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 his 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 senility, 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.

CHAPTER ONE

INTRODUCTION

> There is something special and unique about being a member of the human species, quite apart from the particular skills and attributes that humans use to actualize and realize the gift of life they've been given. Human beings are persons by virtue of the fact that they are human beings, particular objects of God's love and salvific intentions.
>
> ... Our personhood is not defined by what we can or cannot do but by whose we are and where we come from. Creationally we are seen as 'very good.' All are members of the human family.[2]

> The stigmatized individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His (sic) deepest feelings about what he is may be his sense of being a 'normal person,' a human being like anyone else, a person, therefore, who deserves a fair chance and a fair break.[3]

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[2] Wannenwetsch, Bernd. "Angels with Clipped Wings: The Disabled as Key to the Recognition of Personhood." In *Theology, Disability and the New Genetics: Why Science Needs the Church*, edited by John Swinton and Brian Brock, 182-200. (London and New York: T & T Clark, 2007), 11-12.

[3] Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. (Englewood Cliffs: Prentice-Hall, Inc., 1963), 7.

1.1 Background to the Extended Reflection[4]

In 2001 I was appointed by the Uniting Church in Australia, Synod of South Australia, as Disabilities Ministry Chaplain. The appointment included resourcing, teaching, and ecumenical responsibilities designed to raise awareness of people living with a disability, and their needs, to the church. It also sought to promote, for those living with a disability who are so inclined, the right to full inclusion in the life of the church.

Complementing this largely church-based ministry was the role of part-time chaplain at two Adelaide institutions that cater for adults who live with a wide range of intellectual and physical disabilities. I was appointed to spend three days per week as the first chaplain to a large institution for people with intellectual disability in Adelaide's southern suburbs, with a principal facility that incorporates a wide range of services distributed across the southern suburbs. This institution caters for approximately 1100 residents and people with intellectual disabilities, supported by approximately 900 staff. Its services include campus and community accommodation, respite, home support, retirement services, leisure options and vocational opportunities.

Apart from the principal, pastoral role with the people who are accommodated there, there are various other chaplaincy responsibilities. They include the conducting of worship services, including services of song and thanksgiving; funerals; remembrance services; and commitment ceremonies. I also conduct staff training in grief and loss, and provide support for the ministry of church volunteers, as well as participating on palliative care and ethics committees. The chaplaincy role is ecumenical in religious orientation.

I was also appointed to spend a half-day per week at an institution in Adelaide's eastern suburbs. Services offered at this facility include campus and community accommodation, home support and respite services. Its campus presently accommodates approximately 100 people with intellectual and/or

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[4] The reason for referring to this thesis as an *extended reflection* is because this fundamental methodological element concerns qualitative reflection upon narrative over an ongoing period of time, for the purpose of authentic narrative analysis and understanding. This methodological concept will be further detailed in this chapter under *1.5 Introduction to the Extended Reflection Process*, and in chapter 5 where the hermeneutical process/spiral will be described and illustrated.

physical disability, with this number in gradual decline as many of those living there are in a state of transitioning to community accommodation.

The denominational role involves pastoral care to adherents and members of the Uniting Church,[5] as well as a monthly Sunday ecumenical service of Holy Communion conducted at the chapel located on the institution's grounds.

It was during my first few years at these institutions that I began to develop an understanding of the nature and working life of a secular institution designed to cater for the needs of people living with disabilities. I also regularly reflected on how best to engage in pastoral relationship with the accommodated people given the unique, atypical environment in which they lived.

The pressing issue that emerged from this reflection concerned how someone committed to pastoral care in this environment, either professional or volunteer, could engage in pastoral relationships that would be complementary and alternative to the dominant medical discourse. How could such a relationship be defined in pastorally liberating terms?[6] Whilst a concept such as 'liberating' lacked clarity and specificity in my initial thinking, it did become patently evident that some new and carefully considered mode of care, liberating in nature, specific to the socio-political context in question, needed to be developed. It needed to address the perceived capacity of these institutions to oppress those for whom they bore responsibility.[7]

It became apparent that, as long as people with disability lived in these facilities, pastoral carers ought to implement a model of care that more adequately addressed the professional and socio-political restraints imposed on these people.

I was most ably assisted to reflect on this pressing issue through the support and wisdom of giving mentors. Through counsel, it became apparent that the considered thinking and reflection appropriate to doctoral level study was a most appropriate vehicle for addressing my pastoral concern.

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[5] In reality, pastoral care to the adherents and members of one denomination has proven difficult, if not somewhat pointless, given that for many residents of this institution, issues of denominational allegiance appear to wane in significance once a part of this living environment.

[6] Issues concerning the definition and understanding of medical discourse will be detailed in ensuing chapters.

[7] The terms *oppression* and *liberation* will be defined in this chapter under 1.6.4 Liberation Theology: Liberation/Oppression.

In beginning the process of more academic reflection on this pastoral issue, it soon became patently clear that I needed to make a declaration. No matter the shape of pastoral care that could emerge from this process of extended reflection, it could only ever be a partial response to the ideal need for all people to freely grow and be sustained in healthy, human, God-given relationships. Such relationships ought not occupy the social margins, but be in the midst of a fully supportive and inclusive social context.

Nonetheless, while institutional living in various communal forms remains an option for people living with intellectual disabilities, a meaningful model of pastoral relationship for such people ought to be seriously considered.

1.2 Focus of the Extended Reflection

The focus of this extended reflection concerns the development of a liberating, pastoral relationship with people with an intellectual disability who live in institutional accommodation. Thus, it analyses the nature of the relationship between these people and those who seek to engage in care with them. The analysis will reflect upon this relationship from two perspectives.

Firstly, the extended reflection will consider the nature of this relationship. Through careful reflection upon significant institutional themes, as well as analysis of contemporary narratives, as expressed in congruence with the medical model of disability,[8] the context for this institutional relationship will be realized.

Secondly, a model of a mutually-enriching and liberating pastoral relationship that can be developed within the institutional context will be proposed. This will be principally undergirded by a model of disability which integrates a social understanding of disability,[9] and the embodied perspective, insofar as this latter perspective describes what it means to bodily live with an intellectual impairment.

This pastoral model will be derived from pastoral, theological reflection upon the narratives of those who live with intellectual disability in an institutional

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[8] The medical model of disability will be generically defined later in this chapter at 1.6.1 Disability/Disablism and will be more fully discussed and defined in chapter 2.

[9] The social model of disability will be generically defined later in this chapter at 1.6.1 Disability/ Disablism and will be more fully discussed and defined in chapter 2.

context. These narratives will be of an institutional, collective type, rather than literal, individual stories. They will strive to give faithful expression to the lives of those in question. They will detail the nature of institutional life and its effect upon the individuals and communities of people for whom the institution bears responsibility. In doing so, expression will be given to an alternative form of pastoral care that seeks to foster a mutually-caring, liberating relationship.

The need for the articulation of such a model of pastoral care will be based on the fundamental need of all human beings to be affirmed for their sense of worth as those created in “the likeness of God” (Genesis 1:26).[10]

1.3 The Extended Reflection Question

With these issues in mind, the fundamental extended reflection question is this:

Given the oppressive constraints imposed upon people with an intellectual disability who live in institutional accommodation, what is the pastoral care model that most authentically and validly affords a mutually-enriching, liberating form of pastoral relationship between carer and accommodated individual, and which most faithfully reflects the worth invested in all, created as all are in the image of God?

1.4 Justification for Extended Reflection

There are two main reasons for pursuing this extended reflection question. Both are concerned with marginalising narratives constructed by the able-bodied about people with intellectual disabilities. These are narratives concerned with the development of social norms that serve to exclude these people from full inclusion and participation in mainstream society. By identifying these narratives and then detailing an appropriate pastoral response, a necessary measure of liberation is offered to a people who, both historically and contemporaneously, have been, and remain, oppressed.

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[10] National Council of the Churches of Christ in the United States of America. *The Holy Bible – New Revised Standard Version*, Old Testament, (Nashville: Thomas Nelson Publishers, 1989), 1.

1.4.1 Narrative of Silence and Lost Identity

Whilst there is a significant body of literature that addresses issues concerned with disability and institutions where people living with intellectual disability are accommodated, there is a dearth of literature and narrative addressing a pastoral perspective on such matters.

Historic and recent literature points to a silence in institutional, disability narrative, a silence generated by dominant socio-political discourses that describe attitudinal and behavioural norms that exclude ‘the mad’, or those otherwise described, from participation in mainstream society.

From a feminist perspective Brita Gill-Austern refers to this silence, or loss of voice, as “the loss of the authentic I”.[11] Similarly, social historian Catherine Coleborne refers to the collective and individual silencing of the voice of ‘the mad’ prior to the twentieth century as shutting down “the possibility of our engagement with their words, their agency, and with them”.[12]

From an historical, clinical perspective, pastoral theologian Alastair Campbell claims that it is in the glimpsing of the historical and social autobiography of people with disability, including those with an intellectual disability, that we perceive a discourse, otherwise mute, that extends far beyond the medicalised view that is taught to health care professionals, a discourse in need of articulation. He asserts,

> It is no wonder that when we think about the lives of the disabled people with whom we come in contact, we confront a yawning silence – we do not really know anything about the things that the theory of individual health writes large – horizons, power, ideals, and fantasies of the soul. [13]

Disability theologian Stanley Hauerwas describes the institutionally-sourced silence that can only be broken by the first-hand observations of family and friends. As he states, “[t]hose stories are necessary to break the silence that

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[11] Gill-Austern, Brita. "Pedagogy under the Influence of Feminism and Womanism." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie Miller-McLemore and Brita Gill-Austern, 149-68. (Nashville: Abingdon Press, 1999), 153.

[12] Coleborne, Catherine. "Hearing the 'Speech of the Excluded': Re-Examining 'Madness' in History." In *History on the Couch: Essays in History and Psychoanalysis*, edited by Joy Damousi and Robert Reynolds, 17-25. (Melbourne: Melbourne University Press, 2003), 17.

[13] Campbell, Alastair, Grant Gillett, and Gareth Jones. *Medical Ethics*. 4th ed. (South Melbourne: Oxford University Press, 2005), 184.

too often isolates us from one another, making friendship impossible. Without such narratives, suffering can too quickly become an invitation to narcissism."[14]

As researcher Claudia Malacrida notes, it is a legally-constituted silence that prevents researcher access to institutional 'survivors' through legal guardianship orders, and to archived materials that otherwise describe oppression stories. Nonetheless, there are survivors who have provided "a rich and powerful testimony to the brutality of institutionalisation, and provide us with an emancipatory history from the perspectives of those most oppressed by disability policies and practices."[15]

Within contemporary debates, such as within the biomedical arena, the voice of people with disability is observed as a tragedy thus disqualifying them from such discourses which are regarded as the privilege of those without disability.[16] Similarly, Gerard Goggin and Christopher Newell speak of the "catastrophe of disability" and a "culture of cure" negating a democratic representation of the voice of people with disability in media-represented biomedical debates.[17]

This silence extends to theological institutions where theology's oft-held silence concerning disability issues, such as regarding matters of embodiment, as well as social and institutional barriers, renders critical, theological reflection and pastoral critique as incomplete.[18] Where institutional theological reflection has occurred, ethicist and theologian Christopher Newell argues that it has occurred as a form of rejected knowledge where disability is associated with problem, thus aligning it with other secular arenas of debate. As he claims,

> Throughout written history, the experience of living with disability has been discounted and may be seen to be a form of rejected

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[14] Hauerwas, Stanley. "Reflection on Dependency: A Response to Responses to My Essays on Disability." In *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology*, edited by John Swinton, 191-97. (New York: The Haworth Pastoral Press, 2005), 197.

[15] Malacrida, Claudia. "Contested Memories: Efforts of the Powerful to Silence Former Inmates' Histories of Life in an Institution for 'Mental Defectives'." *Disability & Society* 21, no. 5 (2006): 397-410, 397.

[16] Clapton, Jayne. "Irrelevance Personified: An Encounter between Bioethics and Disability." *Interaction* 13, no. 4 (2000): 1-15, 4-5.

[17] Goggin, Gerard, and Christopher Newell. *Disability in Australia: Exposing a Social Apartheid*. (Sydney: University of New South Wales Press Ltd, 2005), 107.

[18] Anderson, Robert. "In Search of the Disabled Human Body in Theological Education: Critical Perspectives on the Construction of Normalcy." In *Graduate Theological Education and the Human Experience of Disability*, edited by Robert Anderson, 33-55. (New York: The Haworth Pastoral Press, 2003).

> knowledge. Predominantly, in the major spheres of life such as medicine, law, theology, economics and all other disciplines, the approach has been on managing and dealing with 'the problem of the disabled' as deviant individuals, as opposed to recognising that narrow norms have oppressed people with disabilities via systems and attitudes.[19]

Pastoral theologian Deborah Creamer confirms this rejected knowledge argument by asserting that when people with disabilities occasionally become a source of debate in theological circles it is often against a background of historical, theological thinking that has not regarded them as human. As she states,

> ... when people with disabilities have been considered at all by religious communities, they have been looked at as objects to be avoided, admired, pondered, or pitied – very rarely have people with disabilities been considered first as people.[20]

It would appear that, from a contemporary Australian perspective, the emerging pastoral theological and disability narrative discourse is largely located beyond the parameters of the church’s mainstream institutions.

With people with an intellectual disability living today in an era where community-based accommodation is generally considered a preferable option to traditional institutional contexts, it could be argued that this silence would be less overwhelming. However, many people with an intellectual disability remain in traditional accommodation, and others, whilst having moved into community-based contexts, continue in settings where their voice remains relatively unheard. This is due to the abiding dominance of a traditional institutional, service delivery discourse within these settings. It will be argued later in this extended reflection that the trend in disability services towards community accommodation has not necessarily meant that disability health care service has divested itself of institutional philosophy and practice.[21] The geographical location and

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[19] Newell, Christopher. "Encountering Oppression: The Emergence of the Australian Disability Rights Movement." *Social Alternatives* 18, no. 1 (1999): 47-51, 48.

[20] Creamer, Deborah. *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*. (New York: Oxford University Press, 2009), 50.

[21] Those who speak from the perspective of *social role valorisation* argue that those with a disability who live in community-based accommodation can, despite the change in geographical location and more contemporary architectural forms, nonetheless find themselves living in what can still be described as ‘mini-institutions’. See, for example,
Ziegler, Harriet. *Changing Lives, Changing Communities*. revised ed. (Melbourne: Wesley Mission Melbourne, 2004).

architectural forms of present-day practice may have assumed a more contemporary and seemingly enlightened form; however, there is far more to deinstitutionalisation than changes to location and physical design, and this includes issues related to people with an intellectual disability having their voice and story heard.

However, to speak of the historical and contemporary silencing of the disability voice does not fully describe the extent to which people with disability have been and are excluded across secular and theological arenas of society. As significant as it is in itself, the loss of voice points to an even broader loss for those of the disability community. For when the narratives of people with disability are not heard – either for institutional or other socio-politically derived reasons – and where the contribution of people with disability to contemporary secular or theological debates is discounted, it is not only the voice of people with disability that has been silenced, it is their identity. Furthermore, where the silencing of communities of people with disability occurs, the community identity is also silenced. When people with disabilities within institutions and other congregate settings are denied access to each other's narrative then personal understanding of identity gained through interpersonal interaction is denied.[22] Not only do people with a disability lose the right to speak and be heard, access to a first-hand understanding of who these people are is also lost. Identity understanding then becomes a second-hand discourse of being talked about by the able-bodied.

Therefore, as one of the very few chaplains in Australia offering pastoral care to people living with intellectual disability in the institutional context, I claim a unique capacity to reveal a measure of the identity of these silenced people through authentic description of their narrative and lived context[23] It is

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For further discussion of this term see 3.2.4 Mini-Institutions.

[22] Darling, Rosalyn. "Toward a Model of Changing Disability Identities: A Proposed Typology and Research Agenda." *Disability & Society* 18, no. 7 (2003): 881-95, 889.
This issue is also acknowledged from an historical, institutional perspective in,
Schweik, Susan. *The Ugly Laws: Disability in Public*. (New York & London: New York University Press, 2009).

[23] Further reference to the importance of narrative, both in terms of epistemology, method and pastoral practice is included in chapter 5. Claims to authenticity will be justified in this chapter.

through clear, well-conceived narrative articulation that institutional silence can be overcome,[24] and a liberating pastoral model described.

1.4.2 Narrative of Otherness

Within liberal, Western societies, people with intellectual disability have often been regarded as being less than fully human. The loss or perceived loss of intellectual functions such as thinking, remembering, future planning and reasoning have been and are often viewed as leading to a loss of human identity.[25] In the contemporary setting, some ethicists and moral philosophers argue that, without the rational capacity for self-awareness, that is, the ability to differentiate between one's self and the other person, full human identity is lost.[26] It is when we consider this issue of identity and self-awareness that we are confronted with the notion of difference, that is, the differentiation of ourselves from others. As Clapton indicates, the difficulty here arises when certain human characteristics such as the capacity for reason are normalised and that which is deemed normal is regarded as dominant. Difference from this norm can then easily become regarded as inferior. Such negative regard leads the one so viewed to assume the status of 'the other.' This other then becomes an object of fear, the outsider whose own frailties threaten to reveal the vulnerabilities of the status quo. Thus, for the status quo, the close proximity of this object is untenable, and inevitably leads to social and moral alienation and exclusion.[27]

This conceptualisation of exclusion can thus take on the image of a body purging itself of that which is deemed unclean according to a prescribed code or

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[24] Owen, Frances, Dorothy Griffiths, Donato Tarulli and Jacqueline Murphy. "Historical and Theoretical Foundations of the Rights of Persons with Intellectual Disabilities: Setting the Stage." In *Challenges to the Human Rights of People with Intellectual Disabilities*, edited by Frances Owen and Dorothy Griffiths, 23-42. (London and Philadelphia: Jessica Kingsley Publishers, 2009), 36

[25] Swinton, John. "Remembering the Person: Theological Reflections on God, Personhood and Dementia." In *Ageing, Disability and Spirituality: Addressing the Challenge of Disability in Later Life*, edited by Elizabeth MacKinlay, 22-35. (London & Philadelphia: Jessica Kingsley Publishers, 2008), 22.

[26] See, for example,
Kuhse, Helga, and Peter Singer. *Should the Baby Live? The Problem of Handicapped Infants*. (Oxford: Oxford University Press, 1987).
Singer, Peter. "Speciesism and Moral Status." In *Cognitive Disability and Its Challenge to Moral Philosophy*, edited by Eva Kittay and Licia Carlson, 331-44. (Chichester: Wiley Blackwell, 2010), 338-40.
Tooley, Michael. "Abortion and Infanticide." In *Applied Ethics*, edited by Peter Singer, 57-85. (New York: Oxford University Press, 1988).

[27] Clapton, Jane. "Disability and Moral Constructions." (Brisbane: Griffith University, 2005), 3-10.

norm of cleanliness. Such a purging can be located in specific ethnic, cultural and religious contexts.[28] The language of purging resonates with the wider societal attitude to the institution. Society is relieved "when the deviant body and unhinged mind are consigned to an institution"[29] and its segregating services.[30] The societal body finds a suitable repository for its waste.

Indeed Clapton and Fitzgerald go so far as to assert that people with disabilities can be viewed as 'the Other' of 'the Other.' They argue that amongst those who can lay claim to being oppressed and silenced because of their difference from proscribed social norms people with intellectual disabilities are further from that norm than others. Not only is otherness imposed by dint of disability, but a further layer of otherness is added to those with an intellectual disability because of the loss of the deeply-valued social function of reason. Sociologist Carolyn Thompson confirms this level of socio-political dislocation in asserting that disability concerns fail to even be recognised as forms of social injustice, instead being consigned to religious prayers and charitable appeals.[31]

As will be noted in the following chapter, when addressing the Disability Rights model of disability, this sense of otherness has even been contributed to

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[28] In a nationalistic, ethnic context, Miroslav Volf describes otherness as the "filth that must be washed away from the ethnic body ... " – that is, ethnic cleansing. See,
Volf, Miroslav. *Exclusion and Embrace: A Theological Exploration of Identity, Otherness, and Reconciliation*. (Nashville: Abingdon Press, 1996), 57.
This image bears some relation to the outworking of Old Testament purity laws – Leviticus chapters 13 & 14 – that see the *leper* purged from the local community and consigned to life outside the city walls. See National Council of the Churches of Christ in the United States of America *Holy Bible,* Old Testament, 98-102.
David Tracy speaks of the teachings of the three great monotheistic religions, Christianity, Judaism and Islam, producing a projected other to their prophetic faith in the God of the covenant: they have named this *other* the *pagan.* This projected other becomes a source of contempt. See,
Tracy, David. *Dialogue with the Other: The Inter-Religious Dialogue*. Edited by Raymond Collins, Thomas Ivory, Joel Delobel, Lambert Leijssen and Terrence Merrigan, *Louvain Theological & Pastoral Monographs*. (Grand Rapids: Peeters Press/William B. Eerdmans Publishing Company), 1991, 49.

[29] Goggin, Gerard, and Christopher Newell. "Harvie Krumpet: Narrating the Ethics of Disability and Death." *Interaction* 18, no. 3 (2005): 24-28, 25.

[30] Cain, Paul. "Right Policy – a Critique of the Australian Government's Welfare to Work Policy for Australians with Intellectual Disability." *Interaction* 19, no. 2 (2005): 18-28, 20. Here, the author asserts that institutional services such as the sheltered workshop partly stem from the 'false science' of eugenics, which sought to breed out people with intellectual disability from mainstream society through programs of segregation. More will be said of eugenics in chapter 3.

[31] Thompson, Carolyn. "Ableism: The Face of Oppression as Experienced by People with Disabilities." In *Injustice and the Care of Souls: Taking Oppression Seriously in Pastoral Care*, edited by Sheryl Kujawa-Holbrook and Karen Montago, 211-26. (Minneapolis: Fortress Press, 2009), 212.

by those within what can be broadly referred to as the disability movement. Here, disability advocacy and the claiming of disability rights have at times disregarded the rights of people with intellectual disability on the basis that such rights assume the autonomy that accompanies full intellectual capacity.[32]

Thus, given this level of alienation, an argument can be made for suggesting that amongst those with disability, people with intellectual disability have been even more marginalised and alienated from mainstream society than those with other forms of disability. It is in the honouring of people with intellectual disability who live in the institutional context that, through the careful detailing of their narrative, such marginalisation can be pastorally redressed.

1.5 Introduction to the Extended Reflection Process

The extended reflection process, and its constituent elements, will be thoroughly discussed in chapter 5. Nonetheless, the following four-part approach to this process is proffered as a holistic and comprehensive framework by which the extended reflection process can be best understood. It is argued that it most effectively honours the need for an authentic framework by which the extended reflection question can be reflected upon and understood given the specific context and people under consideration.

1.5.1 Theoretical Perspective: Liberation Theology

The theoretical perspective represents "the philosophical stance informing the methodology and thus providing a context for the process and grounding of its logic and criteria."[33] The perspective that will inform the methodology to be applied to this extended reflection is that of liberation theology. This stance will provide both the fundamental oppression orientation through which the institutional context will be interpreted, as well as the liberating model of pastoral care that will be proposed. Furthermore, praxis, concerned as it is with contextualised reflection upon theories of understanding from which authentic

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[32] Reinders, Hans. *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology and Ethics*. ed. (Grand Rapids: William B. Eerdmans Publishing Company, 2008), 5. More details on the Disability Rights model will follow in chapter 2.

[33] Crotty, Michael. *The Foundations of Social Research: Meaning and Perspective in the Research Process*. (St. Leonards: Allen & Unwin Pty Ltd, 1998), 3.

models and actions can emerge, will be methodologically employed with close reference to liberationist principles.[34]

1.5.2 Epistemology: Reflection-in-Action

Epistemology concerns “the theory of knowledge embedded in the theoretical perspective and thereby in the methodology."[35] Reflection-in-action is a qualitatively-oriented mode of knowledge acquisition that seeks for knowledge derived from within a particular context. In the case of this extended reflection this concerns those institutions that accommodate people with intellectual disability. It sources knowledge discerned from reflection upon the actions of those who live and work within this context. Owing to its particularised orientation, and focus on ongoing knowledge acquisition, it is highly responsive to the nuances and changes in behaviours that accompany the ongoing nature of life in the considered context.

1.5.3 Methodology: Hermeneutics

Methodology is "the strategy, plan of action, process, or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes."[36] It is the hermeneutical perspective that meets the need for a dialogue between fundamental philosophical assumptions and the socio-political context in which the reflection occurs. In this case, the assumptions are theological, both historic and contemporary. It is this methodology that will best allow for reflection upon the lived experience of those who are the focus of the reflection-in-action process. Furthermore, through the spiral shape of methodological design, knowledge acquisition and understanding are seen as ongoing in nature. Acquired truth is regarded as impermanent in nature, constantly open to re-analysis and new layers of interpretation and understanding.

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[34] Reinhartz, Adele, and Marie-Theres Wacker. "Some Reflections on Feminist Biblical Hermeneutics for Liberation." In *Feminist Interpretation of the Bible and the Hermeneutics of Liberation*, edited by Silvia Schroer and Sophia Bietenhard, 34-47. (London: Sheffield Academic Press, 2003), 42-44.
The concept of *praxis* will be further defined in chapter 5.

[35] ibid.

[36] ibid.

1.5.4 Method: Pastoral Visitation/Narrative Analysis

The research methods are "the techniques or procedures used to gather and analyse data related to some research question or hypothesis."[37] To appropriate the required information regarding the extended reflection question, the qualitative material will be gathered by means of pastoral visitations and careful observations of those who are the focus of reflection. Subsequently, narratives will be written that represent stories and 'narrative threads' of an institutional type. These narratives will be non-literal and derivative in character, and do not represent any attempt to seek understanding through the detailing of literal events. Following a considered reflective, analytical process, they may eventually be determinative in ongoing pastoral understandings.

1.6 Introduction to Key Terms

Whilst these key terms will be discussed at length in chapter 2 the following prefacing definitions are offered so as to give a broad-based understanding of the concepts.

1.6.1 Disability/Disablism

Disability is a particularly complex and fluid term to define. It is complex owing to the various philosophical perspectives and values of the person or persons who claim understanding of the term. It is fluid because the definition of the term has significantly changed over the generations according to ever-shifting cultural values and norms. Whilst the complexities and fluidities of the term will be discussed in the following chapter, at this preparatory stage, two largely contrasting and generic definitions need to be noted. These are the medical and social definitions of disability. They, more than other understandings, have, over recent decades, formed the basis of most definitions. Whilst each term has often been considered in exclusivist terms, with little acknowledgement of the merit of the other, today the seemingly contrasting terms are generally being understood from a more integrated perspective.

The medical construction of disability is generally defined as that which views "disability as a defect or sickness which must be cured through medical

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[37] ibid.

intervention."[38] Here, disability is perceived as being embodied in the individual, and as that which defines that person in terms of a medical problem requiring health care intervention.

This definition has reflected a prevailing understanding of disability stemming back to at least the European Age of Enlightenment when the medical community began to analyse 'the mad' in terms of scientific classifications.[39] However, in recent decades, the social model has challenged the medically-embodied notion of disability.

A social definition of disability began to gain clear articulation in 1976 when the Union of the Physically Impaired Against Segregation (UPIAS) defined disability as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities."[40] In 1983, disability academic and advocate Mike Oliver termed this the *social model of disability*.[41] This model has undergone redefinition since that time. However, its most critical contribution to the defining of disability remains its emphasis on redirecting the notion and realm of disability away from the physical body and into the realm of the socio-politically constructed environment in which the person or persons live. It is the environment that has the disabling effect on those concerned. The notion of problem is moved away from the person and into the arena of the environment which generates disabling consequences for those who don't measure up to socially-constructed norms.

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[38] Kaplan, Deborah. *The Definition of Disability* The World Institute for Disability, 2006 [cited 11/10/2006]. http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper. sec.1, par.2. Website no longer available.

[39] See,
Foucault, Michel. *Madness and Civilization*. (London: Routledge, 2003) and Porter, Roy. *A Social History of Madness: Stories of the Insane*. (London: Weidenfeld Paperbacks, 1989), 24.

[40] Union of the Physically Impaired Against Segregation. *Fundamental Principles of Disability*. Union of the Physically Impaired Against Segregation, 1975 [cited 28/4/2008. Available from, http://www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/fundamental%20principles.pdf, 20.

[41] Light, Richard. *Social Model or Unsociable Muddle?* Disability Awareness in Action, 2006 [cited 28/2/2012]. Available from, http://disabledpeopleprotest.wordpress.com/2011/01/19/social-model-or-unsociable-muddle/ sec.4, par.1.

