey. I hope the conclusions to this reflection bear faithful testimony to your scholarly and faith-based promptings. I also wish to offer gratitude to my secondary supervisor, Dr Neil Pembroke, whose detailed and constructive levels of analysis necessarily challenged me to develop thoughtful and well-considered argument. You stimulated me to develop a thesis built upon a well-conceived and applied academic framework.

I also wish to express thanks to Rev. Richard Miller. Your belief that I could make a worthy pastoral contribution as a disability chaplain, and your sustaining support, encouraged me in my vocation and assisted me in becoming an enquiring student of disability.

I am also grateful for the wise counsel and collegial support I received from my fellow chaplains, Rev. Noel Bekker, Rev. Anne Hewitt and Rev. Bruce Stocks. Your commitment to the narratives that I presented to you for pastoral critique added crucial rigor to the hermeneutics of analysis and understanding. You saw things that I was too close to see.

And finally, but of utmost importance, I express deep gratitude to my wife and loving companion, Lyn. Despite the intrusion of academic demands into the domestic context your constant support and care proved utterly reassuring.

You graciously gave me the space in which to work well, and your trust enabled me through to the completion of the last sentence. I owe you a considerable debt.

To all other friends, colleagues and scholars not named but who offered generous counsel, wise critique and sustaining encouragement, I am very thankful.

This extended reflection has been constructed on the back of the named and nameless of this page. I hope this work is seen as a fitting tribute to their resourcefulness and support.

Viewer's Guide

The titles attributed to each of the slave figures to be viewed at the beginning of chapters 2 to 7 are not determinative of their identity. They represent the names given to them by the author of the website from which they are sourced (i.e. http://entertainment.howstuffworks.com/arts/artwork/michelangelo-sculptures.htm). As is noted and exemplified in chapter 2 different authors afford different names to the same image.

For the purpose of this extended reflection I am suggesting that each figure be regarded by the viewer as oppressed. However, beyond this fundamental perspective, the onlooker is invited to view the figure before them from their own standpoint. Questions concerning the imagined circumstances of the enslavement, and the understood relationship between onlooker and oppressed figure, are for personal interpretation.

I am also proposing that the narratives detailed in chapter 6 be viewed as a fabric that depicts institutional life, and the lives of those who live in that environment. From this perspective, the strong threads of the fabric, that is, those threads that most determinatively and commonly describe and facilitate understanding of the institution and its people, will be discerned through careful narrative reflection.

PROLOGUE

I work as a paid church chaplain within this institution, and have been offering pastoral care here, and conducting regular services of Holy Communion in the institution's chapel, since March 2001.

This is an institution that presently accommodates and serves people who live with a variety of forms of disability, both physical and/or intellectual. Those with an intellectual disability may be classified as living with one of various forms of impairment, such as Huntington's Chorea, Motor Neurone Disease, Cerebral Palsy, Multiple Sclerosis or perhaps some form of Acquired Brain Injury. The age of the residents varies from the 20s to the 80s.

Some people have been here for just a few months, whilst a handful have lived here for over 40 years, through the era when this institution was a bustling community of many hundreds. But times and disability service philosophies have changed. In recent years a number of people have moved into supported community accommodation.

This is no longer a bustling community. It is a fragile community, in transition. It is an institution with empty spaces and uncertain futures. As of January 2012 about 100 residents remain. Some are waiting their turn to leave. Some want to stay here till they die.

On this day I have come to visit Molly. She is a gentle woman, in her late 60s, with a significant level of intellectual impairment. She has lived in this place for about 25 years. I look for her in her room where she can often be found lying peacefully in bed with soft music playing in the background. However, today she is not there which means that she should be in the common dining area. Why do I sound confident as to her whereabouts? Because in all the time I have been regularly coming to this institution, and in the 50 or so visits I have had with Molly over that time, I have always found her in one place or the other, save for those times when she is being bathed or toileted.

I walk past the nurses' station where a couple of nurses are engaged in idle chatter and a social worker has her head buried in case notes. One of the younger male individuals who lives here, Tim, can be seen sitting in his wheelchair next to the station looking down the long hospital-like, cream-painted *corridor, taking account of all the comings and goings of staff and colleagues on this floor.*

I enter the shared dining area, a utilitarian space about 10 metres square, with four dining tables in the middle. Once again, the walls are painted in that all-purpose and ubiquitous cream. There are windows on two sides and a television at one end with morning programs droning on to no one in particular.

Alongside the television is a pin-up board of past and present residents. Some of the faces I recognise as those who have moved to community-supported accommodation, and a few are deceased. I gaze for a moment at these photos. Mixed memories and feelings are aroused. My heart is warmed at the remembrance of relationships that have enriched me so much, people who lived here and who trusted me with their life stories, who shared with me their living and dying, and countless feelings and experiences in between. I am reminded of those who, in the face of isolation from community, and endless institutional regimentation and tedium, have shown remarkable resilience over all the years of living in this their adopted home. With admirable pragmatic spirit they have made this place their home in the face of no obvious alternative.

And I am reminded of all those who never made it onto this or any other pin-up board. Some who raged, others who easily acquiesced, and those who quietly lived and died, lying mostly in bed, or sitting in a corner.

There are three people sitting in this room today. One is sitting opposite the window rhythmically turning the pages of a magazine without looking at the contents. I should know her name but it escapes me. She's one of those people who seem to always occupy the same space in the dining room. She doesn't complain or interact. She draws little attention to herself. She just seems to blend into the environment. I feel a pang of guilt that she is the type of person I can find myself just passing by.