Commensurate with the social definition of disability, the associated term of *disablism* also requires understanding. This term has come to be regarded as being grounded in the prejudicial and oppressive beliefs and attitudes of individuals and groups within a particular society who regard people with disabilities as lesser beings on the basis of their impairments.[42]

1.6.2 Institution/Institutionalisation

In 1961, American sociologist Erving Goffman, in referring to various types of socially isolated, communal living situations, described what he referred to as the 'total institution.' This was "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life."[43] The qualities of this type of facility included control by a single, administrative authority; a single, rational institutional plan; ownership of the institution by staff; and long-term institutional residency leading to a sense of deculturalisation from the norms and values of the wider community and, consequently, the adoption of the cultural values and norms of the institution.[44]

This definition was viewed as being applicable to various communal contexts involving the mass control of people under a hierarchical system of authority. It applied to contexts such as army camps, prisons, monasteries, mental health facilities and facilities for those living with a wide range of physical and intellectual disabilities.

It can be claimed that this was a definition 'for its time' and that since then Western societies have differentially sought alternative ways of addressing the accommodation and other needs of people who live with disabilities. However, it can well be argued that Goffman's initial definition still bears relevance on two counts.

Firstly, there are still people today who live with disabilities, including intellectual disabilities, in mass accommodation contexts under hierarchical

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[42] Miller, Paul, Sophia Parker, and Sarah Gillinson. *Disablism: How to Tackle the Last Prejudice* Demos, 2004 [cited July 2 2004]. Available from http://www.demos.co.uk/files/disablism.pdf?1240939425
See also,
Sapey, Bob, John Stewart, and Glenis Donaldson. "Increases in Wheelchair Use and Perceptions of Disablement." *Disability & Society* 20, no. 5 (2005): 489-505.

[43] Goffman, Erving. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. (Harmondsworth: Penguin Books Ltd, 1982), 12.

[44] ibid., 12-23.

systems of authority. The institutions that are the focus of this extended reflection are making certain efforts towards more community-oriented forms of service delivery, focusing more on ‘client choice.’ Nonetheless, they still offer mass forms of accommodation and health care amidst a highly bureaucratic administrative structure.

Secondly, as will be argued in more detail later, even the more community-oriented forms of accommodation available today for people with intellectual disability, bear what can be described as an ongoing institutional character in terms of adherence to traditional institutional qualities. This includes prevailing notions of staff control, lack of autonomy and lack of integration into the life of the local community,[45] leading to what Goggin and Newell refer to as a “problematic reinstitutionalisation.”[46]

1.6.3 Pastoral Care

In broad generic terms, pastoral care can be defined as “that aspect of the ministry of the Church which is concerned with the well-being of individuals and of communities.”[47] This definition raises the debatable issue concerning whether or not the Christian church can justify an exclusive claim to the role of pastoral care, and whether Christian theology alone can lay claim to a philosophical understanding of pastoral care.[48] Notwithstanding consideration of the multi-faith

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[45] See, for example,
Walmsley, Jan. "Institutionalization: A Historical Perspective." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelly Johnson and Rannveig Traustadottir, 50-65. (London and Philadelphia: Jessica Kingsley Publishers, 2006).
Gardner, Julian, and Louise Glanville. "New Forms of Institutionalization in the Community." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelly Johnson and Rannveig Traustadottir, 222-30. (London and Philadelphia: Jessica Kingsley Publishers, 2006), and Holburn, Steve. "Rules: The New Institutions." *Mental Retardation* 28, no. 2 (1990): 89-94.

[46] Goggin, & Newell. *Disability in Australia,* 129.

[47] Campbell, Alastair. "Nature of Pastoral Care." In *A Dictionary of Pastoral Care*, edited by Alastair Campbell, 188-90. (London: SPCK, 1987), 188.

[48] There is a growing body of literature today from religious, non-Christian sources, that challenges narrowly defined Christian understandings of pastoral care. For example, for a Buddhist perspective see,
Hawkins, Peter. "The Buddhist Insight of Emptiness as an Antidote for the Model of Deficient Humanness Contained within the Label 'Intellectually Disabled'". In *Voices in Disability and Spirituality from the Land Down Under*, edited by Christopher Newell and Andy Calder, 45-54. (New York: The Haworth Pastoral Press, 2004).
Monnet, Mikel. "Developing a Buddhist Approach to Pastoral Care: A Peacemaker's View." In *Injustice and the Care of Souls: Taking Oppression Seriously in Pastoral Care*, edited by Sheryl Kujawa-Holbrook and Karen Montago, 125-30. (Minneapolis: Fortress Press, 2009).
For an Islamic perspective see,

perspective, I accept the ecclesial orientation of this definition not out of any desire to be religiously exclusive, but because of the prevailing influence of the Christian faith orientation and traditions of this pastoral practitioner which are determinative in shaping his pastoral practice.[49]

It is a definition that places the understanding of the term in both the private and public domain thus affording pastoral ministry a holistic perspective. In so doing, it allows for pastoral ministry to an individual to be interpreted in terms of the effect that the socio-politically situated institution has upon those for whom they bear responsibility. Pastoral theologian Don Browning stresses this point when he asserts that: "... the pastoral counsellor must be just as interested in the value symbols that govern the social structures and social roles impinging on the troubled individual's life as he is in the sanctioned retreat so necessary for the restoration of that person's health."[50]

It is also a definition that does not neatly define the nature of caring for the well-being of others. As such, it remains open to ministry from spiritual, material, emotional and socio-political perspectives. The person, or persons, is regarded as having a multi-faceted, whole human identity.

These issues and others will be elaborated upon in later chapters.

1.6.4 Liberation Theology: Liberation/Oppression

These terms are drawn from the pastoral theological discipline referred to as liberation theology. It is liberation theologian Gustavo Gutierrez who succinctly and broadly defines this theological pursuit as “a critical reflection on

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Kobeisy, Ahmed. "Light at the End of the Tunnel: Pastoral Care for Muslims." In *Injustice and the Care of Souls: Taking Oppression Seriously in Pastoral Care*, edited by Sheryl Kujawa-Holbrook and Karen Montago, 89-102. (Minneapolis: Fortress Press, 2009).
For a Jewish perspective see,
Cohen, Howard. "Pastoral Care from a Jewish Perspective." In *Injustice and the Care of Souls: Taking Oppression Seriously in Pastoral Care*, edited by Sheryl Kujawa-Holbrook and Karen Montago, 89-102. (Minneapolis: Fortress Press, 2009).
Jones, Melinda. "Judaism, Spirituality, and Disability: An Australian Perspective." In *Voices in Disability and Spirituality from the Land Down Under*, edited by Christopher Newell and Andy Calder, 55-88. (New York: The Haworth Pastoral Press, 2004).

[49] As a pastoral carer in the institutions that are the focus of this extended reflection the expectation of the institution and of my religious employer is that ministry is duly cognisant of the faith orientation, Christian or other, of each and every person for whom care is offered. This may, for example, involve passing on a pastoral concern of a person of a non-Christian faith persuasion to the person’s preferred religious carer.

[50] Browning, Don. *The Moral Context of Pastoral Care*. (Philadelphia: The Westminster Press, 1976), 37.

Christian praxis in light of the word of God."[51] This definition reflects a contextualised understanding of theology. It represents a Christian endeavour located within the realm of the pastoral carer, and amongst the people of that context, and amidst the determinative socio-politically constituted structures of that realm. It regards Christian practice as requiring critical reflection in light of the Word of God located within that context. It is also a definition which Gutierrez understands in terms of commitment to a process.[52] That is, the nature of this critical reflection, unlike the more systematised theological endeavour, is understood as ongoing, commensurate with commitment to the particular context. This highly contextualised, processional understanding of the theological endeavour represents the broad reason for applying its usage to the institutional environment under consideration in this extended reflection. After all, the pastoral, theological reflection seeks critical, reflective and ongoing engagement with the institutional environment.

However, for this pastoral carer, the most important reason for employing a liberationist theological approach concerns its fundamental commitment to the poor and marginalised. This is to be carefully equated with the institutionalised people who are the focus of this extended reflection. As liberation theologian Rebecca Chopp asserts in Marxist terms,

> In liberation theology the bourgeois individual is no longer the primary subject, and authenticity and meaning no longer the central crisis for theology. Now the focus of theology is the nonsubjects of history, those who have been denied any voice or identity in history by their fellow humans. Through this focus Christianity converts, becoming a praxis of solidarity with those who suffer and working for the transformation of human agency and social structures. Through this focal center the sacrament of God's grace makes visible the identification of suffering and hope, while the service of God's love opens faith toward a future.[53]

It is a fundamental concern of this pastoral carer to engage in a pastoral, theological process that is expressive of solidarity with those who, in the historic and contemporary sense, have been and remain without a clear voice or honoured identity.

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[51] Gutierrez, Gustavo. *A Theology of Liberation*. Translated by Sister Caridad Inda and John Eagleson. (New York: Orbis Books, 1988), xxix.

[52] ibid., xxix-xxxiii.

[53] Chopp, Rebecca. *The Praxis of Suffering: An Interpretation of Liberation and Political Theologies*. (New York: Orbis Books, 1986), 3-4.

Whilst liberationists speak of oppression and liberation in developmental and socio-political term,[54] this pastoral carer seeks definition from his institutional context. In pastoral terms, oppression is concerned with the constraints imposed upon people with intellectual disability through the imposition of a dominant medicalised discourse. Liberation is understood in reference to freedom.[55] This is freedom from the constraints of the dominant medicalised routine through an affirmation of mutuality of relationship as realized through the relationship with a gracious God.

1.7 Scope of Extended Reflection

1.7.1 Institutional Context

As indicated previously in this chapter, the institutions forming the basis of this extended reflection will be those in which this pastoral carer practises pastoral care in South Australia as a Uniting Church of Australia chaplain. However, at times, pastoral reflections based upon pastoral practice at these institutions will, where relevant, be given broader institutional application within the wider South Australian and Australian context.

1.7.2 Persons who are the Focus of Pastoral Reflection

For the purpose of balanced pastoral reflection, a range of people with intellectual disability from the institutions under consideration will be sought.

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[54] Various liberationists, secular and theological, speak in developmental terms of oppression in regard to marginalised and impoverished people being maintained in a disempowered state by those who seek to preserve their power over these others. They also speak of liberation in terms of solidarity with the poor, and structures of powerlessness being replaced by those that enable people to speak with their own voice and regain their humanity. See, for example,
Coleridge, Peter. *Disability, Liberation and Development*. (Oxford: Oxfam Publishing, 2001).
Freire, Paolo. *Pedagogy of the Oppressed*. (Harmondsworth: Penguin, 1972).
Volf, Exclusion and Embrace, 102.
Others speak in theological terms of liberation as a salvific endeavour, coming under the realm of the Kingdom of God and/or the activity of Jesus. See,
Gutierrez, A. Theology of Liberation.
Gutierrez, Gustavo. *The Truth Shall Make You Free: Confrontations*. (New York: Orbis Books, 1990). Segundo, Juan. *The Liberation of Theology*. (Dublin: Gill and Macmillan Ltd., 1977).

[55] Bietenhard, Sophia. "Freedom, Liberation and Context as Hermeneutical Tasks." In *Some Reflections on Feminist Biblical Hermeneutics for Liberation*, edited by Silvia Schroer and Sophia Bietenhard, 126-36. (London: Sheffield Academic Press, 2003). The author claims a strong philosophical relationship between *liberation* and *freedom*. The former term refers to a concrete form of conduct or action with the goal of a theologically-redemptive breaking free from socio-political forms of oppression. The latter refers to a goal that is fundamental to human existence, that is, the individual and collective human call to thwart injustice.

This will include people from young adults to the elderly, from those who have only lived in the institution for a few months, to those elderly persons who have lived in institutional accommodation since childhood.

The narratives of people living with a range of intellectual impairments will be considered. There will be those born with impairments such as Down Syndrome, as well as a wide range of other syndromes. There will be those with various forms of autism. There will be others who have acquired some form of brain injury through alcohol abuse, vehicle accident or stroke, as well as those living with the degenerative effects of Alzheimer’s disease. There will also be a number who, along with their intellectual impairment, will have some form of physical disability caused by an impairment such as Cerebral Palsy or Motor Neurone Disease.

The people under consideration in this extended reflection are those with an intellectual disability who are located in institutional accommodation. However, the findings of this extended reflection may bear relation to those who live in alternative, although not completely dissimilar, institutional contexts, such as nursing homes and other aged care facilities.

1.7.3 Persons Considered as Pastoral Carers

For the purposes of this extended reflection, pastoral carers will be regarded as those who engage in pastoral relationship with those institutionally-accommodated persons who are the focus of this extended reflection. There will be issues discussed and narratives analysed that pertain specifically to the pastoral carer in a paid, professional capacity. However, it is envisaged that the pastoral model to be detailed in the final chapter will contain pastoral principles and theological understandings that generally allow for ease of integration into volunteer pastoral understandings and practices.

1.8 Situating the Extended Reflection

Broadly speaking, the extended reflection is situated at the interface of theological and social science disciplines.[56] The theological discipline will consider both pastoral and systematic theological discourses.

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[56] The pursuit of interpretation and understanding at the interface of such disciplines comes under the interpretative framework referred to as Revised Correlational Method. See, for example,

The pastoral, theological discourse will principally emerge from consideration of those narratives to be described in chapter 6 that will form the basis of narrative analysis and pastoral understanding. Clear consideration will be given to the Word of God as it is to be discerned within this context. Such contextualised, theological reflection will also occur alongside consideration of the inherited faith traditions and biblical understandings of the pastoral carer. The exact nature of the interplay between these two theological discourses will be fully described in chapter 5 where methodological concerns will be considered.

The significance of the social science paradigm is evident through the specific socio-politically constituted location of the institutional context under consideration. Authentic pastoral reflection needs to take careful account of the location in which pastoral ministry is situated, and its effect on the nature of the pastoral ministry within its purview. As pastoral theologian Stephen Pattison indicates, pastoral care cannot be considered as a neutral activity. It needs to account for the socio-political circumstances in which it is contextualised.[57] Furthermore, feminist pastoral theologian Susan Dunlap earths the work of pastoral caregivers in this dialogue between discourses by stating that they “must be trained to instinctively ask the contextual questions, to ask questions regarding the relative power accorded by virtue of social location.”[58]

As with the theological discourse, the exact role of social science considerations, particularly those that are sociological or historical in nature, and their interplay with the theological discourses, will be fully described and illustrated within the wider methodological considerations of chapter 5.

1.9 Core Principles

There are three core principles that undergird the question under consideration in this extended reflection, all of which will be validated in coming chapters. Firstly, there is the fundamental inability of institutions established to

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Browning, Don. *A Fundamental Practical Theology*. (Minneapolis: Fortress Press, 1991), 44. Here, the author points to the process of correlation, not only of theological and non-theological sources, but also of narrative-based and propositional theological forms. See also, Tracy, David. *Blessed Rage for Order: The New Pluralism in Theology*. (New York: The Seabury Press, 1975).

[57] Pattison, Stephen. *A Critique of Pastoral Care*. (London: SCM Press Ltd, 1988), 90.

[58] Dunlap, Susan. "Discourse Theory and Pastoral Theology." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie Miller-McLemore and Brita Gill-Austern, 133-47. (Nashville: Abingdon Press, 1999), 144-45.

accommodate people with an intellectual disability to offer those for whom they bear responsibility, mutually enriching, liberating relationship. This inability derives from the understanding that the contemporary institution is principally designed to offer professional, health care service based on a fundamental objectified, medicalised regard for those for whom they bear responsibility.[59]

Secondly, those who are so regarded are socially oppressed and marginalised by dint of living in a facility that isolates and limits them from participation in what may be reasonably considered as a socially-lived context and lifestyle that approximates an acceptable sense of social normality.[60] Such

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[59] The medical conceptualisation of the institution will be contextualised in later consideration of the historic background to the modern institution in chapter 3. It will also be included in consideration of the institutional narratives that are the focus of this extended reflection in chapter 5. Amongst the wide range of literature on this subject, the medicalised nature of the contemporary institution is well detailed in, McKnight, J. *The Careless Society: Community and Its Counterfeits*. (New York: Basic Books, 1995). Literary sources that describe the institution from a biographical and autobiographical 'resident' perspective are particularly instructive. See,

Allen, Thomas, Rannveig Traustadottir, and Lisa Spina. "Sixty Years in the Institution." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelley Johnson and Rannveig Traustadottir, 33-49. (London: Jessica Kingsley Publishers, 2006).

Hall, Victor, and Sheena Rolph. "'I've Got My Freedom Now': Memories of Transitions into and out of Institutions, 1932 to the Present Day." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelley Johnson and Rannveig Traustadottir, 163-70. (London: Jessica Kingsley Publishers, 2006).

Johansen, Emil, and Kristjana Kristiansen. ""Gone Fishin": From Institutional Outing to Real Life." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelley Johnson and Rannveig Traustadottir, 171-76. (London: Jessica Kingsley Publishers, 2006).

[60] Early consideration of the importance of social normality is found in the work of the pioneers and early advocates of the concept of *normalisation* whereby people with an intellectual disability are observed to experience the conditions of life that approximate the norms of everyday society. See,

Nirje, Bengt. "The Normalization Principle and Its Human Management Implications." In *The History of Mental Retardation: Collected Papers, Volume 2*, edited by Marvin Rosen, Gerald Clark and Marvin Kivitz, 361-76. (Baltimore: University Park Press, 1969). The author posits a definition that approximates the above. See 363.

See also,

Wolfensberger, Wolf. *Normalization: The Principle of Normalization in Human Services*. (Toronto: National Institute on Mental Retardation, 1976), and,

Bank-Mikkelsen, Niels. "The Growth and Development of a New Administration for the Mentally Retarded, Set up in Denmark in 1959." In *Minda Lectures: Series One to Eight - 1963–1980*, edited by Minda Inc., 38-50. (Adelaide: Minda Inc., 1967).

Criticism of the normalisation principle has included concern over a perceived emphasis on social conformity, rather than respect for difference. See,

Rapley, Mark, and Steve Baldwin. "Normalisation – Metatheory or Metaphysics? A Conceptual Critique." *Australia and New Zealand Journal of Developmental Disabilities* 20, no. 2 (1995): 141-57.

The strident criticism of social worker and disability advocate Michael Oliver is of particular note, especially in regard to his concern that normalisation fails to address issues regarding the systemic oppression of people with disability, and even the capacity for normalisation to contribute to that oppression. See, normality relates to issues such as ease of access to a broad spectrum of personal relationships, community facilities and lifestyle opportunities.

Thirdly, in the face of the objectified, medicalised form of care thus described, pastoral care offers a meaningful and necessary form of care that has a fundamental regard for the worth of the person in question as a human being created in "the likeness of God" (Genesis 1:26).[61]

1.10 Conclusion

It is the purpose of this extended reflection to propose and describe a pastoral care model that most authentically and validly affords a mutually-enriching, liberating form of pastoral relationship between pastoral carer and the person with an intellectual disability accommodated in an institutional context. A model of care will be proposed that affirms worth on the basis that all people are created in the image of God, including those institutionalised people with intellectual disability.

In undertaking this task, Molly, as described in the Prologue to this extended reflection, is understood as a person principally related to by institutional staff as someone in need of professional health care service. However, she is also to be regarded from the perspective of one of a community of people with intellectual disability thus defined from a socio-political perspective. Later narrative and pastoral considerations will serve to highlight the interplay between these two institutional spheres of relation, as it will also consider the role of the pastoral carer and his or her mode of pastoral understanding and practice.

Oliver, Michael. *Understanding Disability: From Theory to Practice*. 2nd ed. (London and New York: Palgrave Macmillan, 2009), 87-105.

Despite such criticism it can still be argued that normalisation points to the incapacity of institutions to address the basic needs of people with intellectual disability.

[61] National Council of the Churches of Christ in the United States of America. *The Holy Bible*, Old Testament, 1.

PART 1

DEFINING THE PARAMETERS OF THE EXTENDED REFLECTION

CHAPTER TWO

GUIDING VALUES, USE OF METAPHOR AND DISABILITY MODELLING

"One of the things that pastoral care can distinctively offer is care situated within the quest for meaning and generative symbols."[62]

" ... the concepts employed to distinguish among groups of people [who live with disablement] are not purely scientific, descriptive concepts, but have a value-based dimension."[63]

"To understand how the power of definition [of disability] is exercised and experienced, we have to ask who does the defining in practice, for what purposes and with what consequences for those who are deemed to fit the definitions."[64]

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[62] Pattison, Stephen. "Some Objections to Aims and Objectives." In *The Challenge of Practical Theology: Selected Essays*, edited by Stephen Pattison, 90-109. (London and Philadelphia: Jessica Kingsley Publishers, 2007), 106

[63] Edwards, Steven. "Definitions of Disability: Ethics and Other Values." In *Arguing About Disability: Philosophical Perspectives*, edited by Kristjana Kristiansen, Simo Vehmas and Tom Shakespeare, 30-41. (London and New York: Routledge, 2009), 30.
Bracketed words are those of thesis author.

[64] Wendell, Susan. *The Rejected Body: Feminist Philosophical Reflections on Disability*. (New York and London: Routledge, 1996), 23.
Bracketed words are those of thesis author.

Plate 2.1

‘Blockhead Slave’

by

Michelangelo Buonarotti

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[65] Ruehring, Lauren. *Blockhead Sculpture by Michelangelo* HowStuffWorks, Inc, 2011 [cited 30/12/2011. Available from
http://entertainment.howstuffworks.com/arts/artwork/michelangelo-sculptures16.htm

2.1 Values

In order to develop an appropriate perspective for discerning the identity of people with intellectual disability, as well as describing the institutional context in which that identity is shaped, core values need to be acknowledged and consistently honoured throughout the extended reflection process. The explicit detailing and application of fundamental values is nothing less than the claiming of humanity for those for whom we care. As disability theologian Stanley Hauerwas claims, "... to raise the question of the criteria of the human is not first an empirical question, but a conceptual-moral claim about how the nature of man (sic) should be understood."[66]

The values listed are to be categorized in terms of 'instrumental' and 'terminal' values. Terminal values are concerned with desirable end-states, whilst instrumental values are concerned with the means by which those end-state objectives can be achieved.[67] The tabling of those categorized values pertinent to this extended reflection is therefore done from a pastoral, theological perspective.

Table 2.1 Pastoral, Theological Values

Terminal values	*Instrumental values*
Liberation	**God as Creator of humankind**
Equality	**All humankind created in the image of a loving God**
Personal worth	**All people are unique spiritual beings**
	Authenticity of process
	Pastoral respect
	Unconditional regard

2.1.1 Pastoral, Theological Terminal Values

The terminal values listed above are expressive of the development of a pastoral model that seeks liberating relationship. This relationship is expressive

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[66] Hauerwas, Stanley. "The Retarded and the Criteria for the Human." In *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology*, edited by John Swinton, 127-34. (New York: The Haworth Pastoral Press, 2005), 130.

[67] Rokeach, Milton. *The Nature of Human Values*. (New York: The Free Press, 1973).
Also cited in,
McLeod, John. *An Introduction to Counselling*. 2nd ed. (Buckingham & Philadelphia: Open University Press, 1999), 266-67.

of freedom from oppressive institutional modes of relationship and from the exercising of power from a position of institutional hegemony.[68] This form of relationship will be characterised by a fundamental sense of equality of relationship between pastoral carer and the person with an intellectual disability. It also concerns the pastoral carer showing equal regard for all people with whom he or she relates in the institutional context, both those with an intellectual disability and the staff alike. This is in contradistinction to institutional modes of relationship where inequity is expressed through the person with the intellectual disability being regarded as objectified 'problem,' dependent upon the medical expert, leading to the possibility of diminished self-worth of the one who is objectified.

Such understanding by the pastoral carer concerning equality of relationship makes possible the realization that both the pastoral carer and those with whom the carer engages in relationship are people of equal worth. This is realized through acknowledging that each other's worth is not based on the perceived quality of contribution, or genetic make-up, but of their presence as a human being.[69] This realization is theologically derived from an appropriately conceived God-given regard as understood from discussion of the instrumental values below.

2.1.2 Pastoral, Theological Instrumental Values

All life, including all human life, emanates from God as Creator.[70] The act of being created, and being sustained in that state of being, is the act of a creative, loving God. All people are created in the image of this gracious God regardless of whether or not they profess any form of relationship with that God. Love given is

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[68] Poling, James. *The Abuse of Power: A Theological Problem*. (Nashville: Abingdon Press, 1991), 91. Here, the author refers to the "structure of dominance" within institutions that allows for an abuse of power, and, by implication, a sense of powerlessness by those who are so abused. Such an abuse of power contributes to a sense of "client" inequality in the institutional setting. More will be said of this in reference to the medical and genetic models of disability.

[69] Swinton, John. "Introduction: Re-Imagining Genetics and Disability." In *Theology, Disability and the New Genetics: Why Science Needs the Church*, edited by John Swinton and Brian Brock, 1-25. (London and New York: T & T Clark, 2007), 21-22.

[70] Owen, Michael. *Witness of Faith: Historic Documents of the Uniting Church in Australia*. Edited by Owen, Michael. (Melbourne: Uniting Church Press, 1984).
see 'The Apostles' Creed,' 42 and 'The Nicene Creed,' 52.

unconditional. All people are created equally as spiritual beings, inasmuch as all people, each in their own way, seek for a sense of meaning by which to live.[71]

It is incumbent upon the pastoral carer to exercise authenticity in the manner in which the extended reflection process is enacted. Firstly, this concerns hearing, detailing, analysing and understanding the "institutional story"[72] as told by, or discerned from, the people with intellectual disability, in a manner that is true to their life situation. Secondly, it concerns faithful interpretation of the nature and dynamic of the relationship that exists between the institution and those for whom it bears responsibility. Thirdly, it concerns the pastoral carer taking appropriate cognisance of the presuppositions and prejudices that he or she brings to their pastoral engagement with people with intellectual disability.[73]

It is also incumbent upon the pastoral carer to exercise respect in the manner in which the extended reflection process is enacted. Firstly, this concerns showing full regard for people with intellectual disability as human beings created in the image of God. Secondly, it concerns modelling a form of pastoral care that honours the right of people with an intellectual disability to engage in a liberating form of relationship, one that assists them to live as those wholly loved by God.

It is also important for the pastoral carer to relate out of a sense of inclusivity. Ethicist and theologian Herman Meininger, in describing modern health care practices as predicated on the concept of the autonomous individual, indicates that this form of care cannot serve as a moral ground for caring for people with intellectual disabilities. In advocating for an 'inclusive anthropology' he asserts that a moral view of care for people with intellectual disabilities has an emphasis on inclusion, along with authenticity and community.[74] To give full effect to this form of relationship the carer will seek to show complete acceptance of the person with an intellectual disability both in terms of their shared human

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[71] This conceptualisation of spirituality will be further extrapolated in chapter 4, 4.1.4 Principles that Shape the Pastoral Role.

[72] The term *institutional story* refers to a story that is of a type that is common to various, if not most or all, of the people with intellectual disability who live in the institutional setting.

[73] The issue of cognisance of personal presuppositions and prejudices will be accounted for in chapter 5 in relation to rigorous, collaborative reflection.

[74] Meininger, Herman. "Authenticity in Community: Theory and Practice of an Inclusive Anthropology in Care for Persons with Intellectual Disabilities." In *Spirituality and Intellectual Disability: International Perspectives on the Effect of Culture and Religion on Healing Body, Mind, and Soul*, edited by William Gaventa and David Coulter, 13-28. (New York: The Haworth Pastoral Press, 2001), 13-14.

identity, as well as in terms of the type of disability or disabilities with which they live.[75] This conceptualisation of the pastoral relationship seeks to give full effect to the notion of care being that which is offered not just to particular individuals with intellectual disability, but unconditionally to the whole community.

The realization and implementation of the above terminal and instrumental values will give practical expression to the fundamentally caring character of pastoral care exercised in the context under consideration in this extended reflection.

2.2 *In Search of a Valid Perspective for Understanding the 'Authentic I'*

As cited in the previous chapter, the 'authentic I' is a term coined by Gill-Austern to express the need to discern the first-hand narrative of the lives of people with disability, including people with intellectual disability. The expression of this narrative assumes an urgency given that people with disability have had, and still do have, first-hand stories to tell that have been silenced. Consequently, with voices muted, people with intellectual disability have identities that largely remain hidden from public discourse.

In order to hear the 'authentic I' of those who live with an intellectual disability in the institutional context, there is a need to unearth a linguistic tool that will both hear the personal narrative and describe the socio-political and lived context as authentically as possible. As will be asserted in the following section, more didactic forms of linguistic communication are helpful in terms of quantitative description and propositional statements. However, there is a need for greater, more nuanced insight. This needs to be derived from a more interpersonal pastoral mode of encounter which can justly describe the narrative under consideration and the context in which that narrative is grounded.

2.2.1 The Import and Power of Metaphor

Speaking in poetic terms, philosopher and theologian Paul Ricoeur describes the metaphor as "... that strategy of discourse by which language divests

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[75] Characteristics of an inclusive relationship with people with an intellectual disability, including issues related to unconditional love and acceptance, are further discussed from an institutional perspective in, Clapton, Jane. "A Transformatory Ethic of Inclusion: Rupturing 'Disability' and 'Inclusion' for Integrality." (Queensland University of Technology, 1999), 383.

itself of its function of direct description in order to reach the mythic level where its function of discovery is set free."[76] Here we have a mode of linguistic expression that invites the interpreter to seek insight[77] beyond the boundedness of more conceptual, dogmatic forms of expression. It points to the metaphor as making a vital contribution to the development of a more holistic and deeper level of narrative analysis and understanding, beyond the level of the rational and discursive, amidst the realm of imagination where life is truly known and celebrated.[78] It is the metaphor that “gives rise to a creativity in narrative that goes beyond the immanent sense,”[79] a creativity that allows insight into that which would otherwise remain a mystery. Therefore, metaphor, as expressed through narrative, as well as ritual, parable and other creative forms, attunes us to the “more basic hermeneutical task of understanding the creative imagination as that which uniquely allows us to see and say the conceptually imperceivable and inexpressible.”[80]

The biblical parallel to this is revealed in the role of the parable which, because of its detailed, storied form of linguistic expression, is referred to by feminist theologian Sallie TeSelle as an “extended metaphor.”[81] In its ambiguity of meanings this metaphorical form can challenge complacency and touch our points of vulnerability as uncomfortable meanings are revealed.[82]

This metaphorical form allows for layers of meaning and ambiguity. It is well-suited to language that seeks to speak of an incomprehensible God, and of that God’s activities in human affairs. As TeSelle states of parabolic theology,

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[76] Ricoeur, Paul. *The Rule of Metaphor: Multi-Disciplinary Studies of the Creation of Meaning in Language*. (Toronto: University of Toronto Press, 1991), 247.

[77] Here, the term *insight* is deliberately employed rather than more cognitive terms such as *understanding*. It suggests metaphor as a creative, imaginative linguistic form that offers alternative or ambiguous layers of interpretation of a text or context. Sallie McFague speaks of the capacity to be “shocked into a new awareness … (of the) existential, worldly, sensuous story of *human life.*” by the power of metaphorical imagery. See,
McFague, Sallie. *Models of God: Theology for an Ecological, Nuclear Age*. (Philadelphia: Fortress Press, 1982), 13.
Bracketed words in the above explanatory footnote are those of the thesis author.

[78] Bausch, William. *Storytelling: Imagination and Faith*. (Mystic: Twenty-Third Publications, 1989), 17.

[79] Browning, *A Fundamental Practical Theology*, 129.

[80] TeSelle, Sallie. *Speaking in Parables: A Study in Metaphor and Theology*. (London: SCM Press Ltd, 1975), 24.

[81] ibid., e.g. 5.

[82] Anderson, Herbert, and Edward Foley. *Mighty Stories, Dangerous Rituals: Weaving Together the Human and the Divine*. (San Francisco: Jossey-Bass, 2001), 14.

> [i]t recognises not only the inconclusiveness of all conceptualization when dealing with matters between God and human beings (an insight as old as religion itself) but also the pain and skepticism – the dis-ease – of such reflection. Theology of this sort is not neat and comfortable; but neither is the life with and under God of which it attempts to speak. The parables accept the complexity and ambiguity of life as lived here in this world and insist that it is in *this* world that God makes his gracious presence known. A theology informed by the parables can do no less – and no more.[83]

Although speaking here of the limitation of more conceptual forms of theological expression TeSelle nonetheless advocates for the interplay of the more imaginative and systematised modes of theological endeavour. She states that "the parable lies somewhere behind systematic theology,"[84] giving expression to that which remains incomprehensible in its purely conceptual form. The nature of this interplay is descriptively explained by pastoral theologian Donald Capps when he states that "... the ostensive reference is the springboard for the world-disclosure. The world-disclosure occurs when the metaphorical idea is freed from its ostensive meaning, but without this ostensive meaning there would be no world-disclosure."[85] Feminist pastoral theologian Carrie Doehring speaks of the interdependence and complementarity of these two linguistic forms when she describes metaphorical language feeding conceptual language, and conceptual language disciplining metaphorical language, and the sterility of one without the other.[86]

In terms of this extended reflection, the interplay of systematised theological understanding with the pastoral theology derived from the narrative image will be more fully described within the methodological considerations of

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[83] TeSelle, *Speaking in Parables,* 7.

[84] ibid., 63.

Similarly, pastoral theologian David Tracy speaks of this interplay when he states,

> To rediscover that metaphors and metonyms are present in all systems of conceptual thought is not to disparage efforts at second-order thought. We enrich all thought by the use of concepts faithful to the original symbols, metaphors, and metonyms. ... We shall also often need those refined forms of argument – theories, methods, and explanations – to test further our best insights and all our claims that we have indeed recognized some manifestation of truth.

Tracy, David. *Plurality and Ambiguity: Hermeneutics, Religion, and Hope*. (San Francisco: Harper & Row, Publishers, Inc., 1987), 30.

[85] Capps, Donald. *Pastoral Care and Hermeneutics*. Edited by Don Browning, *Theology and Pastoral Care*. (Philadelphia: Fortress Press, 1984), 24.

[86] Doehring, Carrie. "Developing Models of Feminist Pastoral Counseling." *The Journal of Pastoral Care* 46, no. 1 (1992): 23-31, 27.

chapter 5. Suffice to say, at this point, that the use of metaphor to describe the institutional context is crucial to the liberationist foundation of this extended reflection. It is through the appropriate application of the language of symbol that the lives of those who live with intellectual disability in the institutional context within the oppression/liberation paradigm can be most appropriately interpreted and understood. It is Poling who justifiably advocates for the deployment of metaphor and symbol in the narratives of the oppressed so that their stories can be truthfully heard within the context of their lived community.[87] In terms of this reflection, such symbolic deployment and interpretation invite the possibility of revealed pastoral vulnerabilities, and of challenging meanings described. Such can be the path of truthful understanding.[88]

2.2.2 Towards a Metaphorical Vision

Therefore, a metaphorical vision is sought that will creatively feed into this extended reflection, that will afford creative insight into the nature of the relationship between people with an intellectual disability who are accommodated in an institutional environment, and those who seek to engage in care with them.

2.2.2.1 Journey to Florence

On a journey to Italy, and to Florence, in the European autumn of 1997, I went in search of Michelangelo's *David*. This is a statue that, over the centuries, has become one of the defining works of art, amidst the extraordinary flourishing of creative expression, that was the Italian Renaissance. The statue of *David* is located in the Galleria dell'Accademia. It is to be found at the end of a long corridor and stands beneath the museum's imposing dome.

Already raised on a dais approximately one and a half metres off the ground, and standing at over four metres in height, its legendary and physically larger than life proportions immediately draw me past other statues that border the way towards *David*. The statue of the youthful, future King of Israel expresses a languid, yet serene confidence following his slaying of the Philistine giant, Goliath, with a single stone from his slingshot.

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[87] Poling, The Abuse of Power, 189.
See also,
Schmidt, William. "Power as Theological Problem." *The Journal of Pastoral Care* 46, no. 1 (1992): 71-77, 77.

[88] Pattison, "Some Objections," 103-07.

Yet this statue was always intended to signify much more than simply a heroic Old Testament figure in a moment of triumph. *David* also signifies a more subtle, far-reaching vision. Sala indicates, in reference to the socio-political circumstances of the day, that the city of Florence, around the turn of the sixteenth century, was caught in an uneasy position "between the military might of the Sforzas[89] of Milan and the spiritual and temporal influence of the Roman papacy."[90] The city was seen as needing to describe itself as ready to exert its military power amidst its regional competitors. Therefore, this physically sublime, victorious, military figure firmly stands his ground in all his glory, yet he gazes into the distance as if warning political and military rivals who might seek to usurp that self-same ground. As Sala states, "here stands not just the heroic youth of the Old Testament, but also the symbol of a tremendous civic force that is ready to be unleashed with devastating effect if unduly provoked."[91]

And as I and many others gaze up at *David*, at every angle, I feel overwhelmed with an admiration bordering on envy. Superficially, it is an admiration of Michelangelo and the seemingly divine powers that he appears capable of commanding in order to create such a masterpiece. But beyond this insight there is an admiration of all that this *David* epitomizes. I feel admiration that in the one person I can observe perfection, beauty, success, public acclaim and devotion. In the language of the contemporary vernacular, it seems unfair that one person should 'have it all.' Yet this sentiment doesn't revile me, but rather has me gazing longer. Such charisma and achievement, although unattainable, contains a certain magnetic force.

As I finally withdraw from this source of admiration I approach the series of four statues that I passed in order to observe *David* in the first place. These are what are collectively called the *Boboli Slaves.*[92] They too are the creation of

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[89] The Sforzas were the ruling Milanese family of that time.

[90] Sala, Charles. *Michelangelo: Painter, Sculptor, Architect*. (Bologna: Konecky & Konecky, 2004), 24 & 28.

[91] ibid., 29.

[92] A further two *Slaves* are located at The Louvre in Paris.
ibid., 168.
They are named *Boboli Slaves* for having once been on display in the grotto of Florentine architect, Bernardo Buontalenti, in the Boboli Gardens. See,
von der Haegen, Anne, and Ruth Strasser. *Art & Architecture: Tuscany*. (Cologne: Konemann, 2000), 259.

Michelangelo who was originally commissioned to create a series of figures to adorn the tomb of Pope Julius II.[93]

However, upon Michelangelo's death in 1564, these figures remained unfinished. And so I gaze upon these four figures which, in their unfinished state, generate a physical appearance and subsequent discourse far removed from the original intention of their creator. Each figure displays a partial human form seemingly held captive within the inescapable confines of the crude, unshaped marble. As art historian William Wallace indicates, "with the excess envelope of marble sheathing each of the unfinished statues, we see the figures "emerging" from the blocks, the figures in a titanic struggle to free themselves from the raw material."[94]

I too see figures, each in their own distinctive way, struggling to break free. And I feel a sense of futility and sadness, for these human figures, each muscular and striving, are restrained by an inescapable burden and are ultimately doomed to be forever contained by it.

2.2.2.2 The Emerging Metaphorical Vision

In the years following my visit to the Galleria dell'Accademia the images of *David* and the *Boboli Slaves* stayed with me. Once I began as a chaplain to people with intellectual disability living in institutions the images broke into my consciousness with even more vigor. It was as if I was being compelled to draw parallels between these Renaissance figures and their circumstances, and the lives of the people with intellectual disability with whom I engage in pastoral relationships.

I reflect upon the juxtaposition between the confident, victorious and free *David,* and the beleaguered and bound *Slaves*. I reflect upon why it is that *David* is richly admired by many whilst the *Slaves* receive relatively scant attention. I reflect upon the contrasting emotions that each evokes in me as an onlooker. I read the speculations of commentators as to the socio-political discourse presented by the *Slaves* in their unfinished state. I wonder why it is that different social commentators can label the same 'slave' with a different ascription,[95] thus

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[93] Sala, *Michelangelo*, 170.

[94] Wallace, William. *Michelangelo: The Complete Sculpture, Painting, Architecture*. (New York: Beaux Arts Editions, 1998), 96.

[95] For example, one of the unfinished *slaves* is seen seemingly bearing a large, crude block of marble on his head. Sala refers to this figure as *Atlas.*

inviting a variety of oppression discourses to emerge. I speculate as to what the discourse might have been if indeed they had been finished and enabled to assume their intended place around the tomb of Pope Julius II.

And I keep thinking of the lives of those beleaguered and ever-bound *Slaves.*

2.2.2.3 A Contemporary Metaphorical Perspective: Who Do We See?

Discourses concerning the Slave metaphor raise penetrating questions as to perspectives on people with an intellectual disability living in institutional accommodation today. These questions are as follows:

- What is the nature of the oppressive burden that people with an intellectual disability experience living in an institutional context today?
- To what extent is that burden a part of who they are as a person living with a disability, and to what extent is it imposed by their lived context?
- To what extent are people with an intellectual disability stigmatized by the labels that individuals and institutions place on them?
- To what extent do such labels limit their capacity to view themselves as people of worth, and to achieve their own goals and ambitions?

However, most pointedly, these questions are not simply there to be asked of others who live and work in this institutional environment. These questions apply to the pastoral carer who seeks to pastorally engage with people with an intellectual disability in this context. Therefore, as a pastoral carer, I consider my capacity to oppress and to acquiesce to the oppressive nature of institutionally-imposed relationship. I reflect on my capability to prejudicially construct labels and stigmatize, and my capacity to let my pastoral focus be diverted from those with whom I seek to offer caring relationship towards those more widely regarded as admirable.

I am also compelled to consider who it is I view when I look upon those with whom I offer care. To what extent are they to me simply figures representing oppression, or human beings with whom I can engage pastorally,

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Sala, *Michelangelo*, 170.

Wallace refers to this same figure as *The Block-Head Slave.*

Wallace, *Michelangelo*, 96-97.

This ascription is shared by the website author to which the plate that prefaces this chapter is attributed.

sharing a God-given status of equal regard? To what extent do I seek to keep distance from these figures out of fear of having personal security threatened? To what extent do these people threaten any personal sense of self-sufficiency or omnipotence? And amidst such questions I have cause to remember the questioning, pastoral frailty expressed by 1960s' American chaplain to the 'mentally retarded,' Robert Perske, who, in the face of overwhelming institutional oppression, sorely questioned his own pastoral capabilities and theological assumptions[96].

The answering of such issues will contribute significantly to understanding how those who seek to engage in pastoral relationship with these oppressed people can best offer and develop liberating model relationships with them.

2.3 Models of Disability

As a preface to such deliberation, it is noted that people who live with a disability, both intellectual and other, are the subject of much considered discourse as to how they and their lived environments ought to be best interpreted and understood. It is also noted that some disability models and critiques have emerged from movements and discourses beyond that of disability, such as that of the feminist movement.[97] These can bear application to people with a disability and their lived circumstances on the basis of discernibly similar socio-politically

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[96] Perske, Robert. "The Gap between the Mentally Retarded and the Pastor: A Case Study of the Gap between Ministry and People." In *The Pastoral Voice of Robert Perske*, edited by William Gaventa and David Coulter, 93-102. (New York: The Haworth Pastoral Press, 2003), 94-96.

[97] See,
Rothschild, Joan. *The Dream of the Perfect Child*. (Bloomington: Indiana University Press, 2005). Here, the male/female Western duality is described in terms of the superior male self which represents mind, reason, culture, spirit and self, while the female self represents nature, body, matter and other. See 8.
The stigmatized *otherness* of the female reinforces the *perfectibility of man*. See 38.
This parallels the stigmatized institutional deviant who becomes the object of fear for wider society and the focus of a eugenics agenda.
See also,
Chesters, Janice. "A Horror of the Asylum or of the Home: Women's Stories 1880-1910." In *'Madness' in Australia: Histories, Heritage and the Asylum*, edited by Catherine Coleborne and Dolly MacKinnon, 135-44. (St Lucia: University of Queensland Press, 2003).
Here, a feminist critique of Australian institutionalisation defines such facilities as being controlled by male figures of oppression, such as clinicians, police and judges, who specifically sought the incarceration of women.
For example, see 136.

constructed understandings of issues such as oppression, freedom, embodiment and minority rights.

Thus the following disability models are worth articulation and critique so as to discern the most appropriate model for engaging with and reflecting upon the nature of the lives of those who live with an intellectual disability in an institutional context.

2.3.1 The Christian Tradition Model

The development of a disability model based on a rendering of Christian tradition is an inexact art. Amidst the plethora of biblical scholars and theologians who have, since soon after the time of Christ, posited their scriptural interpretations for consideration, the selection of those regarded as representative is inherently subjective in character. For example, as disability theologian Brian Brock asserts, the historic 'Western canon' of biblical interpreters who are commonly cited in scholarly debates today is mostly comprised of white males.[98] Countless worthy voices from recent and more distant times are silent. Therefore, the scholarship offered here can only be regarded as "... a beginning, a first sampling of what has traditionally been considered the main stream of Western Christendom."[99]

A significant difficulty also arises when the thinking of the distant past, before the word 'disability' had even come into usage, is found to be seemingly incongruous with more contemporary insights regarding disability from a Christian perspective. Brock asserts that it is the concept of 'communion of saints' that serves as the necessary bridge between past and present. It is from within this culturally diverse yet unifying ecclesial concept that Christians throughout the ages recognise that they "... have read a single set of scriptures within a shared confession of the role of the person and work of Jesus Christ ... with a theologically inflected understanding of the very concepts of tradition and history."[100]

A search of the Patristic literature by ecclesial historian Almut Caspary begins with the teachings of Basil the Great, Gregory of Nyssa, and Gregory of

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[98] Brock, Brian. "Introduction: Disability and the Quest for the Human." In *Disability in the Christian Tradition: A Reader*, edited by Brian Bock and John Swinton, 1-23. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 5-6.

[99] ibid., 6.

[100] ibid., 7.

Nazianzus. All 3 scholars focus on similar concepts, namely, a common humanity, the superiority of actions over words, and charity as the highest Christian endeavour. Gregory of Nazianzus particularly highlights the importance of philanthropic care for the disfigured as the epitome of loving action, the greatest of all virtues.[101] The ethical concern here is that all people should live well with each other. The sick are regarded as fellow brothers and sisters in Christ who share the same nature with us all.[102] The outsider, shunned from human community, is theologically and actively connected to all humanity.[103]

Augustine's teachings, while not expressive of a disability theology, have, through his assumptions on human nature, sickness, and health, proved influential in the formulation of such theology in later centuries. For example, he challenges notions of normality in the light of the one perfect human being, Jesus Christ. As such, all human beings fall short of this Christological ideal.[104] In terms of those born with infirmity he affirms their fundamental resurrected identity when he states:

> 'Concerning monsters [monstra] which are born and live, however quickly they die, neither is resurrection to be denied them, nor is it to be believed that they will rise again as they are, but rather with an amended and perfect body ... the true form of human nature.' [105]

In terms of those who are the focus of this extended reflection it is interesting to note that though Augustine upholds the importance of rationality to human identity he does not equate loss of reason with any loss of full human status. As Brock explains:

> To be human is to be the bearer of a set of traits, including rationality, whether they are empirically expressed or not. The

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[101] Caspary, Almut. "The Patristic Era: Early Christian Attitudes toward the Disfigured Outcast." In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 24-64. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 35.

[102] For example, Gregory of Nazianzus is cited by Caspary in *Oration 14* as stating, " 'For we are all one in the Lord, whether rich or poor, whether slave or free' [Gal.3:28], whether in good health of body or in bad; and there is one head of all, from whom all things proceed: Christ."
ibid., 59.

[103] ibid., 36-37.

[104] Brock, Brian. "Augustine's Hierarchies of Human Wholeness and Their Healing." In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 65-100. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 68-70.

[105] ibid., 69. Here, the author is citing Augustine's *The Enchiridion*.

> question of inclusion in the human family, then, is *not* a matter of expressed functional capacities, but descent by birth.[106]

Similarly to Augustine, Thomas Aquinas upholds that all human beings are born in the image of God. All are whole in terms of their created soul, and in their essential aptitude for knowledge and love of God.[107]

For Aquinas, the rationality of the human being is not derived from individual cognitive capacity. The soul's rationality is located in the image of God in the human being.[108]

Within his 'theology of bodily weakness' Aquinas does not see cognitive impairment impeding a person's capacity for relationship with God. In Christ, restorative grace is received by baptism, through which all are made members of the Body of Christ. Through this all human beings find hope in the promise of bodily resurrection.[109]

Christian ethicist Amy Hall describes Julian of Norwich as "... intensifying and maternalizing ... the account of grace of Thomas Aquinas, by describing Christ's blood as that which feeds, nourishes, joins, and transforms us."[110] Writing as a woman amidst a highly patriarchal society, and as one who sought what may be termed today as a 'disability identity' with the suffering Jesus, she discovers Christ's heart for the poor and the outcast.[111] Through the example of Christ's Passion, " 'we should bear our sufferings gladly and lightly ...' "[112] Such identity suggests that it is through the suffering of the needy that they, rather than the powerful, who receive the greatest mercy.[113]

For some, the legendary story of reformer Martin Luther suggesting a twelve-year-old boy from Dessau, presumed to be suffering with Prader-Willi Syndrome, should be suffocated, raises the question of what benefit he can

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[106] ibid., 72.

[107] Romero, Miguel. "Aquinas on the *Corporis Infirmitas*: Broken Flesh and the Grammar of Grace." In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 101-51. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012,, 103.

[108] ibid., 105.

[109] ibid., 123.

[110] Hall, Amy. "A Ravishing and Restful Sight: Seeing with Julian of Norwich." In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 152-215. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 154.

[111] Brock, "Introduction," 14.

[112] Hall. "A Ravishing and Restful Sight," 182. Here, the author is citing Julian in *Revelations of Divine Love.*

[113] ibid., 159.

contribute to a disability discourse.[114] However, his teachings, on what we refer to as disability, remain instructive.

Most significantly is his rejection of a discourse that renders people with disability as ‘different’ from those who are deemed to be ‘normal.’ Through the work of Christ on the Cross all human beings are justified by faith. Therefore, what human beings are is not defined by their attributes, but by the grace bestowed on them through Christ.[115] As Luther states, the human being (i.e. all human beings), “ ‘can be freed and given eternal life only through the Son of God, Jesus Christ ...’ ”[116] With this point of recognition rebuffed a source of exclusion and discrimination is negated. He goes on to indicate that all human beings, no matter their physical particularities, are instruments through which God addresses other human beings.[117]

In the teaching of John Calvin, as with Luther, we see a theologically transcribed sense of equality amongst all human beings, inasmuch as he regards all people in a state of sinfulness.[118] While he speaks more in terms of community than the needs of discrete individuals he does affirm the inclusion of the sick and the prisoner in the life of the church community, including participation in the sacraments.[119] The church is to be a source of hospitable presence to the foreigner, widow and orphan within society. Such needy people are, in Calvin’s words, “ ‘... under the guidance and guardianship of God and are protected by his hand.’ ”[120] Of some concern is that, despite his affirmation of equality, his focus on intellectual capability as intrinsic to human identity could reflect a bias against those with an intellectual disability.[121]

In the later Enlightenment period philosopher Georg Hegel, though limited in his commentary on those we would judge as having an intellectual disability, proffered significant input into disability discourse from an ecclesial perspective.

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[114] Heuser, Stefan. "The Human Condition as Seen from the Cross: Luther and Disability." In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 184-215. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 185-89.

[115] ibid., 191.

[116] ibid.

[117] ibid.

[118] Creamer, Deborah. "John Calvin and Disability." In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 216-50. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 225.

[119] ibid., 220 & 225.

[120] ibid., 247.

[121] Ibid., 226.

He sees human beings as fundamentally relational in nature. Christianity is the highest form of religion because it is the one that can best nurture freedom and autonomy. Human beings are fundamentally relational in nature, having been created by the Triune God.[122] Therefore, from a theological perspective, the world is communal.[123] While Hegel does assert that the inability of those with cognitive impairment to live as autonomous beings limits their capacity to be regarded as fully functioning selves, defined in terms of spirit, he does, at this point, assert the role of religion. This is the realm of absolute spirit, of narrative, symbol and liturgy, which is accessible to people with cognitive impairment, along with all others.[124] In today's language, the church becomes a place of hospitality for all.

While Soren Kierkegaard had no concept of 'disability' in a contemporary sense he does assert that the one factor to limit the flourishing of all human beings is the problem of sin. It is sin that limits self-understanding, impedes relationships and prevents wholeness of being.[125] In terms of a disability discourse one of the beneficial outcomes of this fundamental theological assertion is that it primarily describes human weakness in terms of relationship to sin, and not in terms of physical abilities and health. This discredits the later social tendency to create normalcy divisions on the basis of ableist / disabled distinctions.[126]

In moving to the twentieth century we see disability theology and ecclesiology at the heart of Dietrich Bonhoeffer's implacable resistance to the Nazi regime's distorted theological idealization of strength and human prowess,[127] along with its barbaric implementation of a programme of eugenics towards those deemed 'weak'. In defence of these marginalised people he asserts:

> 'Life created and preserved by God possesses an inherent right,

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[122] Brock, "Introduction," 15.

[123] Wendte, Martin. "To Develop Relational Autonomy: On Hegel's View of People with Disabilities." In *Disability in the Christian Tradition: A Reader,* edited by Brian Brock and John Swinton, 251-85. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 258.

[124] ibid., 262.

[125] Brittain, Christopher. "Between Necessity and Possibility: Kierkegaard and the Abilities and Disabilities of Subjectivity." In *Disability in the Christian Tradition: A Reader,* edited by Brian Brock and John Swinton, 286-320. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 288-89.

[126] ibid., 289-90.

[127] Brock, "Introduction," 16-17.

> completely independent of its social utility. ... There is no worthless life before God, because God holds life to be valuable. Because God is the Creator, Preserver, and Redeemer of life, even the poorest life before God becomes a valuable life.'[128]

Bonhoeffer railed against a mainstream church that acquiesced to the will of its political masters, preaching a gospel of "... the creaturely bond that unites all human beings ..."[129] In doing so he was conceiving of a church welcoming of all.

The impetus for his theological and ethical position had come from a visit in 1933 to Bethel, a village designed to care for the weak. This visit led to an initial statement of faith termed the Bethel Confession. However, what we also see emerging at this point is a 'theology from below,' based on first-hand human experience as opposed to purely academic or prosaic considerations.[130]

Though his vast tomes dealt little with a disability discourse influential German theologian Karl Barth informs the tradition through his emphasis on a theocentric account of humanity. A contemporary disability discourse may focus on a variety of cultural values. However, by focussing on the "... one real human, Jesus Christ, theology draws from revelation a deeper and more unifying definition of the human and so of the relationships between humans within which disability language does its work."[131] This theocentric character is well described when he states,

> 'As the man Jesus is himself the revealing Word of God, he is the source of our knowledge of the nature of man as created by God. The attitude of God in which the faithfulness of the creator and therefore the changing relationships of the human being created by him are revealed and knowable is quite simply his attitude to the *man Jesus*: ...'[132]

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[128] Wannenwetsch, Bernd. " 'My Strength Is Made Perfect in Weakness': Bonhoeffer and the War over the Disabled Life." In *Disability in the Christian Tradition: A Reader,* edited by Brian Brock and John Swinton, 353-90. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 353.
Here, the author is citing Bonhoeffer in his text, *Ethics.*

[129] ibid., 361.

[130] ibid., 354-55.

[131] Brock, "Introduction," 17.

[132] Wood, Donald. "*This* Ability: Barth on the Concrete Freedom of Human Life." In *Disability in the Christian Tradition: A Reader,* edited by Brian Brock and John Swinton, 391-426. Grand Rapids & Cambridge: William B. Eerdmans Publishing Company, 2012, 407.
Here, the author is citing Barth's *Church Dogmatics III.*

Amongst the wide range of disability theologians who inform the Christian disability tradition today Jean Vanier is particularly significant. As with Bonhoeffer, his theology emerges from practical experience with the poor. In 1964 he established the first of his faith-based L'Arche community homes for adults with intellectual disability. Today these homes are spread across much of the world. His theology has been described as "theological realism," signifying the Christian understanding that emerges from the outworking of God in our lives, which in the case of L'Arche concerns its members being informed by 'the poor' who guide them in becoming friends with God,[133] by being the face of Christ. As Vanier states,

> 'Jesus calls his disciples not only to serve the poor but to discover in them his real presence, a meeting with the Father. Jesus tells us that he is hidden in the face of the poor, that he is in fact the poor… Jesus is the starving, the thirsty, the prisoner, the stranger, the naked the homeless, the sick, the dying…'[134]

In the early twenty-first century this 'theology from below' is one of the strong threads informing the ongoing and ever-developing Christian disability tradition.[135]

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[133] Reinders, Hans. "Being with the Disabled: Jean Vanier's Theological Realism." In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 467-511. Michigan & Cambridge: William B. Eerdmans Publishing Company, 2012, 472. Here, the author is citing Vanier in *Community and Growth.*

[134] ibid., 486

[135] Alongside this theological discourse there was, in Western, pre-Enlightenment society, a prevailing interpretation and application of Judeo-Christian values which could determine how people with an intellectual disability, or those thought to be so on the basis of misunderstood behaviours, were understood. For example, bodily characteristics that fell outside of such normatively held values could denote 'the insane' as evil. The apparently irrational rantings and writhings of those confined in asylums were viewed as signs of demon possession, causing such persons to be regarded by mainstream society as objects of fear. See,
Foucault, *Madness and Civilization*. 189-209.
However, such people were also viewed by others as denoting the 'suffering Christ,' and perceived to be of transcendent status, and a blessing to others. See,
Clapton, Jayne, and Jennifer Fitzgerald. *The History of Disability: A History of 'Otherness'* Renaissance Universal, 1997 [cited 1/04/2005].
With the onset of the Age of Enlightenment religious stigmatization was challenged by more scientific forms of categorization, and yet religious labelling, such as that of the 'Holy Innocent,' persisted. See,
Wolfensberger, Wolf. *The Origin and Nature of Our Institutional Models*. (New York: Human Policy Press, 1975), 14-15.
The residual effect could also be evidenced through people with an intellectual disability being regarded in charitable tones. Amongst Australia's disability institutions, that which is now known as Minda Incorporated but which at the time of inauguration in 1898 was referred to as Minda – The Home for Weak-Minded Children, referred to their caring task as, ".... this beneficient and Christian work." See,

So, as we scan theological scholarship across the ages, what factors emerge as determinative in shaping an abiding model of disability in the Christian tradition? There are 3 key issues that are common to much of this tradition's scholarship.