Another person, an older man, is calling out persistently for a nurse. From a distance, a voice replies, "Hang on Vic, I'm doing something." I call out, "What do you want, mate?" but he just keeps calling out.

And adjacent to the far window is Molly, in a recliner wheelchair, legs covered with a knitted granny blanket. She is gazing out the window to the hills beyond. Her expression, like the hills on this cool, summer's day, is distant, and melancholic.

I introduce myself to her once again and sit beside her. I look into her face searching for thoughts she may be expressing with her eyes, for words that may be close to her lips, but she appears to be in another world, a world that she alone inhabits. Whilst she does sometimes utter a few isolated words, as well as having an occasional charming smile or, in contrast, a look of deep sorrow, few of her communications appear to be responses to anything I may say or do. To me they seem to come from private spaces deeply embedded within her being. She may utter the occasional phrase – 'pretty birdy', 'good girl' – and I'm left wondering where they come from. I 'play' with these phrases so as to evoke some form of response, but her replies, if indeed that is what they are, usually lack coherence to my ear.

Amidst her growing frailty and senilit, she seems to barely acknowledge my presence, and I'm sure she has no idea who I am. But she seems content to have me sit beside her.

She has a kindly-looking face, a few wrinkles around the eyes but seemingly less than many people her age. Her dark, greying hair is neatly combed over in a simple, rather utilitarian manner. She wears clothes that seem apt for a woman of her age – neat, pastel blouses and comfortable slacks. To me, it seems that she bears something of the appearance of a soulful Granny but, in fact, there is no one in her life who bears that relation to her. I'm only aware of one surviving relative, a younger sister, who visits on special occasions.

I continue to sit, mostly in silence, looking for changes to her gaze. She has a teddy bear cradled between her torso and the arm of her chair. I know quite a few elderly people here who have teddy bears and/or dolls adorning their room. Perhaps it's a companionship thing, the cat or dog you have when the place you live in doesn't allow pets. I suppose that's another Occupational, Health and Safety issue.

I reach out and stroke her arm. Her skin is soft and pale, beginning to lose a little of its elasticity. I say a few words about the girl she sometimes vocalises, who sometimes brings a warm, whimsical smile to her face. And I wonder, "What girl? What was she like? Was she real, a favourite doll, or …?" The sounds I hear from Molly are unintelligible to my ear and probably they're not answers to my questions at all. But her smile continues. For the moment, she's in a happy place oblivious to my incomprehension.

I look through the dining room doors. The social worker has been replaced at the station by a doctor who has his own case notes to ponder. He converses with an attentive nurse. Another staff member enters the dining room and gently assists Vic with his persistent request. There's a volunteer accompanying a person back to the dining room after a relaxation session. I think I can hear the tea lady not far away bringing the morning cups of tea and coffee to people who often welcome her usually cheerful mid-morning intervention.

Another ward assistant enters the dining area:

"OK, Mol, time for your bath ... Oh, sorry mate. Didn't know Mol had company. I'll do Nance and be back in twenty if you like."

"Yeah, thanks. That'd be good."

A few moments of silence pass.

"It's all systems go around here, isn't it, Mol?"

But Molly remains oblivious to all the fuss. Whether it's a learnt reaction to living amidst the routine and regimentation of this place, or the result of her disability, a bit of both or something else, for the most part Molly simply remains in her world. And I wonder ... Is it a peaceful or noisy world? Is it a happy or sad world? Is it filled with memories, good or bad, colourful or dark? Is it a place of dreams or resignation? Is it a place that sustains and enriches her, or a place she's too afraid to leave? I don't know, and perhaps I don't need to know.

As I continue to stroke her arm, I notice that the whimsical smile has been replaced by a more pensive expression. But she remains far away.

My thoughts turn to all the staff who relate to Molly through any given day, to all the tasks they do to sustain her being. There are the doctors and nurses who attentively monitor changes to her medical condition. There's the social worker who attends to concerns raised by her sister. There are the physios who come twice weekly to take her for an assisted walk up and down the corridor. There's the dietician who monitors her food intake and assesses her swallowing capability. And there's also the occupational therapist who checks the suitability of her chair and other assistive equipment according to her declining health condition. There are also the ward assistants who bathe, toilet and feed her. There's the tea lady who knows of Molly's unrequited sweet tooth. There's the volunteer who knows her favourite music, and there are various *others who intervene to help at her points of need, of which she has a growing list.*

Some staff have been working here for many years; many are relatively new agency staff, still finding their feet in the 'disability industry.' Some of these people seem to display a genuine commitment to their tasks, whilst there are others for whom it seems to be just a job, and who may not stay in this place for too long. Working daily with people with disabilities can prove too challenging or unrewarding for some.

It is principally a medicalised environment where paid professionals sustain dependent people with disabilities at their point of need with their pertinent expertise, amidst this highly-regulated institutional environment. However, there is something oppressive about a lived context where your most regular relationships are with medical professionals and your accommodation resembles a ubiquitously-coloured hospital ward. What of familiar faces and homely contexts shaped around your routine and no one else's? What of the domestic symbols and routines that enrich and sustain?

And amidst all this, as another paid, yet pastoral, professional, I ask myself, 'What am I actually doing here with Molly?' 'What can I do?' 'What purpose am I achieving in this predominantly health care environment?' 'How might I offer some sense of liberation to Molly in an environment which I judge as having the capacity to regulate and contain, to suppress, indeed oppress, her human and God-given identity?

I cannot benignly and uncritically sit beside Molly content in the knowledge I can now tick off my 51st visit to her side, as if to do so is to fulfil all righteousness. My pastoral calling impels me to strive to draw near to her with due integrity, regard and love.