Firstly, Christian thinkers, each in their own way, affirm the sense in which human beings are related to each other through Jesus Christ. To inject such a fundamental theological theme into contemporary definitional and activist disability discourses that can serve to make exclusionary distinctions between 'normal' and 'other' is to assert our shared humanity in God.[136]

Secondly, there is a clear emphasis in the Christian tradition away from empirical definitions of normality. As soon as such criteria are applied, such as those that relate to levels of cognitive capacity, then people with intellectual disability can be deemed less than fully human, and assume a socially marginal status.[137] In Christ created humanity is welcomed and loved unconditionally. All are recipients of grace.

Thirdly, Christian activists from the Patristic era to the present have called for embodied, practical expressions of God's love for the outcast. To love incarnately is to embody God's love for the world. In the terminology of Vanier it is to be Christ to our neighbour.[138]

From the perspective of this model the Slave is regarded as my brother or sister in Christ. So-called marks of slavery are not marks of abnormality at all, are not causes for exclusion, but are the marks of a shared humanity that create bonds of mutual love. Such marks, though real, do not obscure the face of Christ I see in this human being before me, and which they are invited to see in me. I open my arms wide in an act of genuine, embodied love, and wait to see if the gesture is reciprocated.

2.3.2 The Limits Model

Minda. "Prospectus: With Report of the Opening." 1-15. Adelaide: Minda - The Home for Weak-Minded Children, 1898, 12.

Even today, amidst the highly medicalised formulations of disability-related health care service, Judeo-Christian conceptualisations of sin, weakness, burden, and the need for wholeness and healing, towards those with disability, including those with intellectual disability, remain. See,

Clapton & Fitzgerald, *The History of Disability*, sec.2, par.2.

[136] Brock, "Introduction," 19.

[137] ibid., 19-20.

[138] ibid., 20-21.

This model of disability has emerged in recent times from the historical portrayal of people with a disability as “suffering personified (to be pitied), images of saintliness (to be admired), symbols of sin (to be avoided) or signs of God’s limited power or capriciousness (to be pondered).” Whether such religious perceptions were initially intended to be viewed with either positive or negative, utterly incarnate or transcendent, regard, they deny the opportunity for people with disability to be principally viewed as human beings, and as those created in the image of God. Instead, regard is based on their perceived disabled identity.[139]

The Limits model thus seeks to move away from the notion of those embodied and disabling characteristics that can define a person principally as disabled, but that reflect on the universal experience of limitation as defined through embodiment and social context. In the process, this model negates the notion of disability by emphasising the sense in which all people live with limits, within the context of bodily and social restraints, to varying degrees.[140]

From a theological perspective, limits are understood as an expression of what it means to be a created being, as opposed to being regarded as a negative or evil human characteristic.[141] Thus, whilst the categorization of people as ‘disabled’ seeks to marginalise and separate, the notion of limits affords a point of commonality amongst all humanity, and the opportunity to respond to our limitations with expressions of human creativity.

This model, whilst constructing a perspective that regards those otherwise viewed as disabled in terms that emphasise common human worth and positive regard, in doing so, defines disability as ‘problem.’ This avoidance of the notion of disability means, as sociologist Tanya Titchkosky argues, that disability cannot be regarded as a “productive agent bringing something new or important into the world.”[142] Thus, because of its negative regard, it eventually denies the possibility of disability being the ground of positive self-regard or creative, fulfilling self-expression.

Regarding the Slave, the person with the disability who is so regarded bears a burden that places limits on their human identity and social contribution.

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[139] ibid., 59-60.
[140] ibid., 65.
[141] ibid.
[142] Titchkosky, Tanya. "Disability in the News: A Reconsideration of Reading." *Disability & Society* 20, no. 6 (2005): 655-68, 662.

The observer becomes less the onlooker and more the one who recognises a sense of kinship or solidarity with the burdened other. She/he and the other both live with limits, seeking to aspire and achieve in life amidst the limitations imposed upon them. The relationship develops an egalitarian character. The kindred observer invests a sense of positive regard and worth in the other as they see the other both sharing with them in the limits of the human condition, and in the capacity to achieve amidst those limits.

Contrastingly, but with certain parallels to this model, disability theologian Amos Yong promotes a model that describes all people as experiencing disability at some time. Whilst, unlike the limitations model, disability is not to be avoided, it does approximate this model in terms of common kinship and true interrelationship.[143]

2.3.3 The Medical Model

As referred to at the beginning of this chapter, the Medical model of disability is generally defined as that which views “disability as a defect or sickness which must be cured through medical intervention.”[144] Much of our understanding of disability has been dominated by this model, and the subsequent categorizing of disability under the headings of sickness, disease and rehabilitation.[145] Until recently this model has largely stood unquestioned by the wider community.

According to this model the locus of disability lies solely in the person, and thus it is the person who is in need of a cure, hence the role of rehabilitation. However, where the disability cannot be cured, the social response in Western society has, generally speaking, been to institutionalise the person in question,[146] thus separating the one who is considered diseased or sick and, according to the prevailing social norms, abnormal, from an otherwise healthy society.

The consequence of being widely regarded as diseased or sick is that the person in question then becomes in need of rescuing or saving by those with the requisite professional medical skills to do so.[147]

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[143] Yong, Amos. *Theology and Down Syndrome: Reimagining Disability in Late Modernity*. (Waco: Baylor University Press, 2007), 257.

[144] Kaplan, *The Definition of Disability*, sec.1, par.2.

[145] Hyland, Tanya. "A Critical Analysis of the Ontario Disability Support Program Act and Social Citizenship Rights in Ontario." (quantitative research, Carleton University, 2001), 19.

[146] ibid., 20.

[147] Campbell, Gillett, & Jones. *Medical Ethics*, 184.

Thus, as Newell asserts, because of the dominant medicalised conception of disability, “people with disability continue to be the objectified others to be acted upon …"[148] The person with the disability becomes the needful, dependent client, the one who relinquishes power and autonomy to the health care service. As Smart and Smart indicate, "the Biomedical model is often conceived to be a model of experts in control, therefore reducing individuals with disabilities to the role of passive and compliant patients,”[149] and negating the role of the individual as decision-maker. Where the individual has an intellectual disability and thus has diminished cognitive capacity, the possibility of even greater levels of passivity and compliance emerges.

The Medical model of disability highlights the embodied nature of disability, the sense in which disability is attributed to and contained by the one who is medically diagnosed as being disabled. Whilst this model highlights the person diagnosed with disability as requiring medical care in order to live as well as possible, it negates the possibility of disability as that which happens to the person in question by their lived context, and the socio-political influences that come to bear.

In terms of the Slave metaphor, the person with the disability who is viewed from the perspective of the Medical model is regarded as a burden to herself or himself, as well as to society. She or he is in need of help from those with the requisite professional skills for easing the burdens of others. As systematic theologian Paul Tillich states, the one who is objectified and regarded as burden has the capacity to evoke in the observer fears of their own non-being, and a subsequent desire to resist and be protected from the source of such fear.[150] Thus the space between us and the burdened one is a space not to be transgressed by either us or them.[151] We then allow our gaze to be diverted towards the entirely more admirable and attractive vision of *David*, a figure deemed utterly

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[148] Newell, Christopher. "Disabling Health Systems." *Interaction* 12, no. 4 (1999): 13-16, 14.

[149] Smart, Julie, and David Smart. "Models of Disability: Implications for the Counseling Profession." In *The Psychological and Social Impact of Illness and Disability*, edited by Paul Power and Dell Orto, 75-100. (New York: Springer Publishing Company, 2007), 81.

[150] Tillich, Paul. *Systematic Theology: Volumes 1-3*. (New York: Harper and Row Publishers, 1967), 75.

[151] The language of *us and them* can be justified because of the objectified regard generated by the perception of the other as non-being. That which defines the other in terms of human being has been cast to one side.

more commensurate with worthy social norms related to socio-economic status, identity and behaviour. [152]

2.3.4 The Medico/Bio-Technological Model

A contemporary manifestation of the Medical model of disability can be viewed in the the Genetic or Bio-technological model of disability.

In this model people with a disability are viewed as having an impairment in the form of their ‘bad’ genes, and their disability elicits the social desire to have those genes eliminated.[153] Whereas the eugenics movement sought through the sterilisation of women and minors to eliminate the possibility of reproduction for people with disabilities, thus eliminating people with a disability as a social grouping, more recent advances in bio-technological research have led to the capacity for science to manipulate human genes in such a way so as to ensure that ‘bad’ genes that could lead to a person giving birth to a baby with a disability can be eliminated. This gene manipulation could hypothetically, for example, take the form of:

- gene insertion – the insertion of copies of ‘normal’ genes into the chromosomes of diseased cells so as to eliminate a perceived inherited genetic deficit [154]
- gene modification – the chemical modification of defective DNA sequences[155]
- gene surgery – the removal of a faulty gene from a chromosome. [156]

Similarly, discussion on stem cell research is predicated on the religiously-inspired notion of saving or delivering one from disability,[157] and the construction by those whom Goggin and Newell refer to as the socio-politically “privileged voices”[158] of who ought to be included or isolated from or eliminated from mainstream society.

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[152] The means by which one becomes drawn towards the one perceived as similar to oneself, and/or sees the other as admirable or enviable, is referred to as the ‘attraction paradigm’, and will be discussed further in chapter 2.

[153] Clapton & Fitzgerald, *The History of Disability*, sec.5, par.1.

[154] Suzuki, David, and Peter Knudtson. *Genethics: The Ethics of Engineering Life*. (Sydney: Allen & Unwin, 1988), 184.

[155] ibid.

[156] ibid., 185.

[157] Goggin, Gerard, and Christopher Newell. "Uniting the Nation? Disability, Stem Cells and the Australian Media." *Disability & Society* 19, no. 1 (2004): 47-60, 56.

[158] ibid.

As with the more general medicalised perception of disability, such bio-technological concepts are predicated on the notion of disability as ‘private catastrophe’[159] or ‘tragedy.’[160] It therefore negates the possibility of people with a disability being regarded as those of intrinsic worth, or of having the capacity to make a meaningful social contribution by dint of their impaired skills and abilities. It also negates the notion of people with a disability as relational beings capable of engaging in a mutually-enriching relationship with others.[161] In equating human value with the precise nature of one’s DNA, it eliminates, in a value-neutral manner, the fundamental intuitive connection with the ‘human family.’[162] Therefore, in eliminating genetic difference for the sake of a scientific representation of human worth, the opportunity for a pluralistic expression of society is diminished.

And the Slave is observed as one whose burden is deemed unacceptable. The burden is regarded as being capable of elimination by those with the requisite skills. The likes of those who bear such burdens are deemed capable of being bred out of existence. The observer is relieved of the burden associated with such a gaze. The right to live autonomously and with pride amidst the perceived bearing of burden is withdrawn by the observer. The right to regard oneself as more than a slave is removed.

2.3.5 The Social Model

The Social model of disability emerged, both in an enacted and academically articulated form, from the felt need to develop an understanding of disability that moved the locus of disability away from the pathologically, embodied individual, and into the realm of society’s capacity to disable. While this perspective wasn’t specifically named as the *social model* until 1983[163] such attribution represented an emerging paradigm by which people with a disability could be understood in relation to their environment.

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[159] ibid., 57.

[160] e.g. ibid., and
Clapton, Jayne. "Disability, Ethics, and Biotechnology: Where Are We Now?" In *Voices in Disability and Spirituality from the Land Down Under*, edited by Christopher Newell and Andy Calder, 21-31. (New York: The Haworth Pastoral Press, 2004), 26-27.

[161] ibid., 28.

[162] Edmonds, Matt. *A Theological Diagnosis: A New Direction on Genetic Therapy, 'Disability' and the Ethics of Healing*. (London & Philadelphia: Jessica Kingsley Publishers, 2011), 91.

[163] Light, *Social Model or Unsociable Muddle?* sec.4, par.1.

However, the term ‘social model of disability’ had been variously interpreted prior to the early 1980s and continues to be critiqued and reinterpreted to the present day. Each new interpretation usually reflects the socio-political and cultural perspectives of its authors. Those perspectives include the following socially-based models.

2.3.5.1 The Social Oppression Model

In 1976 the Union of the Physically Impaired Against Segregation (UPIAS) defined disability as,

> the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.[164]

This definition philosophically encapsulates a radical re-orientation of the understanding of disability in terms of location and social justice. This new understanding moves the locus of disability from the individual to society and its capacity to be a source of disablism. What emerged was the first clearly articulated Social model of disability which was prefaced on the radical redefining of disability expressing that “disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.”[165]

Therefore, disability is no longer regarded as the direct consequence of an impairment, but is viewed as “the interaction between an impaired individual and an essentially hostile environment."[166] This hostile, unjust environment expresses its capacity to disable by means of social oppression, inequality and exclusion.[167]

The disabling effects of social oppression, inequality and exclusion are, according to UPIAS, constructed and expressed through oppressive interpretations of social and environmental issues such as income, access and

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[164] ibid., sec.3, par.2.
The UPIAS definition of *disability* and *impairment* will be elaborated upon when the issue of the Social model and codification is considered.

[165] Union of the Physically Impaired Against Segregation, *Fundamental Principles of Disability*, 20.

[166] d'Aboville, Etienne. "Social Work in an Organisation of Disabled People." In *Social Work: Disabled People and Disabling Environments*, edited by Michael Oliver, 64-85. (London: Jessica Kingsley Publishers, 1993), 69.

[167] Thomas, Carol. "How Is Disability Understood? An Examination of Sociological Approaches." *Disability & Society* 19, no. 6 (2004): 569-83, 570.

institutionalisation as they impinge on the lives of people with disabilities.[168] Other commentators developed their own lists of social and environmental exclusion based on their own unique, cultural and time-specific considerations. For example, Barnes and Mercer cite Bowe's 'Handicapping America' where he lists six major arenas where people with disabilities in America experienced exclusion in the late 1970s. These were architecture, attitude, education, occupation, legal affairs, and personal issues ranging from possessing few material resources to stigmatization based on the reality of living daily with an impairment [169]

2.3.5.2 The Socio-Structuralist Model

In contradistinction to the Medical model the Socio-Structuralist perspective of disability focuses on the wider environment in which a person with a disability lives, and the macro social phenomena such as economy, culture, political systems and institutional practices which constitute that environment.[170] The focus is on that particular environment and its capacity to disable the individual and limit his or her capacity to lead a fulfilling, socially-integrated life commensurate with accepted social norms.

The emphasis on the wider environment and its socially-constituted components is driven by the understanding of the primary causative effect that the environment has on the individual. As Fougeyrollas and Beauregard state:

> Variation of human development and the disability creation process is closely linked to its cultural construction. … Demonstrating that environment is the key, one must assert that nothing can be said in advance. With regards to human development and the disability creation process, the environment cannot be considered as an accessory. Everything should be put in context, along with the difficulties and complications that result from this, particularly from the administrative and mechanistic logic points of view.[171]

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[168] Union of the Physically Impaired Against Segregation. *Union of the Physically Impaired against Segregation* Union of the Physically Impaired Against Segregation, 1974 [cited 28/04/2008]. Available from, http://www.leedsdisability.ac.uk/-studies/archiveuk/UPIAS/UPIAS.pdf. e.g. sec.16, par.1 & sec.18, par.1.

[169] Barnes, Colin, and Geof Mercer. *Disability*. (Cambridge: Polity Press, 2003), 10.

[170] Gleeson, Brendan. *Geographies of Disability*. London: Routledge, 1999. 19.

[171] Fougeyrollas, Patrick, and Line Beauregard. "An Interactive Person-Environment Social Creation." In *Handbook of Disability Studies*, edited by Gary Albrecht, Katherine Seelman and Michael Bury, 171-94. (Thousand Oaks: Sage Publications, Inc., 2001), 190.

The emphasis on the socially causative effect on the individual has, for supporters of the Social model, appropriately undermined “the authority of medical construction, and the notion that disability is an ‘illness’ which can be healed, or at least ameliorated, through health technologies and practices.”[172]

Gleeson critiques this model in terms of the extent to which it disembodies the human form from the shaping of social experience. As he states, “we must not abandon and neglect the critical fact that it plays a foundational, if historically and spatially specific, role in the constitution of human society.”[173] Similarly, Shakespeare, amongst various criticisms, critiques this model for its reference to a narrow group of physical impairments, thus neglecting the narrative of people with intellectual disability. He also admonishes the authors of this model for focusing so much on the disabling effects of society, out of the desire to disown medical conceptualisations, that they risk rejecting the embodied and problematic nature of impairment.[174]

2.3.5.3 The Socio/Rights-Based Model

The emergence of disability advocacy groups in the United States and Europe in the 1960s followed the silencing of people born with a disability in the earlier decades of the twentieth century, both through domestic concealment and institutionalisation. Both responses were generated by those born with and living with disability being widely regarded as objects of shame, non-productive in terms of function, and pathological in nature. This shame-based objectifying of people with a disability extended to the families of children born with a disability who were branded with shame through association.[175] The emergence of disability rights activism in the 1960s was accompanied by the emergence of socially active young people with physical disabilities who grew up believing in

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[172] Gleeson, Geographies of Disability, 20. Here Gleeson is summarising the position of Oliver, Michael. *Understanding Disability: From Theory to Practice*. 2nd ed. London and New York: Palgrave Macmillan, 2009.
Gleeson does state that Oliver is not endorsing the Structuralist model.

[173] ibid., 20.

[174] Shakespeare, Tom. "The Social Model of Disability." In *The Disability Studies Reader*, edited by Lennard Davis, 266-73. (New York and London: Routledge, 2010), 269-70.

[175] Eiesland, Nancy. "Barriers and Bridges: Relating the Disability Rights Movement and Religious Organizations." In *Human Disability and the Service of God: Reassessing Religious Practice*, edited by Nancy Eiesland and Don Saliers, 200-29. (Nashville: Abingdon Press, 1998), 202.

their right to social participation.[176] Out of this foment emerged a disability rights movement that claimed its civil rights amidst the overall atmosphere of political activism of various oppressed and/or minority groupings, such as women and Afro-Americans, throughout the 1960s and 1970s. And so by the mid-1980s countries like Australia were enacting legislation that embraced a rights-based agenda rather than relying on the more protectionist and custodial discourse.[177]

The disability rights movement pointed to barriers that have contributed to institutionalised, societal discrimination, such as prevailing forms of physical infrastructure and attitudes,[178] and the subsequent loss of individual autonomy. In doing so, disability and the attendant rights to which people with disabilities lay claim, have been strongly placed in the realm of socio-political construct.[179]

Nonetheless, it can be argued that in the struggle for disability rights, those who articulated their claim for an autonomous lifestyle have been heard more clearly than those whose words lacked coherence. Social historian Kathryn Ellis has claimed that the emerging environment of disability protest elevated the rights of those with physical disabilities over and above the rights of those with intellectual disabilities. She asserts that the,

> ... privileging of the cognitive, … arguably underpins the civil rights agenda pursued by the disability movement. After all, civil rights are based on the notion of the autonomous human being whose capability for rational thought (and bodily control) means that the individual should be allowed to make decisions and choices for him or herself, provided they do not impinge on the rights of others to do likewise.[180]

Such an argument affirms the capacity for reason to be a defining measure of full and acceptable personhood.

The other concern is that, as some assert, “it has become a way of constructing disability into an identity which is based upon membership of a

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[176] Eiesland, Nancy. *The Disabled God: Toward a Liberatory Theology of Disability*. (Nashville: Abingdon Press, 1994), 54-55.

[177] Clapton & Fitzgerald. *The History of Disability*, sec.4, par.2.

[178] McNamara, Laurence. "Ethics, Ageing and Disability." In *Ageing, Disability and Spirituality: Addressing the Challenge of Disability in Later Life*, edited by Elizabeth MacKinlay, 36-44. (London & Philadelphia: Jessica Kingsley Publishers, 2008), 41.

[179] Clapton & Fitzgerald. *The History of Disability*, sec.4, par.1.

[180] Ellis, Kathryn. "Disability Rights in Practice: The Relationship between Human Rights and Social Rights in Contemporary Social Care." *Disability & Society* 20, no. 7 (2005): 691-704, 701.
Bracketed words are those of author.

minority group"[181] The disability rights agenda defines identity in terms of political cause rather than in a more integrated understanding of personhood, and of what a person with a disability can contribute to their culturally-lived context.

2.4 Cautiously Towards a Workable Disability Model

Each of the models of disability outlined above contributes to a definition of disability. Even where a disability model may be completely discarded as having little or no positive contribution to a contemporary definition, discussion of what is not helpful serves to sharpen thinking as to what is helpful.

Even the Limits model, with its negation of *disability* as a definitional construct in pursuit of more universalizing constructs of human identity, makes a helpful contribution to the issue of definition. For those who seek ownership of the term *disability*, in whatever form, the issue of why the term ought to be claimed contributes to the development of a credible definition.

Disability models contribute their own definition of what disability is and is not. The definitions so described reflect the attitudes, values and needs of those who construct the models,[182] and they reflect in some way the dominant or emerging socio-political influences of their era.

For example, the Medico/Bio-technological model of disability reflects the contemporary rise in bio-technological lines of scientific enquiry seeking ways of eliminating the 'disabling' or 'bad' gene, thus reinforcing the embodied disability perspective. The early manifestations of the Social model of disability, as expressed through oppression and structuralist discourses, reflect an initial and radical reaction against the long-held and all-pervasive objectifying effect of the Medical model on people living with disabilities. The Socio/Rights-based model of disability reflects an age of socio-political activism in which minority and otherwise undervalued, silenced and oppressed social and political groupings, such as women, Afro-Americans, and people with a disability, found a voice and sought to claim their rights as a matter of justice. The Christian Tradition model

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[181] Clapton & Fitzgerald. *The History of Disability* , sec.4, par.3.
See also,
Pfeiffer, David. "The Disability Paradigm." In *The Psychological and Social Impact of Illness and Disability*, edited by Paul Power and Dell Orto, 7-10. (New York: Springer Publishing Company, 2007), 9. Here Pfeiffer asserts that, "the oppressed minority perspective is rejected simply because many people with disabilities are not oppressed."

[182] Smart, & Smart. "Models of Disability." 89.

challenges empirical notions of worth through the concept of human identity being shaped by God's love for all in and through Christ.

With the exception of the Christian Tradition model one of the common characteristics of the models is that they describe what disability is or is not in a uni-dimensional, reductionist form, with a tendency to be time and culture-bound.[183] Furthermore, a particular model of disability has often been observed as claiming a position of universality or utmost primacy in terms of seeking to describe what disability is. Distinctions based on alternative models have found themselves under-valued or ignored. For example, the Medical system construes sickness from the perspective of functional impairment or the rehabilitative perspective of the physician,[184] as opposed to having regard for disability as a more socio-politically constructed form of ailment bearing upon the individual or institutionalised community. A Social model of disability may define the dualistic notion of ability/disability according to labour market principles that define such terms according to the individual's capacity to economically and socially support oneself,[185] while ignoring the capacity of the Medical model and its embodied perspective of people with a disability to define, at least in part, what disability is.

The uni-dimensional approach to disability modelling excludes aspects from other models which might lead to a more mature and inclusive definition that more adequately accounts for what disability is and how it interacts with individuals and their duly constituted environments.

Whereas the earlier decades of the twentieth century conceived of people with a disability largely from a pathological and socially non-productive perspective, the latter decades of the century saw the desire to redress what became observed as a tragic, exclusivist emphasis on the Medical model. However, a Social model emerged with its own exclusivist tendencies and lack of engagement with other models. As recently as 1993, British sociologist Vic Finkelstein, a pioneering contributor to the Social model, defined disability in exclusivist terms when he stated that, "[d]isability is manufactured by attitudinal

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[183] ibid., 88-89.

[184] Michailakis, Dimitris. "The Systems Theory Concept of Disability: One Is Not Born a Disabled Person, One Is Observed to Be One." *Disability & Society* 18, no. 2 (2003): 209-29, 222.

[185] ibid.

and environmental barriers rather than functional limitations.”[186] Disability is segregated from the impaired body and is fixedly located within a prejudicial and oppressive socio-political context.

There is a need to account for disability in a less exclusivist, more integrated form, in a way that acknowledges the complexity of how disability impinges directly on the individual as an embodied being. However, there is also the need for appropriate understanding of the sense in which the environment can disable that same individual through the way in which contextual components are manifested and enacted.

In more recent years, there has been a growing call in Australia and internationally for a more integrated or holistic approach to disability. Social workers Kyung Mee Kim and Edward Canda call for a holistic approach to disability that “encompasses the multiple domains of person and environment,"[187] as is reflected through a careful integration and implementation of both the Medical and Social models of disability. Rehabilitative nurses and researchers Barbara Lutz and Barbara Bowers have also argued for greater integration of rehabilitative and social models.[188] Similarly, in 2011, the South Australian State Government’s Social Inclusion Board, in detailing a comprehensive series of recommendations to advance the lives of people with disabilities, their families and carers, underpins its report by stating that it,

> ..... recognises disability is the product of impairment of functionality and the environment that [the] person lives in. Social, economic and cultural barriers can limit a person with disability’s capacity to participate and be included. These barriers compound

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[186] Finkelstein, Vic. "Disability: An Administrative Challenge? (the Health and Welfare Heritage)." In *Social Work: Disabled People and Disabling Environments*, edited by Michael Oliver, 19-39. (London: Jessica Kingsley Publishers Ltd., 1993), 39.
This position is endorsed by social worker and social model advocate Michael Oliver in, Oliver, *The Politics of Disablement*, and Oliver, Michael. "Defining Impairment and Disability: Issues at Stake." In *Exploring the Divide: Illness and Disability*, edited by Colin Barnes and Geof Mercer, 39-53. (Leeds: The Disability Press, 1996).

[187] Kim, Kyung Mee, and Edward Canda. "Toward a Holistic View of Health and Health Promotion in Social Work with People with Disabilities." *Journal of Social Work in Disability & Rehabilitation* 5, no. 2
(2006): 49-67, 64.

[188] Lutz, Barbara, and Barbara Bowers. "Understanding How Disability Is Defined and Conceptualized in the Literature." In *The Psychological and Social Impact of Illness and Disability*, edited by Paul Power and Dell Orto, 11-21. (New York: Springer Publishing Company, 2007), 16-18.

> and further define the experience of disability and associated problems which need to be overcome.[189]

Furthermore, the report particularises disability by asserting the need for individual assistance on the basis of the nature and degree of impairment but, most specifically, in relation to individual circumstances, capabilities and skills.[190]

In the institutional context being considered in this extended reflection, the implication is that an integrated type of model of disability should be considered. This model needs to account for the institutionally-accommodated person both in an embodied sense as well as in terms of the disabling effect the institution has on their capacity to live a life that approximates the normative expectations of those who live beyond the confines of such a facility.

There has emerged in recent years a broad agreement among scholars that "the limitations associated with impairment are a joint product of biological features, environmental factors, and personal goals." [191] However, when discussion evolves to the point of definition and philosophy, agreement quickly dissipates as to the most appropriate form that a more integrated disability model should assume. As Altman notes, in relation to the task of defining disability, it is "a complicated, multidimensional concept" which, in terms of a global definition, is almost impossible to achieve. [192] Complexity emerges from the nuances contained in the cultural and socio-political orientation and basis for each particular definition and model type. The ambiguity contained in simple, one-line statements and classifications has led to misunderstanding and misuse in the application of disability models, whilst more generous classification schemes seek definition through more empirical measures.[193]

The other definitional issue for advocates of some form of Social model concerns the standard by which disability or ability takes its measure, that is,

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[189] Government of South Australia: Social Inclusion Board. "Strong Voices: A Blueprint to Enhance Life and Claim the Rights of People with Disability in South Australia (2012-2020)." (Adelaide, 2011), 18. Bracketed word that of author.

[190] ibid.

[191] Wasserman, David. "Philosophical Issues in the Definition and Social Response to Disability." In *Handbook of Disability Studies*, edited by Gary Albrecht, Katherine Seelman and Michael Bury, 219-51. (Thousand Oaks: Sage Publications, 2001), 225.

[192] Altman, Barbara. "Disability, Definitions, Models, Classification Schemes, and Applications." In *Handbook of Disability Studies*, edited by Gary Albrecht, Katherine Seelman and Michael Bury, 97-122. (Thousand Oaks: Sage Publications, 2001), 97.

[193] ibid.

social normality. The raising of this issue invites the question, ‘What is normal?’ A more prescriptive answer could, for example, pedantically arbitrate on an extensive list of collective and individual social functions and expectations, along with issues related to collective and individual identity. Apart from framing normality in terms of sameness this perspective mirrors the traditional medical approach inasmuch as it all but quantifies and defines its terms of reference within an empirical and legalistic construct.

Stanley Hauerwas, speaking from under the broad umbrella of the Christian Tradition model, proposes an alternative response to the issue of normality by advocating for what he terms “the gift of differentness.”[194] He asserts that:

> … the demand to be normal can be tyrannical unless we understand that the normal condition of our being together is that we are different. If we are to be a good community we must be one that has convictions substantive enough to not fear our differences and, indeed, to see that we would not be whole without the other being different than us.[195]

The issue of difference raises the spectre of a society no longer assuming the form of an organism with clearly defined boundaries. However, David Tracy, speaking from a liberationist perspective, asserts:

> A fact seldom admitted by the moderns, the antimoderns, and the postmoderns alike – even with all the talk of otherness and difference – is that there is no longer *a* centre with margins. There are many centres ... There is a price to be paid for any genuine pluralism – that price many pluralists seem finally either unwilling to pay or unable to see. It is that there is no longer a centre.[196]

While this concept pleads for a more fluid and changeable societal perspective and understanding of normality it does allow for minority and oppressed social groupings, such as those with intellectual disabilities, to come in from the margins of societal habitation and claim a place within the broad and varied parameters of a pluralist society. Such a perspective is crucial to the framing of a disability model that is inclusive in social orientation. At this point

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[194] Hauerwas, "Community and Diversity,” 37. Hauerwas’ concern with social tyranny pertains to the more legalistic interpretation of normality.

[195] ibid., 40.

[196] Tracy, David. *On Naming the Present: God, Hermeneutics, and Church*. Edited by The Catholic Foreign Mission Society of America (Maryknoll), *Concilium Series*. (New York & London: Orbis Books/SCM Press, 1994), 4. Word has been italicized by the author.

the Christian pastoral carer can assert that the theological status of being ‘in Christ’ confronts exclusivist and divisive notions of normality.

Another issue to be noted in the consideration of a workable disability model concerns the predominant focus on physical, functional capacity in most prevailing disability definitions that account for both the embodied and social perspective. In pursuing this goal, the question of functional definition becomes embedded in a cultural discourse. As has been noted in prior discussion of codification, the Cartesian emphasis on defining the essential human being in terms of reason and rationality implicitly denies full personhood to one who is intellectually impaired.[197] Thus, the capacity of those within the broad church that is loosely termed ‘the disability community’ to define people with intellectual disability as ‘others amongst others’ is reinforced.

Adding further complexity to the issue of disability modelling is the matter of gender, whereby it is argued, from the perspective of institutionalised health care, that medical systems need to be assessed from a patriarchal perspective, with power structures in place that oppress and reinforce patient submission to professional authority.[198] According to feminist ethicist Sandra Sherwin such a mode of institutionalised oppression is further reinforced by the viewing of the patient as feminine.[199] The patient thus labelled is characterised as passive, powerless, submissive and receptive.[200] Gill-Austern asserts that it is through the lens of feminist and womanist pastoral theology that such a pedagogical system defines such relationship in terms of sin and evil.[201]

Such gender-based analysis of institutionalised systems of power are sorely lacking from definitions and models of disability. Instead, issues related to the relationship between healthcare deliverers and clients are often regarded from a gender-neutral perspective.[202] A model that asserts liberation from systemic and patriarchal modes of oppression, and that truly upholds the human identity of all, is essential in order to appropriately represent the just claim of people with an intellectual disability to respectful identity and liberating relationships.

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[197] Clapton, “A Transformatory Ethic of Inclusion”, 80-81.

[198] Sherwin, Susan. *No Longer Patient: Feminist Ethics and Health Care*. (Philadelphia: Temple University Press, 1992), 85-86.

[199] ibid., 91.

[200] Moore, Henrietta. *A Passion for Difference*. (Cambridge: Polity Press, 1994), 50.

[201] Gill-Austern, "Pedagogy Under the Influence of Feminism and Womanism," 159-160.

[202] Sherwin, *No Longer Patient,* 55.

2.5 Emerging Definitions

From the mid-1970s onwards, various definitions of disability have emerged that have sought to account for the disabling influences that come to bear on the individual. Analysis of some of these definitions serves to clarify the nature of a definition pertinent to this extended reflection.

2.5.1 Union of the Physically Impaired Against Segregation

In the United Kingdom in 1975 the Union of the Physically Impaired Against Segregation (UPIAS) was formed in order to develop and clearly articulate a series of fundamental principles concerning a Social model of disability.

The UPIAS went on to define and clearly demarcate between impairment and disability as follows:

- Impairment: Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
- Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.[203]

Thus a Social model of disability, although not yet so named, was constructed. Disability was distanced from the realm of a medically-perceived construct, along with the stigmatization associated with being regarded as a sick, deficient being.

However, whilst this definition unequivocally placed disability in the realm of social organisation, it failed to acknowledge the disabling effects of the body and the incapacities specifically attributable to the impairment in question. It can be argued that this total demarcation between impairment and disability is expressive of a fundamentalist definitional perspective.[204]

Also pertinent to this extended reflection is the omission of those with intellectual impairment from the definition of impairment, thus reaffirming these

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[203] Union of the Physically Impaired Against Segregation. *Fundamental Principles of Disability,* 20.

[204] Barnes, & Mercer. *Disability,* 65.

people in their entrenched historic role as being of less than full personhood and lacking the right to claim full citizenship.

2.5.2 Disabled Peoples' International

In 1982, Disabled Peoples' International (DPI)[205] included the intellect in its definition of impairment in terms of the causative effects of limitation, whilst restricting limitation to function alone. As in the UPIAS definition impairment remained separated from disability, thus unequivocally focusing attention on society's capacity to disable the impaired individual. Impairment and disability were thus defined:

- Impairment: The functional limitation within the individual caused by physical, mental or sensory impairment.
- Disability: The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.[206]

This definition raised the issue of social normality and how such a concept might be defined given the cultural specificities of the term.

2.5.3 International Classification of Impairments, Disabilities and Handicaps

In 1980, the World Health Organization developed the International Classification of Impairments, Disabilities and Handicaps (ICIDH), constructing a conceptual framework based around three modalities of understanding, namely impairment, disability and handicap:

- Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function.
- Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- Handicap: a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role

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[205] Disabled Peoples' International is a network of national organisations or assemblies of people with a disability that was established to promote the human rights of people with disabilities through full participation, equalisation of opportunity and development.

[206] Barnes, & Mercer, *Disability*, 66.

> that is normal (depending on age, sex, and social and cultural factors) for that individual.[207]

At one level, the document has been affirmed for the usefulness of its overall framework in explaining how barriers (attitudinal, sensory, architectural and economic) limit the integration of people with disabilities into society.[208] However, criticisms of the model include that it conceptualises disability from a medicalised framework by describing disability in terms of deficiency and abnormality.[209] This leaves the individual being perceived as disabled and the medical profession with the responsibility of rehabilitation.

Furthermore, disability activist David Pfeiffer claims links to the eugenics movement when he asserts that if the ICIDH can link quality of life to abnormality of impairment, "[i]t is only a short step to say that all persons who fit certain D (disability) categories need not live because their quality of life is so poor."[210]

As with the DPI, questions remain concerning the cultural specificities and fluid construction of normality. Furthermore, the definitions continue to fail to recognise those with an intellectual impairment.

2.5.4 International Classification of Functioning, Disability and Health (ICF)

In 2001, the World Health Organization enacted a revision of the ICIDH, producing the International Classification of Functioning, Disability and Health, namely ICIDH-2. This classification described disability from the perspective of the body, the individual and society. These perspectives bear reference to two domains, namely 'body functions and structures' and 'activities and participation'.[211] The following definitions are notable:

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[207] World Health Organization. *3 International Classifications of Impairments, Disabilities and Handicaps (ICIDH)* 1998 [cited 4/5/2008]. Available from, http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442455478 , sec.2, par.1. Bracketed words those of author.

[208] Pfeiffer, David. "The ICIDH And the Need for Its Revision." *Disability & Society* 13, no. 4 (1998): 503-23, 507.

[209] ibid., 508.

[210] ibid., 510.
Bracketed word that of author.

[211] World Health Organization. *I.C.F.* 2001 [cited 5/5/2007]. http://www.who.int/classifications/icf/site/intros/ICF-Eng-Intro.pdf.
Website no longer available.

- functioning: an umbrella term encompassing all body functions, activities and participation
- disability: an umbrella term for impairments, activity limitations or participation restrictions
- impairments: problems in body function or structure such as a significant deviation or loss
- activity: the execution of a task or action by an individual
- participation: involvement in a life situation.[212]

A person's functioning is now regarded as a dynamic interplay between health and contextual factors. As such, in contrast to the ICIDH classification, there is a clear attempt to integrate the concept of disablement with both the embodied and social context.

The person's lived environment is acknowledged with a listing of environmental factors that can contribute to disablement. However, there is a failure "to clearly identify the interaction between the individual and the environment as a central factor."[213]

Furthermore, the focus on body function, as with aforementioned definitions and classifications, comes at the expense of including those with intellectual impairment and their right to full human identity.[214]

In 2008, an updated ICF report sought to comprehensively and methodically detail a wide array of embodied and environmental factors that can contribute to disability. In doing so it acknowledged that:

> Disability is characterized as the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives. Because of this relationship, different environments may have a very different impact on the same individual with a given health.[215]

Consequently, the report proposes its own form of integrated disability model, termed a 'biopsychosocial' approach, whereby an integration of various

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[212] ibid.

[213] Fougeyrollas & Beauregard, "An Interactive Person – Environment Social Creation", 185.

[214] Clapton, "A Transformatory Ethic of Inclusion," 80.

[215] World Health Organization. "International Classification of Functioning, Disability and Health: ICF." (Geneva: World Health Organization, 2008), 20.

perspectives is sought “in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective.”[216]

However, despite this comprehensive approach there remains very limited acknowledgement of the unique life situation of people living with intellectual disabilities.

2.6 A Proposed Integrated Model

I agree with Altman when she states that a multi-dimensional, global definition and model of disability is all but impossible to articulate with precision owing to issues such as cultural, socio-political and gender-based nuances, and the accompanying complexities involved in adequately defining key terms such as disability, impairment, society, environment and normality.[217] The multi-dimensional, global model and definition may thus, at best, always be ‘a work in progress’. Indeed, it can be argued that the focus should be on developing models that, amidst broad universal principles, are adaptable to local circumstances. Nonetheless, in relation to this extended reflection, a modest conceptually-framed model of disability ought to be sought that provides a framework for understanding the nature of disability as it impacts on the lives of those with intellectual impairment living in an institutional environment. As such, reference is made to the preceding discussion concerning disability models and definitions in order to construct such a framework that, at the same time, is consistent with the extended reflection values articulated earlier in this chapter.

Underlining this model is the assertion that people with intellectual disabilities are a particularly marginalised socio-political group of human beings. They are marginalised because disability per se defines them as being of a less than full human identity. However, this is exacerbated because their loss of intellectual function limits their capacity to articulate their needs. In the segregated institutional context this lost identity becomes entrenched, and truly worthy social function is trivialised in the face of medical intervention. It is here that the institutional pastoral carer must stand alongside the person with an intellectual disability and help articulate their human needs.

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[216] ibid., 25.

[217] Altman, “Disability, Definitions, Models, Classification Schemes, and Applications”, 97.

The following framework is proposed by which to develop an understanding of an integrated model of disability. Firstly, a model of disability is required that acknowledges the capacity of the institution to have both a disabling effect on the lives of the people with intellectual disability who are accommodated therein, as well as offering competent, professional health care service in response to the medical needs of its accommodated people. At the same time it needs to account for the embodied and cognitively-experienced nature of disability as it affects the lives of the people with intellectual disability accommodated in that context. It also needs to acknowledge the identity of those with intellectual disabilities as whole human beings with an identity beyond empirical measure.

Secondly, a model is required that reflects a variable and dynamic interplay between the socially-constructed, institutionally-based notion of disability and the embodied experience of disability. Here, variability relates to the extent to which individuals experience disablism as a part of their lived context and of their embodied, cognitive and felt experience. This model also includes an understanding of the nature and influence of disability on the unique lived circumstances of the individual.

Thirdly, a model is required that principally describes the disabling effect of institutional ethos and practice in terms of oppression based on patriarchal forms of relationship established between the institution and those accommodated for whom responsibility is borne. This is to be understood alongside the corresponding diminution of capacity of these people to engage in liberating relationships as autonomous individuals, and for the pastoral carer to serve as advocate for their human rights.

Fourthly, a model is required that acknowledges the capacity of the wider community to disable through oppressive attitudes and behaviours. This includes attitudes and behaviours that maintain oppressive institutional structures and practices, but which can alternatively strive for inclusion within a pluralist expression of that community.

Fifthly, a model is required that does not, from either an environmental or embodied perspective, limit the person with an intellectual disability to being regarded purely as a person with a disability. The person who lives with an intellectual disability in an institutional context has the right to be considered as a whole human being living with a disability, and not exclusively in terms of their impaired body and mind.[218] Theologically, this is affirmed through the fully human status accorded all human beings through the act of creation, and through being ‘in Christ.’

However, if the principal descriptor of people with a disability is, at a societal level, in terms of disability, then the stigmatization that accompanies such labeling can lead to that person or persons being regarded, as Goffmann asserts, as “not quite human.”[219] This is on the basis of these people possessing differentiating attributes from others. Such differentiation causes the person in question to be regarded less in terms of their God-given creational and Christological status, and more so as a being of blemished and discounted worth.[220] Given that people with an intellectual disability have been and are accommodated and served in institutions on the basis of their disability, the risk of being regarded as less than fully human is quite feasible.

The principles undergirding this integrated model are to be seen as having a contributing role in the overall reflective process that will be described in chapter 5. However, it is also possible that the understandings reached, and the subsequent pastoral model, may give rise to a more mature understanding of this present disability model.

2.7 Summary

In this chapter, the task of detailing the parameters by which fundamental extended reflection concepts will be understood has commenced. There is a need to hear, interpret and understand the voice and identity of the person with intellectual disability as authentically as possible. There is also vital need to describe the institutional context carefully and accurately. This extended reflection is fundamentally concerned with the authentic understanding of people with intellectual disability, the contexts in which they live, and the relationship

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[218] Theologically this is affirmed in terms of all people being created in the image of God. In humanitarian terms it is highlighted in the Declaration on the Rights of Disabled Persons when it states that people with a disability (termed *disabled persons* in the declaration) “… have the inherent right to respect for their human dignity.”
United Nations High Commissioner for Human Rights. *Declaration on the Rights of Disabled Persons* United Nations, 1975 [cited January 1 2009]. Available from, http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf. articles 3 & 6.

[219] Goffman, *Stigma*, 5.

[220] ibid., 2-3.

between the two. Pastorally appropriate values will assist in understanding and interpreting the interplay between peoples and context, and the influence of one upon the other. As a consequence of suitably conceived narrative reflection they will also provide the framework in which a valid pastoral model will be described.

Such interplay can be interpreted and described by purely rational means of linguistic interpretation. However, the process of interpretation and description is heightened by the garnering of insight derived from the application of the metaphorical conceptualisation of the oppressed person with an intellectual disability and their institutional narrative. It is the metaphor that can foster imagination for the more abstract dimensions of conceptual linguistic forms, just as the conceptual form can give discipline and structure to the metaphor.

The proposal of a disability model pertinent to this extended reflection proffers a fundamental means for pastorally understanding how the concept of disability is to be interpreted in terms of its environmental and embodied influence. It bears critical comparison to and distinction from dominant Medical models of disability that otherwise inform the nature of relationships within the institutional context.

Detailed exploration of further definitional issues will give greater clarity to the contexts and persons under consideration in this extended reflection. It will challenge the pastoral carer to think more in terms of personal, pastoral engagement with the context and its people, both in regard to care and advocacy.

This exploration will be the subject of the following chapter.

2.8 How Do I Regard the One Before Me?

And so I reflect upon the term ‘Slave’ and my mind turns to contexts, both historic and present, in which the Slave is observed as a commodity, constrained and forced to serve the whims and needs of those who, no matter the extent or lack of excuse, assume the name of Master. I think of individuals and communities, regimes and nations, who have assumed the right to disempower others for their own ends, to deny full personhood to another for the sake of personal aggrandisement.

I think of Emperors and Empires, rapacious despots, evil dictators, self-serving landlords, rulers of sweat shops, of fanatical prophets and cringing pimps, of slimy pushers and abusive parents.

And I think of those who served, either defiantly or compliantly, such as these. I think of those with heads held high and of others with backs broken and spirits crushed, of those who held to a glimmer of light, who still saw glimpses of beauty, and of others for whom all light has dimmed, and beauty has turned to dust and blown away on the winds of time.

Slavery has so many guises, so many justifications and rationalisations, so many pretentious denials and cowardly turned backs, far away and near to home.

And the Slave has so many faces ...
of black and white,
female and male,
homosexual and bi,
infirmed and orphan.

of indigenous and migrant,
farmer and factory worker,
impoverished and malnourished,
ignorant or unknowing,
living or dying.

... so, so many faces.

How can I make sense of it all?

What of the One who raises up the weak?
What of the One who stands with the outcast at the margins?

CHAPTER THREE

INSTITUTIONALISED CARE: SOUTH AUSTRALIAN HISTORY AND CONTEMPORARY ISSUES

“ ... despite the fact that the defects of institutions have been known for the 200 years that they have existed, they have remained unaddressed.”[221]

"The house of confinement was no longer only the lazar house at the city's edge; it was leprosy confronting the town: ‘A terrible ulcer upon the body politic ...’ "[222]

> My name is Tom Allen. I was born in 1912. I was first sent to an institution when I was two or three years old. When I was six years old I became very sick and was sent home because the people in the institution thought I was going to die and they wanted me to die at home.
>
> We were a large happy family. Then my mother died suddenly. My father married again and they could not take care of me at home and sent me to the institution again when I was 15 years old. I was only meant to be there for a year or two but I ended up spending 45 years in this institution ...
>
> I did not like being in this institution. I felt like no one cared about me. I felt all alone in the world, angry and hurt. I was desperate. No one in the institution understood me and the staff punished me for my behaviours. I was sent to the back ward with the most disabled people.[223]

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[221] Oliver, *Understanding Disability,* 93-94.

[222] Mercier, Louis-Sebastien. *Tableau De Paris,* cited in Foucault*, Madness and Civilization*. 192.

[223] Allen, Traustadottir, et al., “Sixty Tears in the Institution,” 33.

Plate 3.1

‘Bearded Slave’

by

Michelangelo Buonarotti

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[224] Ruehring, Lauren. *Bearded Slave by Michelangelo* HowStuffWorks, Inc, 2011 [cited 30/12/2011]. Available from http://entertainment.howstuffworks.com/arts/artwork/michelangelo-sculptures15.htm

3.1 A South Australian History

South Australian institutions that accommodated and served people with disability in general, and intellectual disability particularly, evolved from initial forms of colonial institutionalisation that focused particularly on those defined as destitute poor and/or lunatics.

3.1.1 Early Welfare Support for the Destitute Poor

On the basis that the workforce brought to the colony of South Australia officially, and usually, excluded paupers from British or Irish parishes, it was theorised and argued that there was no need for the implementation of a Poor Law because, in economic terms, there would be no marginalised social groupings and therefore no social dependants.[225]

However, in reality, social dependency soon emerged as a pressing issue that required the attention of the Emigration Agent who had responsibility in the new, freely-settled colony for the supervision of migrants and for attending to their welfare upon arrival. As such, he was soon providing a series of base shelters in the Adelaide parklands that were intended as accommodation for those deemed to be sick or destitute. The agent drew criticism for developing a form of emergency shelter that was seen to attract people of depraved character.

Apart from providing shelter the agent also had responsibility for the administration of rations and medical necessities to these people. He could also impose the requirement of undertaking employment, the refusal of which could lead to significant punitive actions being imposed in accordance with government regulation. This early regulatory system was the basis for government welfare action in the developing colony. [226]

By October 1841 over 2000 men, women and children were in receipt of some form of welfare relief on a weekly basis. This led Governor Grey to appoint a Board of Emigration which was to work alongside the Emigration Agent to develop a more systematised form of welfare support to respond more adequately to the perceived menace of what he referred to as the 'pauper population.'[227]

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[225] Dickey, Brian. *Rations, Residence, Resources: A History of Social Welfare in South Australia since 1836*. (Adelaide: Wakefield Press, 1986), 2.
[226] ibid., 4-5.
[227] ibid., 8-9.

With tighter regulation of relief the Board of Emigration was dissolved and Grey introduced a Maintenance Bill in late 1842.[228] This bill imposed upon direct relatives the legal responsibility for the maintenance of dependent pauper family members. This regulation, which mirrored a characteristic of the British Poor Law, could thus lead to the defining of the ‘deserving poor,’ who were those with no natural protectors and who, without responsibility for their own destitution, were in need of publicly-funded assistance.[229]

3.1.2 The Institutional Response: The Establishment of the Destitute Asylum

A Destitute Board consisting of clergy appointments was established in early 1849. Their initial task was to assist the Emigration Agent in the administration of relief to the destitute poor.[230] However, it soon became the Board’s task to respond to the perceived need of providing the destitute poor with an indoor facility that offered a greater degree of regulation, control, economies of scale, division of labour and supervision. Thus the notion of the asylum emerged whereby a group of buildings designed according to a factory concept were constructed in a manner so as to provide secure, regulated management of those deemed to be in need of such residence. The Destitute Asylum was seen by the Board as an effective means of managing socially dependent people.[231] It was established in 1851 in Adelaide towards the bottom of Kintore Avenue, adjacent to the rear of Government House.

Institutional archaeologist Susan Piddock likens the physical, spatial nature and the organising principles of the Destitute Asylum to those of the English workhouse. The design of both buildings was directly related to issues of supervision, controlled movement and classes based on criteria such as gender. Both provided work areas, skills training areas and spaces for punishment. Both buildings were “fundamentally about the use of the physical environment to reform the inmate, who was either a willing or unwilling participant.”[232]

The idealised function of Australia’s early asylums through to the mid-1800s was curative and educative in nature. However, with the goal of eventually

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[228] ibid., 12.

[229] ibid., 12-13.

[230] ibid., 15-21.

[231] ibid., 21.

[232] Piddock, Susan. *A Space of Their Own: The Archaeology of Nineteenth Century Lunatic Asylums in Britain, South Australia, and Tasmania*. (Adelaide: Springer, 2007), 16-17.

returning inmates and patients to society in a state that enabled them to fulfil 'socially normal' roles, the reality was that the asylums, including the Destitute Asylum, became places where the occupants could be isolated from the rest of society.[233]

Social historian Brian Dickey argues that because the colony was founded by Europeans amidst stringent financial circumstances it was limited in its financial and charitable capacity to generate a viable network of voluntary societies that might otherwise have prevented some destitute people from being subsumed into a punitive and highly regimented mode of institutional, pauperised care. As Dickey asserted in 1980, in relation to the colony's institutionalised mode of care, "… there is little evidence available so far to show any doubts among South Australians that they had created an unworthy or demeaning social welfare system."[234]

The Destitute Asylum gathered into its internal physical spaces a diversity and disparity of destitute men and women. As of 31 December 1859 the membership of inmates is recorded as including the following: aged, blind, rheumatic, epileptic, paralytic, chronically ill, imbecile, convalescent (after childbirth), convalescent sick, single women and children.[235]

The Destitute Asylum remained as a form of controlled, institutionalised care for the colony's paupers until 1917 when it was replaced by the Old Folks Home at Magill. The reason for its demise was that it was constantly operating to maximum capacity with a population of over 600 inmates. A more expansive, better-resourced facility was required.[236]

3.1.3 The Lunatic Asylums

In the early years of the emerging colony, as well as elsewhere across Australia, destitute lunatics were regarded as a threat to both the social order of the community and to the safety of its citizens. Actions were taken with more regard for citizen safety than for the welfare of those regarded as lunatics.[237] The

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[233] Cocks, E., and D Stehlik. "History of Services." In *Disabiliy: A Guide for Health Professionals*, edited by John Annison, Josephine Jenkinson, William Sparrow and Elizabeth Bethune, 8-33. (Melbourne: Nelson ITP, 1996), 15.

[234] Dickey, Brian. *No Charity There: A Short History of Social Welfare in Australia*. (Melbourne: Nelson, 1981), 55.

[235] Dickey, *Rations, Residence, Resources*, 29.
Bracketed words those of author.

[236] ibid., 137-139.

[237] Dickey, *No Charity There*, 8.

citizenry needed to be protected from the lunatic, and the lunatic needed to be isolated from the citizenry.

During the first 10 years of the colony destitute lunatics were accommodated in two ramshackle huts which served as Adelaide’s infirmary and gaol. With an initial medical contracted appointee for the care of lunatics proving inadequate for the task at hand, those designated as lunatics or insane were shuttled between the Destitute Asylum, the hospital and the gaol.[238] Thus, as has been already noted in reference to the population of the Destitute Asylum, those classified as lunatics were indiscriminately accommodated in close proximity to others such as the aged, blind, chronically ill, women and children. So the initial years of the colony provided those designated as lunatics or insane with inadequate, non-specific custodial care, based around strident social concern regarding the perceived threat and public nuisance of the lunatic to the wider colonial community.

The first public lunatic asylum was established in a rented residential house in the Adelaide suburbs in 1846. The men and women accommodated in this facility were moved in 1852 to the new Adelaide Lunatic Asylum located in the Adelaide parklands. Whilst it was planned to house 60 patients, in reality it only housed 40.[239] The first half of the nineteenth century saw lunatic asylums across Australia established with the goal of providing the patients with moral therapy and rehabilitation. However, as has been noted in South Australia, because of stringent financial circumstances, pragmatism in the design and management of the asylum quickly took precedence over issues of moral cure,[240] which included notions of the non-restraint of patients. In the case of the Adelaide Asylum early asylum design planned to give space to the patients for recreation and therapeutic care. However, this soon gave way to immediate, functional requirements. For example, in 1857 the need for a laundry saw the construction of such a facility at the end of the women’s exercise yard. In 1861 the old hospital was being used for temporary accommodation because of

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[238] ibid.

[239] Piddock, Susan. "The 'Ideal Asylum' and Nineteenth-Century Lunatic Asylums in South Australia." In *'Madness' in Australia: Histories, Heritage and the Asylum*, edited by Catherine Coleborne and Dolly MacKinnon, 37-48. (St Lucia: University of Queensland Press, 2003), 40.

[240] Lewis, Milton. *Managing Madness: Psychiatry and Society in Australia 1788-1980*. (Canberra: Australian Government Publishing Service, 1988), 8.

overcrowding pressures.[241] Restraint was practised at the asylum until 1858 when the Colonial Surgeon, Dr Moore, introduced a policy of non-restraint. This practice mirrored English asylum customs, including the use of secluded, padded rooms to quieten patients.[242]

Problems with overcrowding and design led a government commission to recommend the construction of a new asylum that would address these concerns. Thus, the Parkside Lunatic Asylum was opened in March 1870.[243] Despite awareness of the concerns associated with the functioning of the Destitute Asylum, issues of overcrowding and inadequate design soon became apparent with the new asylum. The ideal of rehabilitation was, as with the Destitute Asylum, inhibited by a lack of appropriate design features. For example, by 1883, patients of the Parkside Lunatic Asylum were severely limited in their recreational pursuit by dint of the asylum still having no boundary walls. As such, recreation was limited to airing courts.[244]

Adelaide’s lunatic asylums were developed against the backdrop of the notion of the ‘ideal asylum.’ Whilst there were various models of such an asylum, it is worth noting Piddock’s evaluation of the Adelaide and Parkside asylums alongside John Conolly’s criteria for such asylum facility. Conolly was a British architect who wrote concerning asylum design in the nineteenth century. He referred to the appropriateness of features related to matters such as scenery; building ventilation; classified wards; open areas for recreation; separate rooms for recreation, education, work and religious activity; localised access to hygiene facilities; an emphasis on single room accommodation; and patient privacy, as well as a general predisposition towards light and cheerful physical spaces. Piddock notes that the Adelaide Asylum fulfilled five of Conolly’s 18 criteria or sub-criteria, whilst the Parkside Asylum fulfilled 11.[245] Inadequacies in the design and function of the Adelaide Asylum, such as a lack of space and hygiene, were repeated in the design and function of the Parkside Asylum.[246]

Despite the implied sense of moral care and desire for rehabilitation that accompanied notions of an ‘ideal asylum’ that pre-dated the Adelaide and

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[241] Piddock, "The 'Ideal Asylum,’" 40.
[242] ibid., 40-41.
[243] Piddock, <u>A Space of Their Own</u>, 113-116.
[244] ibid., 125.
[245] ibid., 127.
[246] ibid., 132.

Parkside Asylums,[247] Piddock notes that the Adelaide Asylum represented a more controlled, paternalistic form of patient care, whilst the Parkside Asylum, for all its inadequacies, was representative of a more caring environment with greater emphasis on patient comfort. As such, the Parkside Asylum came closer to approximating a rehabilitative patient environment.[248]

Even though it was regarded as being sub-standard the Adelaide Lunatic Asylum remained in use until 1902. The Parkside Lunatic Asylum remains open to the present time and is now known as the Glenside (Psychiatric) Hospital.[249]

3.1.4 The Emergence of Institutions for People with Disabilities

Institutions for people with disabilities emerged in South Australia out of a socio-political milieu that gradually sought to offer those who were deemed to require institutional accommodation a more specialised form of care. These emerging institutions were regarded as offering a most necessary form of segregated care that, under the umbrella of religiously-based charitable care, afforded society protection from those who, towards the end of the nineteenth century, were regarded as a social menace.

A number of these institutions were created through the charitable endeavours of clergy, philanthropists, politicians, and middle-class men and women engaged in good works.[250]

3.1.5 Eugenics

The institutions that emerged in the latter years of the nineteenth century came into being against a backdrop of international debate that had considerable influence over attitudes towards those diagnosed with some form of mental illness or intellectual impairment. The concept of eugenics emerged from a broader discussion concerning the role and influence of heredity in human identity and activity.[251] This philosophy emerged in Western thinking as a perceived credible mode of scientific thinking and social engineering during the

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[247] Browne (1837) & Jacobi (1841) are noted as predating Adelaide's asylums. See, ibid., 133.
[248] Piddock, A Space of Their Own, 147.
[249] Disability, Information & Resource Centre. *History of Disability in South Australia: Lunatic Asylum*. Disability, Information & Resource Centre, 2007 [cited February 13 2009]. Available from http://history.dircsa.org.au/1800-1899/lunatic-asylum/ sec.4, par.2.
[250] Disability, Information & Resource Centre. *History of Disability in South Australia: Charity* Disability Information & Resource Centre, 2007 [cited February 13 2009]. Available from http://history.dircsa.org.au/1800-1899/charity/ sec.1, par.1.
[251] Lewis, *Managing Madness,* 128.

period from 1890 to 1925, and has been referred to as the Eugenics Alarmist period.[252]

Through the influence and extension of Charles Darwin’s theory of evolution by natural selection Englishman Francis Galton, the ‘father of eugenics,’ asserted that not only should physical characteristics be considered as a product of natural selection but that characteristics involving moral development, and mental and intellectual development, should also be strongly considered as the direct consequence of natural selection. In the early years of the twentieth century Galton and fellow scientific collaborator Karl Pearson were, in the light of the eugenics issue, speaking in terms of ‘race betterment’ and of a Holy War against social practices that impaired the moral and physical qualities of the human race.[253]

Those regarded as having a mental illness or intellectual impairment were negatively regarded as socially deviant. That is, they were viewed as deviating from acceptable social norms. This led such people to be regarded as a social menace. In North America, Dr Walter Fernald, a leading advocate for social control and superintendent of America’s first school for feeble-minded children, is cited by Wolfensberger as referring, in 1912, to deviant males as a “'menace of the greatest magnitude,’” whilst females were described in even more threatening terms when he stated, "[i]t is certain that the feeble-minded girl or woman in the city rarely escapes the sexual experiences that too often result in the birth of more defectives and degeneratives."[254]

Wolfensberger defines the institutions for people with intellectual disability that developed during the Eugenics Alarmist period as instruments of “architectural segregation,”[255] a phrase reflecting the social and scientific desire for institutions to offer control and separation of those regarded as a social menace from wider society.

Institutions also became a source of widespread sterilisation practices,[256] as will be discussed momentarily in the South Australian context.

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[252] Wolfensberger, Normalization, 15, 131.

[253] Lewis, *Managing Madness*, 129.

[254] Wolfensberger, The Origin and Nature of our Institutional Models, 65.

[255] Wolfensberger, Normalization, 131.

[256] ibid.

In South Australia, as elsewhere, belief in the philosophy of eugenics gained considerable traction in academic and scientific circles during the early years of the twentieth century. In 1912, W. Jethro Brown, Professor of Law at the University of Adelaide, asserted that the State had a duty to improve the human race and that this could be achieved through methods such as the control of the right of 'mental defectives' to marry and propagate, as well as the sterilisation of 'diseased' social elements.[257]

In 1924, M.H. Downey, head of the South Australian psychiatric services and lecturer in psychological medicine at the University of Adelaide, addressed the Australasian Medical Congress by stating that 'mental defectives' were a serious drain on the nation's financial and physical efficiency. He proceeded to assert that,

> Even the most degraded idiots ... receive more care ... than self-supporting members of the community ... In the ultimate interests of the race ... the unfit (should) be left to the fate which should overtake them as a result of the free operation of Nature's law of the survival of the fittest ... Male and female patients, admittedly unstable, are discharged from asylums ... Many have to be re-certified, but in the meantime they have been at full liberty to propagate their species and so the vicious circles continue.[258]

This author has not been able to find verifiable data as to the reality or otherwise of early sterilisations being practised in the South Australian institutions that are the narrative source of this extended reflection. However, it is a point on government report that some non-consensual sterilisation practices, as well as the sterilisations of minors, were being carried out in leading South Australian institutions that accommodated people with an intellectual disability as recently as the late 1970s. Concerning the ongoing practice of sterilisation of people with an intellectual disability in the South Australian institutional context in the late 1970s the 1981 State Government Committee on the Rights of People with Handicaps stated the following:

> ... discussion with parents and service providers indicates that there have been a considerable number. We have been advised of a total of 39 sterilizations in recent years in the 2 major institutions – 76% of which have been performed on women, 17% on minors

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[257] Lewis, *Managing Madness*, 131.

[258] ibid., 129-130. Bracketed word that of author.

> (under 18 years of age), and 32% were performed without the consent of the person concerned ...[259]

Whilst the full force of the eugenics debate had subsided decades earlier institutional practices born of the eugenic debate continued until relatively recent times.

3.1.6 Home for Incurables

Following concerns expressed in 1878 by Mrs Julia Farr, wife of the headmaster of St Peter's College, about the fate of people with incurable diseases confined to the Adelaide Hospital and the Destitute Asylum, and with philanthropic and medical support, the Home for Incurables was established on 23 September 1878. It was located on nine acres of land at Fullarton. First admissions were received on 17 October 1879, and by 1881 there were 44 inmates and nine staff.[260]

Over the years, there were further acquisitions of land as well as a steady stream of development of new wards reflecting a growing intake of people with incurable conditions, as well as a diversification of services. By 1929, accommodation numbers had reached 145 patients. The late 1950s to late 1970s reflected a time of considerable development with four additional accommodation blocks established. By 1977, with the completion of the new nine-storey Western block, or what remains today as the Highgate building, accommodation capability totalled 826 beds. The year 1978 marked the institution's centenary with a total of 624 patients, and a total of 1,011 nursing and domiciliary staff. The late 1970s signified the high watermark in accommodation numbers at the Home for Incurables reflecting the priority at that time of institutional accommodation for people with disability, including intellectual disability.[261]

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[259] Committee on Rights of Persons with Handicaps. "The Law and Persons with Handicaps – Vol. 2 Intellectual Handicaps." In *The Law and Persons with Handicaps*, edited by Committee on Rights of Persons with Handicaps. (Adelaide: Government of South Australia, 1981), 123. Bracketed words those of author.

[260] Disability, Information and Resource Centre. *History of Disability in South Australia: Home for Incurables.* Disability, Information and Resource Centre, 2007 [cited February 13 2009]. Available from, http://history.dircsa.org.au/1800-1899/home-for-incurables/ sec.2, par.1.

[261] Information detailed on display wall of café in Highgate building, Disability SA, 103 Fisher St, Highgate, South Australia.

The type of person admitted to the Home for Incurables/Julia Farr Centre/Julia Farr Services/Highgate Park has changed over the years. Initially, those admitted represented a range of destitute people with incurable diseases who were reasonably ambulant. However, by 1954 those being admitted were mostly confined to wheelchairs or were bedridden.[262] With services being outsourced, such as care for those with Acquired Brain Injury being transferred to the Royal Adelaide Hospital's rehabilitation services at Hampstead Gardens in 2001, and people with disabilities gradually moving into community accommodation, the number of accommodated residents at the Fullarton campus has steadily declined since the late 1970s.

By early 2012 there were approximately 100 people with disabilities accommodated at Highgate Park. These consisted of people with a range of physical and intellectual disabilities requiring a high level of care, such as those with Huntington's Chorea and Acquired Brain Injury. Others expressed a personal preference for staying in place rather than moving to community accommodation.

Funding arrangements for the institution have altered over the years. Whereas early income to the institution included considerable philanthropic support, by the mid-1950s, the Home for Incurables depended heavily on State and Commonwealth Government support.[263] Long-term nursing home care became more common in the 1970s. Therefore, along with rising costs and rising community expectations concerning appropriate standards of nursing home care, by the 1980s, the State Government could claim almost complete control over the Julia Farr Centre's capital and operating funding streams.[264]

In 1995 the Julia Farr Centre changed its name to Julia Farr Services reflecting the expanding focus on a range of health care services central to the overall delivery of care to people with disability in need of institutional care.[265]At present those people with disabilities remaining at Highgate Park come under the banner of Disability SA, a government department providing umbrella disability

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[262] Disability Information & Resource Centre. *History of Disability in South Australia: Home for Incurables.*

[263] ibid.

[264] Dickey, Rations, Residence, Resources, 301-302.

[265] Disability Information & Resource Centre. *History of Disability in South Australia: Home for Incurables*.

services to people with a range of disability needs across the state ranging from institutional accommodation, community-based accommodation and respite services to home care.

Today the Highgate building is the only remaining accommodation block at the Fullarton campus. With the configuration of two wards on each of the three remaining accommodation floors each ward is designed to resemble a hospital ward. Two aisles are joined at one end by a central nurses' station with an adjacent room for medical consultation. These two rooms define the central medicalised priority of this living and working space. Down the outer side of each aisle is a mixture of accommodation rooms, various single rooms, each approximately five metres by three metres, a few two-person rooms, and one four-person room. A shared dining and living area is adjacent to the nurses' station. A smaller shared living area is adjacent to the medical consultation room. Shared toilet and bathing facilities occupy the central area. A covered balcony encompasses the perimeter of the accommodation rooms. Whereas in the late 1970s people with disabilities used to occupy seven floors of the Highgate building, they are now accommodated on three floors.

3.1.7 Minda Home

Minda became established through the unlikely alliance of two Adelaide politicians, namely Charles Kingston and Josiah Symon, the former being of a reforming liberal political persuasion and the latter being an independent conservative. Their shared charitable desire developed from Kingston's childless marriage, and for Symon a marriage that produced two children with intellectual impairment.[266]

Following an approach to the government's Chief Secretary by Kingston, Symon and many concerned citizens, the government promised a sum of £500 contingent upon a comparable amount being donated from public sources. Following the procurement of this funding a home was bought in 1897 at Fullarton catering for what were referred to as 'feeble-minded children.' In May 1898, 10 children, so defined, moved into this facility. The home, called Minda,

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[266] Dickey, Rations, Residence, Resources, 116.

an Aboriginal word meaning ‘place of shelter and protection’, was registered as ‘The Home for Weak-Minded Children.’[267]

Information gleaned from the initial Prospectus and Opening of the Home point to the perceived need to provide the children with a segregated environment of shelter and protection in which to receive requisite care. The articulated needs concerned the provision of special care and treatment of the children so that their minds could be “opened to intelligent life ... if they are to be saved from deterioration into idiocy.”[268]

This evangelical spirit is reinforced in Minda’s poetically constructed mission statement of 1900.

> *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, thou full-grown; the page of life a blot.*
>
> *Yet say, shall their affliction be abhorred?*
> *Their need o'erlooked/shall charity pass by,*
> *Leave them to perish with averted eye?*
> *Forbid, the love that burns to serve her Lord!*[269]

Apart from detailing zealously the need of Minda’s children to receive saving care early documentation also describes the need for able-minded family members to be protected from their feeble-minded family members. In reference to the feeble-minded child, it states, “... such a child, however loving and tender the parents, is in the way in a small home, and may, too, be a detrimental influence upon the normally, healthy children.”[270] The concept of feeble-mindedness, fundamental to the founding ethos of the organisation, was recognised widely at the time as the primary classification system for grouping individuals regarded as having inferior intellectual abilities.[271] However, even more significantly, it became the principal diagnostic category that allowed the

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[267] Disability, Information & Resource Centre. *History of Disability in South Australia: Minda Home*. Disability Information & Resource Centre, 2007 [cited February 21 2009]. Available from http://history.dircsa.org.au/1800-1899/minda/ sec. 1, par.1; sec.2, par.1; sec.3, par.1.

[268] Minda. "Prospectus." 6.

[269] Minda. "The Second Annual Report." 1-23. (Adelaide: Minda – The Home for Weak-Minded Children, 1900), 1.

[270] Minda. “Prospectus.” 6.

[271] Snyder, Sharon, and David Mitchell. *Cultural Locations of Disability*. (Chicago and London: The University of Chicago Press, 2006), 79.

popular eugenics movement “to consolidate a host of defective types under a shared heading.”[272] Minda’s philosophical support for this movement is noted in its 1913 Annual Report, to be mentioned soon.

At the opening of the home on 17 September 1898, Lady Victoria Buxton emphasised the place of reason in the formulation of human identity when she stated,

> No one but the flinty-hearted – and they are happily few in this community – can think without tender sympathy of the poor little children in whom the dawning light of reason has not arisen to aid them in the fight for existence, who have never known the meaning of childhood’s simple joys, whose minds are enwrapped in a cloud made unspeakably pathetic by the contrast they present to the happy little ones who brighten so many a home. They are in all truth God’s own children, ... it may be, the glimmering spark of reason shall be fanned into a healthy living fire, and the little clouded minds be tenderly and lovingly instilled with those qualities in which they are so sadly deficient. ...[273]

By 1909, accommodation demands at the Fullarton facility had reached their capacity of 22 children. A larger institution was required and so, with government financial support, a property at Brighton was procured. By September 1911, the institution was incorporated and was officially named Minda Home. Located on more than 52 acres of land between Brighton Road and the beach the organisation expanded rapidly. A building program was conducted to meet the immediate demand for places at the home. From 1913 to 1918 three accommodation facilities were constructed, with further additions built in the 1920s and 1930s. Expansionary plans, including the development in 1934 of a farm and dormitory accommodation at Craigburn Farm in the Blackwood hills, were completed.[274]

Primary documentation from the early years of Minda Home indicates that such expansion occurred amidst Minda holding to a philosophy that, at least at a custodial level, reflected the eugenics debate in the wider community and abroad, along with the prevailing notion of the person with an intellectual

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[272] ibid.

[273] Minda. "Prospectus,” 8.

[274] Disability Information & Resource Centre. *History of Disability in South Australia: Minda Home*.

disability as a menace to society.[275] In the 1913 Annual Report the following institutional accommodation apologetic was articulated by the incumbent administration:

> The Royal Commission on the care and control of the feeble-minded, which recently sat in England for four years has alarmed the nation by pointing out that the great number of feeble-minded who are at large are a menace to the future generation. It strongly recommends that legal power should be given to commit and detain in institutions and farm colonies any who are not under proper supervision. Our Committee has felt obliged to largely restrict the admission to the younger and more improvable cases, but increased accommodation would permit of our taking custodial cases, and safeguarding from bad companions and crime the irresponsible imbecile who would be far happier in our Home than amongst his present environments, and who under the close supervision of trained industrial teachers, could be made to do useful work ...[276]

Accommodation facilities during the early decades of Minda's development were largely dormitory style with males and females accommodated in separate accommodation blocks. Strict boundaries concerning interaction between genders were observed.[277]

In the years following World War II, across Australia, there was little suitable institutional accommodation for those classified as mentally retarded. Various states, including South Australia, had no legislation in place to determine where various classifications of mentally retarded people should be accommodated. For several years Minda Home had offered care to those classified as 'idiots' and 'imbeciles,' according to their psychologically determined intelligence quotient. However, by the 1950s Minda had chosen to only admit those regarded as 'educable defectives' over the age of five. This marked the end of Minda's intake of pre-school age children. Others with more severe forms of mental retardation were accommodated in psychiatric hospitals.[278]

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[275] It cannot be proven conclusively that this expansionary program was specifically in response to the eugenics philosophy, even though Minda indicated support for the philosophy.

[276] Minda. "The Fifteenth Annual Report." 1-42. (Adelaide: Minda Home, 1913), 12.

[277] Based on first-hand recollections made by present-day or recently deceased elderly Minda people with intellectual disabilities who were accommodated at Minda as children in the 1930s and 1940s.

[278] Dickey, Rations, Residence, Resources, 150.

Whilst the early decades of Minda's development were marked by generalised control over the routines of those under its purview (as was common in other comparable Australian institutions), by the 1970s, through influences such as the disability rights movement, and the associated disability philosophy of normalisation, Minda was philosophically moving towards developing more personalised systems of care. This change of service delivery focus was met with resistance by some parents who were seen by Minda as maintaining a protectionist position towards their children. This is reflected in comments by the Minda Director in the 1983 Annual Report when he states,

> Many of the restraints that society accepted as normal in the early days of Minda have not been looked upon in the same way by successive generations and so today we find that much more attention is being focused on the individual needs and rights of intellectually disabled persons, and it is in this context that the idealogical (sic) perspective of normalisation was born and reached maturity. But while the principle is now well accepted throughout most countries in the world, it is still not uncommon to find people who hold strong reservations or acceptance in theory only of the principle. Here at Minda the expression of these reservations by some of our parents can be most sympathetically understood ... [279]

As evidence of a commitment to normalisation principles and community living the report cites the growing development of group homes. Minda purchased its first group home in 1975 and by 1983 had either acquired, converted, or was in the process of converting, a further 15, along with one hostel, Tassie House, on the Blackwood Hills property abutting Craigburn Nursery. A total of 85 people were living in these homes at that time, with an ongoing plan for four new group homes to be developed each ensuing year. [280] Since that time, the overall rate of progress in developing these homes has declined because, as of 2009, Minda was operating 41 community-based homes, along with four community respite homes.[281]

Since 1983 the main advance in accommodation has been the Pat Kaufmann Centre, a modern, well-appointed nursing home facility opened in

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[279] Minda Incorporated. "85th Annual Report." 1-52. (Adelaide: Minda Incorporated, 1983), 12.

[280] Minda Incorporated, 85th Annual Report, 1-52, 13.

[281] Minda Incorporated. *Internal Telephone Directory*. Edited by Minda Incorporated. (Adelaide: Minda Incorporated, 2006), 8-9.

1999 and located at the institution's main Brighton campus. Details of the centre are stated in the ensuing section. Amongst other current complexes used for accommodation design styles vary significantly. For example, a 1970s complex of three accommodation areas abuts the beach and comprises single rooms and common dining and comfortable lounge areas. The accommodation rooms are centred around the lounge room area. Shared toileting and showering areas are maintained in a hygienic state. Contrastingly, four older dormitory-style accommodation houses, built prior to World War II, remain. Lengthy dormitory rooms have been converted to smaller rooms which generally offer single accommodation, although there are some that accommodate two people. The few internally constructed rooms do not offer window space. The accommodation rooms are of linear design. Dining and recreation areas are variously located for groups of people who have rooms in close proximity to those particular spaces. Shared toileting and showering areas are dated in design and hygiene efficiency.[282]

Community-based accommodation facilities across the southern metropolitan area each cater for approximately six people. Facilities used vary from adapted 1950s bungalows to contemporary residential design.

As with the Home for Incurables/Julia Farr Centre/Julia Farr Services/Highgate Park, after World War II Minda relied more and more heavily on State and Commonwealth government funding streams to maintain and develop services. In 1986 71% of operating revenue was derived from State and Commonwealth government sources.[283] By 2008 the figure had increased to 87%.[284]

By 2008 Minda was providing services, including accommodation, and support to approximately 1,050 adults, with ages ranging from late teens to the elderly. These people are served and cared for by 800-900 administrative, medical, recreational and other support staff.

3.1.8 Other Adelaide Institutions Accommodating People with an Intellectual Disability

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[282] These comments regarding accommodation are from the personal observations of the thesis author.

[283] Minda Incorporated. "Minda Incorporated 88th Annual Report." (Adelaide: Minda Incorporated, 1986), 37.

[284] Minda Incorporated. "2007/08 Financial Report." (Adelaide: Minda Incorporated, 2008), 5.

Whilst Highgate Park and Minda represent the oldest continuing Adelaide institutions that accommodate people with intellectual disability other institutions emerged across the Adelaide metropolitan area during the twentieth century to offer a range of services to people in their care, including accommodation.

Although Bedford Industries commenced in 1920 as the Civilian Tuberculosis and Cancer Comfort Fund it changed its name in 1945 to Bedford Industries when it opened a woodwork shop at Glenelg for those recovering from tuberculosis. Factory-size premises were developed on Goodwood Road, Panorama, in 1950, and a sewing business involving people with a disability was started. By 1962 a number of other trade-type courses were added to their training program. By 1976 various commercial manufacturing and crafts programs were added to their business program.[285] In 1974 Balyana, a residential centre, was opened,[286] offering motel-style accommodation and shared houses. Since then further community-based residences for people with disability have been developed. Today Bedford Industries provides a range of employment opportunities, training, day option and accommodation facilities for people with a range of disabilities, including people with an intellectual disability.[287]

The Strathmont Centre, located in Adelaide's northern suburbs, opened in 1971 following concerns first expressed in the 1950s by the South Australian Superintendent of Mental Institutions, H.M. Birch, that improved facilities for 'the retarded,' including 'retarded children,' needed to be developed. Many such children were being accommodated in psychiatric hospitals.[288] Initially, the centre provided accommodation in villa-style accommodation on campus, seeking to approximate a normalised form of community accommodation. The centre also offered training in self-care and social skills with a view to helping trainees eventually transition into community-based hostel accommodation.[289] By the early 2000s Strathmont's goal was to transition all of its campus-accommodated

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[285] Disability, Information & Resource Centre. *History of Disability in South Australia: Sheltered Workshops,* Disability Information & Resource Centre, 2007 [cited February 28 2009]. Available from http://history.dircsa.org.au/1900-1999/sheltered-workshops/. sec.5, pars.1-4.

[286] ibid., sec.5, par.5.

[287] Disability, Information & Resource Centre. *History of Disability in South Australia: Employment*. Disability Information and Resource Centre, 2007 [cited February 28 2009]. Available from , http://history.dircsa.org.au/1900-1999/employment/ sec.6, par.1.

[288] Lewis, *Managing Madness,* 154.

[289] ibid.

residents into community accommodation; however, as will be observed later in this chapter, a government report recommended that for those campus people who were most significantly intellectually impaired appropriate campus accommodation ought to be developed.

3.2 The Contemporary Institution

Whilst institutional practice and accommodation for people such as those with disabilities, mental health patients and those housed in correctional facilities were, until after World War II, largely unquestioned, by the 1960s past and present institutional practice was beginning to receive serious academic critique. In 1961 sociologist Erving Goffman defined what he referred to as the 'total institution' "as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life."[290] He proceeded to further characterise such an organisation as one which was controlled by a single, administrative authority; had a focus on collective activity; had a tightly scheduled and ordered sense of routine; and was administered according to a single, rational, institutional plan.[291] Long-term institutionalisation led to alienation from the prevailing wider culture. This 'disculturation,' as Goffman described it, led to a series of abasements, namely 'civil death' which is the long-term dispossession from normal social rights and expectations such as those concerning education, job advancement and child rearing,[292] losses such as comforts, self-determination and the value of one's own words,[293] and *conversion* whereby the one who Goffman refers to as the 'inmate' assumes a self-understanding based upon the opinion of him or her held by certain staff, or the institution overall.[294]

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[290] Goffman, *Asylums*, 12.

[291] ibid., 17.

[292] ibid., 25.
See also,
Erikson, Kai. "Notes on the Sociology of Deviance." In *The Other Side: Perspectives on Deviance*, edited by Howard Becker, 9-21. (New York: The Free Press of Glencoe, 1964), 16.
Here, the author refers to the capacity of segregated institutional residents "to teach one another the skills and attitudes of a deviant career."

[293] Goffman, *Asylums*, 47-48.

[294] ibid., 63.

Like Goffmann’s work, other early critiques focused significantly on issues concerned with institutional roles and routines. In 1966 psychologist Russell Barton highlighted the sense in which institutional life can lead to neurosis amongst those who live in such environments. Through the results of institutionalisation, namely, the loss of contact with the outside world; enforced idleness; the bossiness of staff; loss of personal friendships, possessions and events; drugs; ward atmosphere; and the loss of prospects outside the institution,[295] residents are seen to develop neurotic symptoms. The signs include an impoverishment of personality, detachment and isolation from others, passivity of behaviour and reinforced submissive behaviour patterns.[296]

Similarly it was sociologist Kai Erikson who spoke in 1964 of the effect of institutions, such as those designed for people with disabilities, on residents, in terms of social deviance that is deemed to require the attention of “social control agencies.”[297] Deviance is here observed as that which can be taught from one to another between those who share institutional accommodation. Such behaviour serves to reinforce alienation from the wider society.[298]

Early proponents of the normalisation principle further contributed to the understanding of the disabling character of institutions. In 1975 Wolf Wolfensberger highlighted how institutions seek the playing out of predetermined, designated roles by the people who they accommodate so that institutional authorities can predict certain behaviours which can then be described as ‘natural’.[299] With predictable behaviours, the routines of large numbers of accommodated, institutionalised people can be more easily monitored and managed.

Wolfensberger also pointed to the role that institutional architecture has in influencing the roles played out by staff and those for whom they bear responsibility. For example, an institutional facility designed along the lines of a hospital ward can help determine the nature of the roles and relationship played

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[295] Barton, Russell. *Institutional Neurosis*. 2nd ed. (Bristol: John Wright & Sons Ltd, 1966), 17.

[296] ibid., 13.

[297] Erikson, "Notes on the Sociology of Deviance," 11.

[298] ibid., 16.

[299] Wolfensberger, *The Origin and Nature of Our Institutional Models*, 2.

out between staff and residents who work and live in that facility.[300] In 1967 Niels Bank-Mikkelsen also highlighted the effect of institutional architecture, calling for designs that enhanced rather than regulated and inhibited the lives of those with intellectual disabilities.[301]

In 1969 Bengt Nirje described the nature of institutional routine in soul-destroying, mechanistic terms:

> Large institutions and the conditions we can observe in their back wards can never offer facilities of the kind and quality that are essential. In the large wards, the rhythm of the day reduces the retarded to an object in an empty, machinelike atmosphere ... not integrated with a meaningful personal experience ... monotonous confinement.[302]

In offering such critique Nirje was advocating for institutional residents to receive living conditions that approximated those in mainstream society.[303]

The likes of Bank-Mikkelsen were also calling into question the long-standing protectionist nature of institutions in regards to the people with disabilities who they accommodated. In claiming that institutions regarded the ‘mentally retarded’ as children, although they were adults, a protectionist attitude by the institution towards its accommodated people was generated and maintained. The loss of civil rights arising from this societal and institutional attitude towards people with disabilities is noted by Bank-Mikkelsen. He described the negative discriminatory policy in which the "mentally retarded were segregated on the general principle of protecting them against an unsympathetic attitude from the community, and of protecting the community against the mentally retarded."[304] Such a mutually protectionist attitude hearkens back to the post-Renaissance period. At that time those deemed ‘mad’ were kept

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[300] For example, the Highgate wing of the then Home for Incurables, latterly named Highgate Park, was constructed in 1977 along the lines of a hospital ward with the nursing bay as a central feature.

[301] Bank-Mikkelsen, "The Growth and Development of a New Administration," 49.

[302] Nirje, "The Normalization Principle," 368.

[303] ibid., 363.

Here Nirje is advocating for a system of social normalisation which he defines as the means of “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.”

[304] Bank-Mikkelsen, "The Growth and Development of a New Administration for the Mentally Retarded," 41.

isolated from mainstream society and accommodated in asylums, which Foucault described in terms of confinement and social protection.[305]

Bank-Mikkelsen was describing a protectionist attitude endorsed by others such as Wolfensberger that served to nurture the ‘professional/client’ relationship that can still be observed in institutions today. It is in such an institutionalised relationship that medical staff offer professional health care to those under their responsibility on the basis that the ‘clients’ are seen as having a problem. That is, their disability requires professional support and rehabilitation. In such an environment, the person with the disability is regarded by staff, either implicitly or explicitly, as ‘client.’

Campbell argues that such a relationship militates against any essential sense of equality and prevents a relationship of love developing in which mutual acceptance and regard are possible.[306] As McKnight asserts, from the perspective of the institutionalised health care system, the client is so defined because they are fundamentally regarded as a deficient being requiring constant professional care.[307]

In more recent years in Australia the academic institutional disability discourse has turned towards a critique of approaches related to deinstitutionalisation and reinstitutionalisation.[308] This has occurred amidst the move towards community-based accommodation. Such discussion, to be detailed later in this chapter, has been located amidst broader debates by disability advocates and academics concerning issues such as normalcy,[309] the inclusion of people with disability in mainstream society,[310] and the inclusion of people with disabilities in ethical considerations regarding recent bio-technological advances.[311]

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[305] Foucault, *Madness and Civilization*, 35-60.

[306] Campbell, Alastair. *Professionalism and Pastoral Care*. Edited by Don Browning, *Theology and Pastoral Care*. (Philadelphia: Fortress Press, 1985), 43.

[307] McKnight, *The Careless Society*, 103-04, 111-12, 122-23.

[308] Goggin and Newell. *Disability in Australia*, and Ziegler, *Changing Lives, Changing Communities*.

[309] Clapton, "A Transformatory Ethic of Inclusion."

[310] Hallahan, Lorna. "Embrace: A Risky Business for the Excluded." Paper presented at the 3rd National Conference on Spirituality and Disability – Exclusion and Embrace: Conversations about Spirituality and Disability, Melbourne 2001.

[311] Newell, Christopher. "Promises, Promises: Reflections on Disability and the Promised Land of Perfection." Paper presented at The Myth of the Perfect Person: Biennial Conference of the Australian Federation of Right to Life Associations, Canberra, September 2001.

Since the late 1970s the academic institutional critique has been supplemented by the considerations of pastoral theologians who have sought to advocate for and describe a pastoral role within the institutional and health care service delivery system. This has involved detailing the pastoral carer’s role at both a personal level, and at a structural level where socio-political issues require critique and advocacy.[312] This commentary, and the advocacy for a pastoral role in the institutional setting, have been offered, either implicitly or explicitly, as a counterpoint to the prevailing medicalised relationship that sees the ‘client’ in terms of problem or deficit requiring professional care. The pastoral carer is seen as an advocate and carer who offers a more personalised model of care according to pastorally-based principles such as unconditional love, justice and a mutuality of relationship.

By 1999 feminist and pastoral theologian Susan Dunlap went so far as to depict this counterpoint to the medical profession in oppositional terms. In describing both the personal pastoral role and the advocacy role of the pastoral carer she asserted, "[b]ecause we (i.e. pastoral carers) are highly vulnerable to implicitly making alliances with both reprivatizing and expert discourses, we must intentionally choose to function as oppositional as well."[313] … "Caregivers must be trained to instinctively ask the contextual questions, to ask the questions regarding the relative power accorded by virtue of social location."[314]

Prior to the 2000s, first-hand institutional disability narrative was very limited in terms of an articulated voice. The published narratives of Robert Perske serve to shed light on the lives of those who had either worked or lived in the institutional setting. For example, in 1965, he offered the following graphic first-hand illustration of institutional life:

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[312] Regarding the pastoral carer’s role of critique and advocacy see,
Browning, Don. *Religious Ethics and Pastoral Care*. Edited by Don Browning, *Theology and Pastoral Care*. (Philadelphia: Fortress Press, 1983).
Campbell, *Professionalism and Pastoral Care*.
Campbell, Alastair. *Rediscovering Pastoral Care*. (London: Darton, Longman and Todd Ltd, 1981).
Nouwen, Henri. *The Wounded Healer*. (New York: Image Books, 1979).
Pattison, Stephen. *Pastoral Care and Liberation Theology*. (Cambridge: Cambridge University Press, 1994). Pembroke, Neil. *Working Relationships: Spirituality in Human Services and Organisational Life*. (London: Jessica Kingsley Publishers, 2004).

[313] Dunlap, "Discourse Theory," 143.
Bracketed words are those of thesis author.

[314] ibid., 144-145.

> KNI is a hellish place. It can't be anything else. When 16, 20 or more children – sick children at that – are forced to live under one roof, you have the makings of a hell. When all of their needs to be helped, guided, encouraged, controlled, and loved is expected to be carried out by two, or less adults, you have the makings of a hell ...[315]

In recent years the Australian institutional narrative has started to find a voice illustrating institutional practice. Accounts have included the effects of long-term institutionalisation, [316] and the effects on women of institutional containment policy,[317] as well as the histories of Australian asylums, and those otherwise contained silently in them.[318] However, at present, the literature would suggest that this institutional voice remains only a whisper. The lack of voice and revealed identity of institutionalised people with intellectual disability remains in place.

As will be mentioned later in this chapter it can be justifiably asserted that Goffman's definition of the 'total institution' pertains to a time when institutions were regarded as an appropriate accommodation setting for people with disability in general, and with intellectual disability in particular. They represented a higher level of mass accommodation and, arguably, less-personalised 'client' practices and routines. Nonetheless, issues and principles pertaining to segregation, style of administration, routine and planning, and lack of autonomy, along with Goffmann's list of abasements, can still be observed in practice today in the institutions that are the focus of this extended reflection. This will be observed in later chapters where the institutional narrative will be detailed and analysed. Therefore, it can be claimed that the principles of Goffman's definition still bear application today alongside contemporary indigenous discourse and critique pertaining to institutional practice.

3.2.1 Contemporary Trends in Institutionalisation

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[315] Perske, Robert. "KNI Is a Hellish Place, Kansas Neurological Institute, December 26, 1965." In *The Pastoral Voice of Robert Perske,* edited by William Gaventa and David Coulter, 53-54. (New York: The Haworth Pastoral Press, 1965), 53.

[316] Allen, Traustadottir, and Spina. "Sixty Years in the Institution."

[317] Johnson, Kelley. "Containing Uncontainable Women." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions,* edited by Kelley Johnson and Rannveig Traustadottir, 66-75. (London: Jessica Kingsley Publishers, 2005).

[318] See, for example, the asylum histories in,
Coleborne, Catherine, and Dolly McKinnon, editors. *'Madness' in Australia: Histories, Heritage and the Asylum*. (St. Lucia: University of Queensland, 2003).

With the focus of this extended reflection being concerned with people with intellectual disability living in institutional accommodation it could be argued that such a focus is becoming increasingly redundant due to a currently changing trend in the style of accommodation being made available to people with disability.

Certainly it can be noted that presently in South Australia, as elsewhere in Australia, there is a philosophic trend away from institutional mass accommodation for people with disability. However, it is worth considering the extent to which this trend is a consequence of a heartfelt commitment to securing a better mode of accommodation and living standard for people with disability, and intellectual disability in particular, or whether it is for more pragmatic reasons. As has been noted both the Home for Incurables and Minda experienced significant increases in the costs of institutional health care through the 1970s and into the 1980s, leading such institutions to rely ever more heavily on government funding. Thus, as Dickey asserts, this has led "to greater government control and a search for less institutionalised solutions to the obvious physical problems being confronted."[319]

An institution such as Minda can point to the influence of a philosophy such as normalisation. This philosophy was directly articulated to the Minda community by Bank-Mikkelsen in 1967 and Wolfensberger in 1980. Subsequently, it influenced Minda's move from the 1970s onwards to develop community-based accommodation from a desire to provide its accommodated people with a more socially normal mode of accommodation and lifestyle. Nonetheless, it cannot be discounted that, to some extent, such a fundamental shift in accommodation practices was influenced by the belief that it would produce more manageable financial outcomes.

It can be argued that the move to community accommodation is beneficial for the accommodated people in question even if it is undertaken for the most economically prudent of reasons. However, it does raise the question concerning the extent to which institutions will continue to support such accommodation should the costs of maintaining and further developing such residences start to outweigh more institutionally-oriented modes of accommodation.

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[319] Dickey, Rations, Residence, Resources, 116.

Today, whatever the motivation, institutions can point to the rise in the number of people with disability living in a growing number of community accommodation sites as evidence of institutional endorsement for a community approach to accommodation. Whilst it can well be argued that the relocation of people with disability away from traditional, mass accommodation signifies a trend towards a more personal, socially normal style of living, various indicators signify that institutionalism is maintaining an entrenched role in contemporary accommodation plans for people with an intellectual disability.

3.2.2 The Institutional Remnant

While today there is physical evidence of accommodation for people with disabilities geographically distanced from the institutional campus the reality is that some people with disabilities, including those with intellectual disabilities, remain in relatively large-scale campus-style accommodation, and may do so indefinitely. For example, the Strathmont Centre, a home for people with intellectual disabilities, located in Adelaide’s northern suburbs, whilst indicating a commitment to relevant community-based accommodation, nonetheless appears to maintain a certain level of commitment to campus accommodation, with a government commitment to updating accommodation at the centre with villa-style residences.

A 2005 report by the State Government’s Public Works Committee regarding the centre, *Strathmont Centre Redevelopment and Community Living Project*, raised the spectre of ongoing institutionalisation as possibly the most appropriate form of accommodation option for those residents with the most significant levels of impairment. In expressing two particular concerns the report states,

> The Committee accepts that deinstitutionalization is the desired outcome for most residents of the Strathmont Centre. However, evidence has been given that the current model of community living is not appropriate for a small number of residents with exceptional needs. **The Committee is concerned that the number of such residents will not be sufficient to warrant the continuation of a separate institution such as Strathmont Centre.**
>
> The Committee is aware that a similar situation is likely to arise as other institutions dealing with disabled clients move towards a community living model. **Accordingly, the Committee recommends to the Minister that consideration be given to determining how many such clients will remain after the**

> **community living model has been fully implemented, and the merit of an alternative form of "institutional" living to meet their accommodation and care needs.**[320]

In 2008 the State Government's Department of Families and Communities indicated that the Strathmont Centre Redevelopment and Community Living Project would enable 150 residents to move from the Strathmont Centre to purpose-built community homes, with 99 residents remaining on-site in improved accommodation.[321]

Whilst these statistics are consistent with the centre's commitment to transfer its accommodated people into community accommodation it raises the distinct possibility of some form of reinstitutionalisation or re-negotiated form of institutionalisation for those deemed unsuitable for community placement.

Furthermore, the 2011 *Strong Voices* report concerning the rights of people with disability in South Australia recommended as a priority action the closure of the Strathmont Centre by April 2013.[322] However, by mid-2012, there was no clear government statement to indicate that this would eventuate.

In recent years the Highgate Park campus of Disability SA has made an intentional move towards deinstitutionalised, community accommodation. In concert with this, in 2006, the then Julia Farr Services received a funding boost in the form of State Government grants totalling $14.8 million to go towards the development of community accommodation for people with a disability, including those with Acquired Brain Injury.[323]

However, by 2009, there remained a group of approximately 30 people accommodated at Highgate Park who live with Huntington's Chorea and Acquired Brain Injury who seem to fit uneasily into a community model of

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[320] Public Works Committee. *Final Report: Strathmont Centre Redevelopment and Community Living Project* S.A. Government Printers, 2005
[cited 5th January 2009]. http://www.parliament.sa.gov.au/NR/rdonlyres/9F3C696F-7249-4E98-8FEF-A2D2CC905980/2734/report.pdf 17. Website not available.
Bold print in the original documentation.

[321] Department of Families and Communities. *Evaluation of the Strathmont Centre Redevelopment.* Department of Families and Communities, 2008 [cited December 28 2008]. http://www.dfc.sa.gov.au/pub/tabid/431/itemid/685/Evaluation-of-the-Strathmont-Centre-Redevelopment.aspx Website not available.

[322] Government of South Australia: Social Inclusion Board. "Strong Voices," 11.

[323] State Government of South Australia. *Funding Boost for Julia Farr*. State Government of South Australia, 2006 [cited January 17 2009].
http://www.ministers.sa.gov.au/news.php?id=341
Website not available.

accommodation, along with others who prefer to stay at Highgate Park rather than move elsewhere. The question thus becomes whether or not these people will remain in some form of relatively large-scale institutionalised accommodation, or in an alternative form of accommodation.

In 2004, at Minda Incorporated, the number of people accommodated at the central Brighton campus was 317.[324] By 2009, this figure had declined to 244.[325] However, recent strategic planning, articulated through the Master Plan development plan, whilst indicating a commitment to developing its community accommodation facilities, also details a wholesale commitment to entrenching Minda's capacity to maintain sizeable accommodation numbers at its main Brighton campus for the foreseeable future. In 2010, the then Minda CEO stated, in reference to the main Brighton campus:

> Many of the existing facilities on site, including accommodation, were built more than 50 years ago and are now outdated for the provision of high quality support. The endorsement of the Master Plan for Minda's Brighton site allows for the delivery of new, purpose-built housing and facilities of the highest standards …[326]

Such strategic planning is still regarded by the institution as a form of deinstitutionalisation inasmuch as it is promoted as providing 'village style' accommodation and services.[327] However, in reality, it remains a form of institutionalisation in that it fails to de-congregate its accommodation facilities and other services.

Furthermore, it was only in 1999 that Minda developed, at its principal Brighton site, a modern nursing home complex, the Pat Kaufmann Centre, providing single-room accommodation for a maximum of 48 elderly and frail people with an intellectual disability. The people are accommodated in one of five eight-person accommodation 'houses,' each managed by a staff team. Additionally, up to eight people can be accommodated in an attached Clinical Health Care Unit for those requiring critical care. Whilst the centre was initially designed to offer single-room accommodation, in 2005 each of the

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[324] Minda Incorporated. "All Accommodation Placements." (Adelaide: Minda Incorporated, 2004).

[325] Minda Incorporated. "Minda Client Listing." (Adelaide: Minda Incorporated, 2009).

[326] Minda Incorporated. "2009/10 Minda Annual Report." (Adelaide: Minda Incorporated, 2010), 13.

[327] Minda Incorporated. *Minda Master Plan.* Minda Incorporated, 2012 [cited April 7 2012]. Available from www.minda.asn.au para.1, sec.1.

accommodation areas, apart from the Clinical Health Care Unit, converted their area's sunroom/recreation area to two-person accommodation rooms. Each of these areas is being fully utilized for accommodation purposes. A centralized management structure oversees the administration of the complex. As of early 2012 56 elderly and frail people with intellectual disability were accommodated in the complex, tending to indicate an ongoing commitment to a form of institutional, nursing home accommodation for a number of Minda's elderly people for the immediate future.[328]

3.2.3 The Political Climate

There have been signs in recent years of institutions making efforts towards deinstitutionalised accommodation. Nonetheless, there is still evidence to suggest that such efforts are not at the expense of the continuance of contemporary forms of institutionalised accommodation, with this accommodation being maintained through the assistance of Commonwealth and State Government funding.

The 2005 findings of the State Government's Public Works Committee concerning the Strathmont Centre regarding "an alternative form of 'institutional' living"[329] tend to suggest that the State Government is not averse to continuing some form of institutional accommodation for those whose level of intellectual disability is such that it may militate against them living in fully deinstitutionalised accommodation.

Minda supports many community accommodation residences and an in-home outreach nursing service for people with intellectual disability, suggesting a certain commitment towards deinstitutionalised support for people with intellectual disability. However, at the same time, the Pat Kaufmann Centre's nursing home beds are funded by the Commonwealth Government.[330] This suggests political support for a form of modern, institutional, campus accommodation at Minda for at least the elderly and most frail of those people for whom it bears responsibility.

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[328] Details concerning the nature of accommodation at the Pat Kaufmann Centre are derived from the thesis author's personal observations.

[329] Public Works Committee. *Final Report*, 17.

[330] Minda Incorporated. *Together We Can Do It* Minda Incorporated, 2008 [cited January 18 2009]. Available from, http://www.mindainc.com.au/services/residential-services/aged-care-and-health-services

In concert with the capacity for contemporary institutions to maintain an institutionalised accommodation presence, or to reinstitutionalise, it is worth noting the inherent, rationalist capacity of institutions to have their accommodation policies (as well as other policies) dictated to by levels of government expenditure for the disability and welfare sectors. In a number of countries in the 1980s, including the United Kingdom, the United States and Australia, the trend towards the deinstitutionalisation of welfare-related services was stimulated by restrictions to government funding.[331] This raises the possibility that if governments reduce welfare-related expenditures then institutional accommodation could reassert itself as an institutional policy. Economic pragmatism can easily override disability-related idealism and principle. As Parmenter notes,

> There is, therefore, an inherent danger that an institutional legacy may live on, especially as the effective community integration of people with intellectual disability has yet to be fully realized in those countries that enthusiastically embraced deinstitutionalization.[332]

3.2.4 Mini-Institutions

In the discussion of 'The Institutional Remnant,' an example was cited and critiqued of an institution seeking what it claims to be a deinstitutionalised 'village' plan, even though it involves accommodating large numbers of people with intellectual disability on its central institutional site. This amounts to a form of institutional consolidation or reinstitutionalisation.

At the same time the number of institution-initiated community accommodation options for people with disabilities, including those with intellectual disability, in Adelaide, is rising. However, whilst these options represent a geographic movement in accommodation services away from the institutional hub they do not represent a complete departure from institutional accommodation. Indeed, they can be regarded as a form of 'mini-institution.'[333] It can be claimed that a growing number of accommodation sites for people with disabilities are being constructed across the metropolitan areas by disability

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[331] Parmenter, Trevor. "Intellectual Disabilities – *Quo Vadis?*" In *Handbook of Disability Studies*, edited by Gary Albrecht, Katherine Seelman and Michael Bury, 267-96. (Thousand Oaks: Sage Publications, 2001), 279.

[332] ibid.

[333] Ziegler, *Changing Lives*, 4.

service providers such as Minda Incorporated, Disability SA, Strathmont Centre and Bedford Industries. However, what can be questioned is the extent to which these developments represent a genuine departure from institutionalism. Advocates of these newer developments can rightly point to accommodation that is located in the suburbs, is geographically closer to community facilities, is visually compatible with other suburban residences, is designed with regard to some sense of domestic normality, and is much smaller in terms of residential occupancy per residence than the traditional institution.

There is also some research that points to improved quality of life in the community setting.[334] Nonetheless, in terms of guiding ethos and values, community accommodation for people with intellectual disability often still bears the marks of institutional accommodation.

As British health care advocate and academic Jan Walmsley says concerning community-based institutional practices:

> Anyone who knows the realities of life for people with intellectual disabilities will ... know that institutional practices can be found in community facilities, large and small. To focus exclusively on institutions as the evil to be fought could conceivably distract attention from the real evils which are inhumane treatment, neglect, and denial of rights.[335]

Scholarship points to a lack of autonomy for people with disability who move from the traditional institutional accommodation into community-based accommodation. Holburn points to this lack of autonomy being expressed via various forms of institutionally imposed residential practices such as excessive regulation, a culture of compliance, rigid routines, centralized control and evaluations of accommodated people based on deficiencies in adherence to rules.[336] Traustadottir and Johnson, in an analysis that includes a contemporary Australian narrative, echo the issue of the control of the routines of accommodated people. However, they also highlight a lack of autonomy expressed through a lack of choice created by a deficiency in resource

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[334] Emerson, Eric. "Deinstitutionalisation in England." *Journal of Intellectual & Developmental Disability* 29, no. 1 (2004): 79-84.
Epstein-Frisch, Belinda. "Deinstitutionalisation: A Review of Literature." *Interaction* 21/1 (2007): 7-16.

[335] Walmsley, "Institutionalization," 64.

[336] Holburn, Steve. "Rhetoric and Realities in Today's ICF/MR: Control out of Control." *Mental Retardation* 30, no. 3 (1992): 133-41. 133-41, 138-140.

availability, as well as administrative practices that amount to surveillance. This is coupled with a culture of dependency by accommodated people towards their staff.[337] This culture mirrors the dependency and power imbalance that describes the relationship between accommodated people and medical professionals in the large-scale institutional setting.

By means of further Australian disability discourse Julian Gardner and Louise Glanville, in describing community accommodation as prisons, offer examples of this lack of autonomy. It is expressed through civil detention, staff-initiated access, lack of administrative accountability, non-reviewable staff processes, and lack of consultation with accommodated people regarding house rules and with whom one lives.[338]

Further commentary by James Mulick and Patricia Meinhold also focuses on rule-making and regulation and its capacity to foster compliance, as well as failing to address the unique nature of individual and environmental needs.[339] This is reinforced by Holburn who describes the incapacity of rules to apply to a community disability accommodation setting, or to cater effectively for natural environmental contingencies. Furthermore, the application of rules to contingencies reduces the capacity of the organisation to respond effectively to situations requiring environmental change.[340]

This notion of contingency gains credence through the broadly applied practice of disability-related risk management strategies and occupational health and safety practices as applied in the institutional setting. Here Traustadottir and Johnson draw a thread between past and present practices and locations when they state that it can be argued “that we have translated the control previously exerted on people through locked doors and high walls into the more subtle

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[337] Traustadottir, Rannveig, and Kelly Johnson. "Introduction: In and out of Institutions." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelly Johnson and Rannveig Traustadottir, 13-29. (London and Philadelphia: Jessica Kingsley Publishers, 2006), 23-25.

[338] Gardner, Julian, and Louise Glanville. "New Forms of Institutionalization in the Community." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelly Johnson and Rannveig Traustadottir, 222-30. (London and Philadelphia: Jessica Kingsley Publishers, 2006).

[339] Mulick, James, and Patricia Meinhold. "Analyzing the Impact of Regulations on Residential Ecology." *Mental Retardation* 30, no. 3 (1992): 151-61.

[340] Holburn, Steve. "Rules: The New Institutions." *Mental Retardation* 28, no. 2 (1990): 89-94.

discourse of risk management with its rituals of assessment and strategic placement."[341]

Epstein-Frisch et al. describe an Australian institutional response to cluster housing, and how that form of accommodation can bear many institutional features. These include the impersonal nature of care, segregation from the wider community, the lack of a home-like atmosphere, and the incapacity of the accommodation administration to respond effectively to the holistic needs of those for whom it bears responsibility.[342] As is stated,

> … there are those for whom deinstitutionalization has meant a move to a different form of accommodation that has some or all of the features of an institution. At worst there are those who continue to experience restrictions upon their freedom of movement and other freedoms of decision-making. At best there are those whose individual needs have not been addressed.[343]

Apart from this description of a penal-style arrangement what is being expressed here is what some would call deinstitutionalisation as a form of reinstitutionalisation. This perception is described by Holburn when he asserts the propensity for rule-making that entrenches staff power hierarchies and subsequently leads to a lack of choice for accommodated people. He states:

> When we view institutions as *practices* that affect people, it is clear that many 'deinstitutionalized' people are still under the tenacious control of familiar institutional practices … old institutions and the new rule-governed organizations have similar origins and promote the same ill consequences. Is it time to deinstitutionalize our discordant regulatory practices?[344]

What is observed here is that these forms of community accommodation for people with intellectual disability are not simply about an expression of institutional practice. They are concerned with practice that reflects entrenched institutional values. In describing community accommodation practices that reflect a lack of autonomy, adherence to rules and regulations, and adherence to risk minimisation procedures, what is observed is the continuing adherence to prevailing and imposed institutional values. These values are imposed by the

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[341] Traustadottir, and Johnson. "Introduction," 21.

[342] Epstein-Frisch, Belinda, Trudy van Dam, and Lesley Chenoweth. "Presenting the Evidence: Accommodation and Support for People with Disability." 1-72. (Epping: Institute for Family Advocacy and Leadership Development, 2006), 3.

[343] Gardner, and Glanville. "New Forms of Institutionalization," 223.

[344] Holburn, "Rules," 92. Italics are those of the author.

institution that continues to bear responsibility for the ownership and ongoing management of the community facility. As Goggin and Newell assert, with the maintenance of institutional values in the community setting, what emerges is "a problematic reinstitutionalisation."[345] Whilst the institution sees fit to transfer traditional institutional values concerned with staff power and control to the community setting, along with risk minimisation procedures and regulations, a form of mini-institutionalisation is destined to remain in place. The geographical location and architecture may be different but the institutional values abide.

What also needs to be accounted for at this stage are the values of the community into which the people with intellectual disability are being located. Efforts at deinstitutionalised accommodation practice can be curtailed by a lack of local community acceptance. As Goggin and Newell assert,

> Ironically, deinstitutionalization was premised on people with disabilities being full and valued members of the community. Yet, so often we see that these quasi-institutionals have little to do with their next-door neighbours, and that residents are too often excluded from the local community.[346]

Proceeding from this discourse it can be argued that the construction of community-based residences for people with intellectual disability cannot ensure that such facilities do not still bear the marks of institutional accommodation. Even though they have been geographically separated from the central institution, and accommodation may approximate normal community architectural design and access to community facilities, such residences can remain fundamentally guided by institutional values, ethos and practice.

3.3 Summary

Intellectual disability has been defined as pertinent to this extended reflection in two important ways. Firstly, people with an intellectual disability have been observed to be the primary source of pastoral relationship which this pastoral carer engages in amidst the institutional context. Secondly, people with intellectual disability, understood as a marginalised socio-political grouping, can be regarded as further from proscribed social norms than other oppressed socio-

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[345] Goggin and Newell. *Disability in Australia*, 129.
[346] ibid.

political groupings. This latter point can be asserted both on the basis of the unique characteristics of their disability and of the extent of their consequential loss of valued social identity and function.

Within the South Australian context the current conceptualisation of the institution, although arguably more enlightened, needs to be understood as emerging from early, colonial forms of segregation, such as the destitute asylum. Such a system of social isolation can be regarded as symptomatic of the widely-held fear of people with disability. This was a fear that led to the call for the ‘elimination’ of the ‘mental defective’ from society, as expressed through the eugenics philosophy.

It can be well argued that there is evidence of a move today to forms of community-based accommodation which can lay claim to being far removed from the historic mass accommodation forms of the institution, both in terms of geographic location and architectural style. These forms of accommodation, and the philosophy undergirding their development, can be observed to be expressive of people with intellectual disability being treated with greater respect than in former generations. Nonetheless, the negative impact of institutionalisation can clearly be seen to remain in evidence in regards to resident compliance, regulation, lack of community access and lack of autonomy, even amidst community settings. Furthermore, the continuation of a culture of institutionalisation can be perceived, both from a political and institutionally-pragmatic perspective, through the ongoing development of accommodation at traditional institutional locations.

3.4 How Do I Regard the One Before Me?

And I observe the one before me as Slave in terms of embodied identity. He has assumed this name because for countless generations that is who he has been told he is. He has been told that he bears the marks of a slave, and thus it is his destiny to be treated as one and to live as one. It has been predetermined. Suggestions of assuming another identity are inconceivable. I see someone who has been told so often that this is who he is that he bears the countenance of one who believes it and who acts accordingly.

This identity sees him bearing a heavy burden upon his shoulders. It weighs him down, it reduces his physical aspect, it limits the fluidity of his movement, it causes him to look downwards in suffering endurance rather than upwards to far horizons. Life is for the present moment.

I see others here who bear similar burdens, whose marks, aspect and behaviours are similarly diminished. They too look down. They too are sustained for the day by those who preserve the body, but not so much the soul.

I observe the location where these Slaves are to be found. It is a bounded, restricted place. It is a place of limited resources and activity. It is a place where one is enabled for the next day, but where greater visions are hard to attain. I observe those for whom this place is their world, who have little conception of a world beyond. This place represents a norm. This place represents reality.

I understand this place as a place of protection, where both the Slaves and I are being protected from each other. I don't really understand why. But what I see as a result of this shared protection is a defined distance between myself and the Slaves. It seems that we are both located where we best belong. It seems we are both safer with a distance in between.

I look to myself. I bear no such burden. My norms seem much less restrictive. Compared to these others I feel no great weight upon my shoulders limiting my aspect or activity. I am able to move where I will, relatively unencumbered, unmarked and free. I can look up to those far horizons and set a course towards them.

Not so the Slave.

CHAPTER 4

TOWARDS AN ADEQUATE UNDERSTANDING OF AUTHENTIC PASTORAL CARE

"The only cure for existence is everlasting, infinite love, applied minute by minute, like an ointment." [347]

"Caregivers ... must cultivate the awareness that meaning is plural, that more than one 'take' on things is legitimate."[348]

"Pastoral care should be aware of structures and injustice."[349]

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[347] Williams, Bill. *Naked Before God: The Return of a Broken Disciple*. (Harrisburg: Morehouse Publishing, 1998), 261.

[348] Dunlap, "Discourse Theory," 137.

[349] Pattison, *Pastoral Care,* 67.

Plate 4.1

‘Beardless Slave’

by

Michelangelo Buonarotti

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[350] Ruehring, Lauren. *Beardless Slave by Michelangelo* HowStuffWorks, Inc, 2011 [cited 30/12/2011]. Available from http://entertainment.howstuffworks.com/arts/artwork/michelangelo-sculptures14.htm

4.1 Towards a Meaningful Understanding of Pastoral Care in the Contemporary Context

Various factors need to be accounted for in order to develop a meaningful understanding of pastoral care that is relevant to the context under consideration in this extended reflection.

Today across Australia, including in South Australia, pastoral care is practised by a range of professionals and volunteers in a wide variety of religious, social and institutional settings such as schools, universities, hospitals, aged care facilities (e.g. nursing homes), hospices, correctional service facilities, mental health organisations, as well as facilities for people living with a range of disabilities. Understanding the nature of the pastoral care required in any such context may vary according to factors such as the values and principles of the appointing organisation, the type of people served in the particular pastoral context, as well as the held values and principles of the designated pastoral carer.

Furthermore, in order to come to a meaningful understanding of pastoral care specific to the contemporary institutional context considered in this extended reflection there needs to be an account of prior notions of the concept and the sense in which it has been shaped by prevailing and time-specific theological and institutional considerations.

4.1.1 Pastoral Care in its Historic and Cultural Context

In terms of biblical history pastoral ancestry can be traced to the leaders of the ancient people of Israel in their pursuit of and settlement in a promised land. In particular, this occurred through the early wisdom traditions of three groups of leaders, namely, the priests, with their responsibility for worship and ritual; the prophets, who spoke on moral issues on behalf of Yahweh; and the wise men and women, who offered counsel on a range of issues related to life and conduct.[351] Whilst these ancient pastoral practices were mainly understood in terms of *guidance*, in later times historians have supplanted this term with *healing, reconciling* and *sustaining*.[352] Furthermore, whilst these pastoral roles were originally seen as focusing upon the individual and family, they began to be

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[351] Gerkin, Charles. *An Introduction to Pastoral Care*. (Nashville: Abingdon Press, 1997), 23-25.

[352] ibid., 25.

understood as caring for the community both in terms of worship and general life.[353]

Also, within later Old Testament traditions, there emerged the notion of the caring leader as shepherd. This metaphor originated as a motif to describe kingly leadership in the monarchical period, although it never assumed the status of an institutionalised role. Within the religious context it was first applied to Yahweh's care for the children of Israel as personified in Psalm 23 where Yahweh is described as the Good Shepherd who leads people in the ways of righteousness, restores people's souls, and walks with people amidst their enemies.[354]

A survey of the exercising of the practice of pastoral care, from the New Testament era till recent generations, indicates the sense in which it has usually reflected the prevailing theological priorities and values of the time. Clebsch and Jaekle, and Gerkin, in outlining eight epochs in the history of Christian pastoral caring, point to each epoch, although not totally to be understood as independent from other epochs, as reflecting the religious and social circumstances of that historic era.[355]

For example, amongst the earlier epochs, that of Primitive Christianity, lasting until 180 AD, detailed the emergence of the early Christian church. It emphasised the spiritual sustaining of Christian persons amidst a sinful world that was viewed by the early Christians as moving rapidly towards the end of civilisation. It was also during this epoch that the formal role of pastor emerged in the life of the early Christian church, emanating from Christ's injunction to the apostle Peter to 'feed my sheep' (John 21:16, 17).[356] Over this and ensuing epochs the role of pastor, understood in its more informal ministerial role, took on the guiding, nurturing and teaching role that has informed much of what the Christian church has understood its pastoral ministry to be.

The epoch described as Under Oppression, from 180 AD to the end of the reign of Diocletian (306 AD), was an era when the Christian church came under

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[353] ibid.
[354] ibid., 27.
[355] Clebsch, William, and Charles Jaekle. *Pastoral Care in Historical Perspective: An Essay with Exhibits*. (Englewood Cliffs: Prentice-Hall, Inc., 1964), 12.and,
Gerkin, An Introduction to Pastoral Care, 12.
[356] Clebsch, and Jaekle, Pastoral Care in Historical Perspective, 12. See also,
Gerkin, An Introduction to Pastoral Care, 27.

oppression from the prevailing paganism of the Roman Empire. It was characterised pastorally as a period when Christian persons were seen as needing to be bolstered in their relationship with God amidst the temptation to waver in faith. Clerics codified sins and their penalties so as to shore up allegiance to God and the Church.[357]

Amongst more recent epochs the one described as Renewal and Reform sought to respond pastorally to the rise of individualism in the Renaissance and Reformation by focusing on the notion of personal reconciliation to God.[358] This concept remains variously interpreted in pastoral contexts today and remains as a strong framework around which pastoral theology and practice is interpreted.[359]

The epoch described as Enlightenment saw the act of Christian pastoring focusing on the sustaining of souls amidst the social upheaval generated by the rapid development in industrialisation. Faith came under threat as a consequence of the growing prominence given to scientific enquiry and the place of reason in the human personality.[360] Consequently, questions concerning the nature of God came more into the realm of rational enquiry and empirical quantification.[361]

Such historic description does not take into account the more nuanced forms of personal pastoral care that at different times occurred in a variety of

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[357] Clebsch, and Jaekle, Pastoral Care in Historical Perspective, 13.

[358] ibid.

[359] Regarding the strong individualist salvific pastoral legacy, Thurneysen claimed that the need for peace with God can only be truly answered when it coincides with the question, ‘Do you know that all your sins are forgiven?’ – forgiveness being the principal concern of pastoral care. See,
Thurneysen, Eduard. *A Theology of Pastoral Care*. (Richmond: John Know Press, 1962), 154.
Andrew Purves appreciates Thurneysen assigning primacy in the ministry of care to Christ’s atoning act, but contends that singling out forgiveness of sin is to fail to embrace the full gospel message. Forgiveness needs to be seen as the means to the end of restoring a broken relationship with God. It is communion with God that is the true aim and destiny of humankind. Pastoral care should therefore be viewed as a ministry of grace in which people are led into restoration of communion with God. See,
Purves, Andrew. *Reconstructing Pastoral Theology: A Christological Foundation*. (Louisville: Westminster John Knox Press, 2004), 176.
Other contemporary pastoral theologians have identified reconciliation as a central element in the ministry of pastoral care. Stephen Pattison, for example, defines pastoral care as “that activity ... directed towards the elimination and relief of sin and sorrow and the presentation of all people perfect in Christ to God.” See,
Pattison, A Critique of Pastoral Care, 13.
van Deusen Hunsinger affirms Christ’s redeeming act as pivotal to Christian faith and hope, suggesting that “we might wish to claim the ministry of reconciliation as the fundamental pastoral task …” See,
van Deusen Hunsinger, Deborah. *Pray without Ceasing: Revitalizing Pastoral Care*. (Grand Rapids: Eerdmans, 2006), 156.

[360] Clebsch and Jaekle, Pastoral Care in Historical Perspective, 13.

[361] Gerkin, An Introduction to Pastoral Care, 45.

institutional settings such as prisons, hospitals and asylums. Nonetheless, it does point to the Church's role in discerning socio-political movements. Furthermore, it does broadly note the development of pastoral understandings and practices that uniquely sought to respond to the socio-political circumstances of the time. At the same time, the mainstream Church's general response to socio-political circumstance was largely religious in nature, focusing on the care and bolstering of the individual soul in response to the oft-regarded threat provided by prevailing social and political institutions and movements.

The early years of the twentieth century continued to regard the concept of pastoral care in terms of care for the individual soul, with such care being understood in terms of personal salvation. In returning to how such care is seen to apply to people with intellectual disability, the early mission statement of Minda Home, first published in 1900, again proves instructive. It refers to the children under its care as having a "closed-soul vision," to which the evangelically charitable and pastoral response is found amidst the "... love that burns to serve her Lord."[362]

4.1.2 Contemporary Understandings of Pastoral Care

The latter decades of the twentieth century, which equate to Clebsch and Jaekle's eighth and final epoch, are for the first time amongst all epochs marked by a lack of clarity concerning the dominant pastoral feature of the era. As they indicate,

> New circumstances of the late eighteenth and early nineteenth century revolutions against the Christendom societies of earlier times, and the concomitant voluntaryism and pluralism of modern Christianity, brought with them an array of pastoral work that has been largely oriented around a type of guidance that educes values and norms from personal convictions and value systems.[363]

The development of systems of theological critique such as historico-literary criticism challenged prevailing dogma and traditional conceptualisations of truth. In concert with this mode of critique, understandings of pastoral care also developed that challenged traditional models of ministry regarding both theory and practice.

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[362] Minda, The Second Annual Report, 1.

[363] Clebsch and Jaekle, Pastoral Care in Historical Perspective, 14-15.

One consequence has been a growth in dialogue between theologically-based notions of pastoral care and those fields of enquiry that impinge on the specific socio-political contexts in which the pastoral care occurs. Doehring notes the 1980s' shift in thinking regarding the role of pastoral theology. She observes the transition from it being largely viewed from a therapeutic perspective to that of practical theology.[364] One consequence has been the growing awareness of the contextual nature of pastoral care. Related to this, sociologist George Furniss points to the contemporary openness of pastoral care as being under the influence of various sociological critiques such as those which emanate from feminism, cross-culturalism, liberation theology and forms of family systems theory such as clinical pastoral education.[365]

Such critique allows for pastoral care to develop a specific relevance to unique socio-political situations and peoples, including people with forms of disability, rather than being presented as a generic or neutral brand of caring deemed irrelevant, unhelpful or harmful by the care receivers. As pastoral theologian Stephen Pattison indicates in criticising pastoral neutrality, "[a]ll pastoral care takes place in a special social and political context and its ideas and practices either question or affirm the values and structure of that order." [366]

However, despite Pattison's assertion, there are those pastoral care forms, such as some that focus on the individuals' personal care, which could be observed to be seeking a politically neutral pastoral position. [367] However, it can also be argued that such a pastoral posture, as a consequence of disregard for or indifference towards the socio-political circumstance, are endorsing the political status quo by default.

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[364] Doehring, Carrie. "A Method of Feminist Pastoral Theology." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie Miller-McLemore and Brita Gill-Austern, 95-111. (Nashville: Abingdon Press, 1999), 100.

[365] Furniss, George. *The Social Context of Pastoral Care: Defining the Life Situation*. (Louisville: Westminster John Knox Press, 1994), vii.

[366] Pattison, A Critique of Pastoral Care, 90.

[367] For example, the strong focus in some forms of pastoral therapy concerning the need for painful self-discovery tends to indicate a certain level of neglect or supposed neutrality towards the lived socio-political context of the individual in question. As pastoral carer Brice Avery states, "The business of pastoral therapy is to create a context between two people where spontaneous exploration can occur. It is only then that the painful and threatening business of unwinding or dissolving some of the false-self cocoon can be contemplated by the client."
Avery, Brice. *The Pastoral Encounter: Hidden Depths in Human Contact*. Edited by Marlene Cohen, *Handbooks of Pastoral Care*. (London: Marshall Pickering, 1996), 11.

From a theological perspective Pattison's questioning of attempted pastoral neutrality is a critique of the systemised form of theological thinking that, when received in isolation from more contextual pastoral forms, nurtures generic conceptualisations of the caring role. For example, with the emergence of liberation theology in South American slums and base communities in the 1970s a form of practical pastoral theology developed that made claims for a more secular form of salvation that was to be found amidst the socio-politically and socio-economically constituted poor. It challenged Christian theology and pastoral practice to engage with this context, not from the long-held and traditional basis of that which was of ultimate concern, but of that which affected the oppressive socio-political circumstances of the poor. In doing so it challenged the theological neutrality of systematic theology which, Pattison asserts, serves the dominant socio-political order by implicitly adopting a neutral socio-political position and, therefore, the "interests of the oppressed are hidden."[368] It also challenges the long-standing and dominant notion, going back to the Middle Ages, of pastoral care as principally or solely concerned with the personal encounter between carer and cared.

It also serves as a strident critique of the contemporary trend towards more globalised forms of theologising.[369] This broad-based perspective is concerned with a theological form that addresses transnational social, economic and political trends, rather than being cognisant of the presence and activity of God and persons at the local, pastoral level. It dangerously serves to dislocate institutions from their local context. As pastoral theologian Daniel Louw asserts regarding this global perspective, "[s]ocial institutions are lifted out of social relations from local contexts, progressively becoming abstract systems. Institutions become locally decontextualized and create a space separate from their environment."[370]

The advantage of a pastoral theology and pastoral care that derives its conceptualisation and practice from within a particular context is that one can

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[368] Pattison, Pastoral Care, 34.

[369] The case for a more globalised theological approach is argued in,
Ott, Craig, and Harold Netland, editors. *Globalizing Theology: Belief and Practice in an Era of World Christianity*. (Grand Rapids: Baker Academic, 2006).

[370] Louw, Daniel. "Pastoral Hermeneutics and the Challenge of a Global Economy: Care to the Living Human Web." *The Journal of Pastoral Care & Counselling* 56, no. 4 (2002): 339-50, 342.

more clearly understand the notion of a God whose love and care specifically addresses the life situation of people such as those who are the focus of this extended reflection. At the same time, those who exercise pastoral care in this context can develop models of care that are specifically shaped by the circumstances of the people in question.

Speaking in opposition to the abiding notion of pastoral care being principally concerned with notions of personal fulfilment, pastoral theologian Alastair Campbell asserts, "[t]he intensity of the one-to-one encounters of professional practice appears to create a blind spot with respect to the socio-political context of care."[371] The creation of a dichotomy between the personal and systemic role and vision of the pastoral carer bears a significant consequence. It neglects to account for the sense in which the socio-politically constituted environment can affect the lives of those being cared for within that setting according to prevailing and imposed environmental factors. Such factors can include institutional values, dominant relational forms, and hegemonic styles of management and control. Neglect of such systemic factors diminishes the possibility of the development of a model of pastoral care that is shaped to the specific contextual needs of the person or persons in question.

Regarding this extended reflection serious consideration of systemic issues invites pastoral care to not only be observed as relating to the person both as an individual human being and as a person living with an intellectual disability, but also as a person who is affected by living in an institutionally-constructed system of care.

Taking into account the socio-political context in which people live requires an accounting for the values that undergird that context and the sense in which those values influence the lives of those who live in that place. As Browning points out, our present epoch is characterised by a growing disparity between public or systemic values and those of the individual. Previous epochs could point to unifying moral and social influences, such as those of the Christian church within Western Judeo-Christian societies. However, today, the Christian church, in various Western societies, including Australia, holds only a marginal influence on the values of wider society. Therefore, there is the emergence of a

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[371] Campbell, Professionalism and Pastoral Care, 53.

diffusion of moral influences and value systems, along with the growing potential for significant disparity between the values of social systems and institutions, and the individual private values of those constituted within those systems and institutions.[372]

In this extended reflection, the pastoral carer, who represents and upholds Western Judeo-Christian values and theological presuppositions,[373] finds himself or herself needing to take account of the secular, Western values of the institutions in which he or she exercises pastoral care. There also needs to be an accounting for the effect that these values have on the individual lives and collective life of those accommodated in the institutions. It is amidst these influences that the pastoral carer seeks to develop a liberating model of pastoral care. Amidst such a potential disparity in value systems, the pastoral carer is required to account for his or her values and to be cognisant of how they can be best interpreted and implemented at the individual and corporate levels of the institution.

4.1.3 What of any 'Abiding' Pastoral Perspective?

Given the pluralist context in which pastoral care often occurs today,[374] it is worth considering whether there are theologically-based presuppositions or values that remain as meaningful and helpful constants in terms of contemporary pastoral understanding.

Campbell raises the question as to whether, under the scrutiny of post-modern critique, there is anything from pre-modern eras that legitimately informs contemporary understandings of pastoral theory or practice.[375] There seems to be limited consensus on this issue. Speaking from a Reformed tradition, Campbell does proffer a case for the pastoral role of teacher and, in particular, the traditional role of the minister as catechist and preacher to the congregation.

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[372] Browning, The Moral Context of Pastoral Care, 27.

[373] Western Judeo-Christian values are taken as the reference point here given that the pastoral carer in this extended reflection is representative of such values. However, it is acknowledged that other pastoral carers may engage in institutional pastoral care from an alternative religious or non-religious value system.

[374] The phrase *often occurs* is used in order to acknowledge that, whilst pastoral care does occur within the values and structures of a pluralist society, there are pastoral contexts and institutions where pastoral care is exercised in accord with a more dogmatic, traditional and constantly-held value system. For example, this might include pastoral care offered within an institution that dogmatically upholds a fundamentalist and/or authoritarian religious perspective where values may be regarded as unyielding in character.

[375] Campbell, Rediscovering Pastoral Care, 2.

However, whilst claiming an instructive role in contemporary pastoral care, he concedes that the authority of this role is undermined by the individualistic search for truth which stands in contrast to more universal and inerrant doctrinal conceptualisations.[376]

Clebsch and Jaekle claim a stronger case for the abiding legacy of pastoral care as the ministry of the cure of souls, a definition they maintain as relevant, in reinterpreted form, across their eight identified historic epochs of pastoral care. In elaborating on this concept, they describe such a ministry as one that, "... consists of helping acts, done by *representative Christian persons,* directed toward the *healing, sustaining, guiding,* and *reconciling of troubled persons* whose troubles arise *in the context of ultimate meanings and concerns.*"[377] This bears close relation to the classical model of pastoral care as the Solicitous Shepherd, that is, the Christian who, on the one hand is akin to the shepherd's guidance of wayward sheep, offering tender care to an individual at their point of need.[378] On the other hand, it also bears relation to the courageous Shepherd who takes as his or her standard Jesus the Good Shepherd who "lays down his life for the sheep" (John 10:11).[379] In the tendering of such care, the carer continues the classical tradition of pastoral ministry as that which gives practical expression to the Christian gospel.

Amidst these understandings, pastoral care is understood as that which is performed by duly-appointed Christians to individuals who need care beyond the repertoire of their self-care resources. Clebsch and Jaekle assert that true pastoral care only takes effect when it can evoke "profound concerns and raise questions about fundamental meanings ..."[380] While this may be so the historic record points to examples of care offered by the church and Christian individuals of a more temporal character even if, on occasion, still associated with concepts of

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[376] Campbell, Rediscovering Pastoral Care, 3-5.

[377] Clebsch and Jaekle, Pastoral Care in Historical Perspective, 4. Italics are those of authors.

[378] Hiltner, Seward. "The Solicitious Shepherd." In *Images of Pastoral Care: Classic Readings*, edited by Robert Dykstra, 47-53. (St. Louis: Chalice Press, 2005), 51.

[379] National Council of the Churches of Christ in the United States of America. Holy Bible, New Testament, 103.
See,
Campbell, Alastair. "The Courageous Shepherd." In *Images of Pastoral Care: Classic Readings*, edited by Robert Dykstra, 54-61. (St. Louis: Chalice Press, 2005).

[380] Clebsch and Jaekle, Pastoral Care in Historical Perspective, 6.

penance and salvation, sometimes through the support of the state, and sometimes without.[381]

In a contemporary pluralist context the strong grounding of pastoral care with ultimate concern could be regarded as an evangelically conservative pastoral expression of Christian faith and practice. It could be regarded as one that reflects

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[381] For example, in the early Christian era Benedictine monasteries adopted the Samaritan motif in offering compassionate care to the guest and suffering stranger. See,
Crichton, J. "Pastoral Care: History – the Roman Catholic Tradition." In *A Dictionary of Pastoral Care*, edited by Alastair Campbell, 195-96. (London: SPCK, 1987), 195.
and,
Pemberton, A. "Rescuing the Good Samaritan: An Exposition and a Defence of the Samaritan Principle in the Welfare State." *Journal of Social Policy* 19, no. 3 (undated): 281-98.
In the Early Christian Church the ministry of healing the sick was seen as an act of Christian mercy for which no monetary reward should be expected. Acts of Christian devotion, such as ministrations at shrines, and pilgrimages, came to be regarded as traditional features of medical cure. See,
Turner, Bryan. *Medical Power and Social Knowledge*. London, (Thousand Oaks, New Delhi: Sage Publications, 1995), 20 & 26.
Early church councils established decrees concerning the poor and destitute. Nicea (325 AD) decreed that Christian villages should establish hostelries for the sick, the poor and the vagrant. Some of these became asylums for children. Vaison (442 AD) made churches available as sanctuaries for abandoned children. See, Scheerenberger, R. *A History of Mental Retardation*. (Baltimore & London: Paul H. Brookes Publishing Co., 1983), 20.
In the medieval period Christian charity and almsgiving, whilst invested with considerable penitential significance, were widely regarded as haphazard, although those deemed to be the most burdensome were congregated into a form of hospital. See,
Scull, Andrew. *Decarceration*. (Cambridge: Polity Press, 1984), 17.
With the onset of the Reformation a number of the Roman Catholic Church's charitable institutions and monasteries were closed or handed over to the state. See,
Scheerenberger, A History of Mental Retardation, 27.
Even so, in 1662, under Charles II, the Act of Settlement put a focus on charity at the local level whereby local parishes were enabled to direct funds for the purpose of household relief. Relatives of those such as the senile, crippled and blind could be provided with pensions to assist with the care of such needful family members. See,
Scull, Andrew. *Decarceration*. (Cambridge: Polity Press, 1984), 18-19.
In ensuing centuries there were some examples of major charitable endeavour. In the 17th century this included, above all, St Vincent de Paul, who cared for the sick, poor, orphaned and mentally impaired through orders he established such as the Confraternity of Charity and the Daughters of Charity. See,
Crichton, "Pastoral Care", 195.
and,
Scheerenberger, A History of Mental Retardation, 44-45.
In 19th century England, on the eve of the era when asylums were developed as a form of harsh confinement and separation from wider society, Samuel Tuke, through the Society of Friends, established a benevolent retreat at York for the non-constrained moral treatment of those deemed insane. See,
Foucault, Madness and Civilization, 229-42.
The increased urbanisation of the Industrial Revolution, the subsequent ostracising of people from communities and families, and increasing levels of incarceration, led to reformers and philanthropists of Christian persuasion advocating for improvement for those who thus found themselves living in degrading urban contexts. See,
Clapton, "A Transformatory Ethic of Inclusion," 131.
Some of the citations in this extended footnote, though individually located, were originally sourced from,
Clapton, "A Transformatory Ethic of Inclusion," 126-130.

the Christian orthodoxy of the mid-1960s era when Clebsch and Jaekle wrote. However, as a twenty-first century counterpoint, it could be conservatively argued, in deference to these scholars' words, that as much as non-Christian concern for troubled persons can include reference to issues of ultimate meaning, "non-Christian ... concern for helping troubled persons is seen in our day to border closely upon Christian pastoral care as we have defined it."[382]

Inasmuch as this concession permits a sense of continuity and evolution in understanding between past and present pastoral epochs it also points to the legitimacy of discerning traditional or classical understandings amidst the pastoral evolution generated by post-modern critique. This is so even if the link may be more in terms of principle rather than practical interpretation.

4.1.4 Principles that Shape the Pastoral Role

From the perspective of the Western Judeo-Christian tradition, it can be argued that those appointed by the Christian church to engage in a particular pastoral ministry have done so with a commitment to honouring the theologically-based principles and traditions of their denomination. This remains so today. Whilst the traditions of different denominations vary, leading to differences in pastoral emphasis both in theory and practice, nonetheless it would be reasonable to assert that Christian pastoral carers have been appointed to their role out of Christian principles and traditions that affirm the centrality of Christ to faith. This faith, however understood, is to be shared with others. It is on the basis of this fundamental Christian tenet that Campbell is able to assert that pastoral care "is no more (and no less) than sharing with another in the experience of grace, a surprising, unsought gift."[383] Furthermore, it can also be claimed that fundamental to the church's pastoral ministry, and appointment of persons to that role, is the church's commitment to care for those whom Clebsch and Jaekle would refer to as 'troubled persons' but which can be described more broadly as 'people in need.' What then constitutes need depends on an array of variables, including the theological orthodoxy or otherwise of the Christian denomination represented, and the context and peoples to which care is offered. Nonetheless,

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[382] Clebsch and Jaekle, Pastoral Care in Historical Perspective, 6.
[383] Campbell, "Rediscovering Pastoral Care", 16.
Bracketed words are those of author.

caring for others has and does constitute a fundamental ministry of the Christian church.

Also, whilst pastoral care has at different times and places varied in its pastoral goal, it has, within Judeo-Christian traditions, normally been concerned with issues of existential import.[384] Whether, as has already been noted, that care has been expressed in terms of a person's personal salvation, or the discernment of ultimate meaning, as will be detailed in the following section, there remains an abiding sense of care for a person or persons beyond the purely temporal.

In accord with the reformed traditions that undergird the ministry of this carer, pastoral ministry is guided by three principles that inform the chaplain's role.

The first principle is *Holism*:

> Chaplaincy is holistic in that it provides a unique pastoral and spiritual contribution, integrated and congruent with that offered by other disciplines, thus adding to the totality and 'completeness' of care provided ...[385]

This principle indicates that the pastoral role of chaplaincy takes place in congruence with the overall care provided for those for whom the institution bears responsibility. This involves working in a complementary manner with other professional carers, whether they are medical, residential or recreational. Thus, care is offered with regard for the person's physical, intellectual, emotional, social and spiritual well-being. In offering care in this manner, the chaplain proffers regard for the person with intellectual disability as a multi-faceted human being, and not purely in terms of spiritual identity.

The second principle is *Spirituality*:

> Spirituality is that which gives meaning and purpose to being. The chaplain provides a spiritual resource that respects and transcends differences of denomination and religion, recognising aspects of grace in all. The chaplain is called to minister to persons with

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[384] Contemporary recognition of the existential component can, for example, be observed in, Greider, Kathleen, Gloria Johnson, and Kristen Leslie. "Three Decades of Women Writing for Our Lives." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie Miller-McLemore and Brita Gill-Austern, 21-50. (Nashville: Abingdon Press, 1999).
Chopp, Rebecca. "Practical Theology and Liberation." In *Formation and Reflection: The Promise of Practical Theology*, edited by Lewis Mudge and James Poling, 120-38. (Philadelphia: Fortress Press, 1987), and,
Tracy, *Blessed Rage for Order*.

[385] Miller, Richard. "Three Pastoral Principles." (Adelaide: Uniting Church in Australia, Synod of South Australia, 2001), sec.1.

> disabilities and their families that enable questions of life and death, reality and meaning, fear and hope, to be articulated in a manner that encourages an exploration of such issues in an honest, caring environment.[386]

This principle defines the existential component of chaplaincy and pastoral ministry in terms that are inclusive of all people, recognising spirituality as that which gives meaning and purpose to all beings. This implies a respect for people that transcends denominational or religious orientation. Existential issues concerning life and death, reality and meaning, fear and hope, are detailed in their universal context. In so doing the people with intellectual disabilities who are accommodated in the institutions in question are located in an all-inclusive pastoral context.

The third principle is *Pastoral Care*:

> Pastoral care is a caring resource (available) at the client's point of need. It allows the client to 'set the agenda', with the chaplain available to journey with the client as a vulnerable, caring, listening fellow human being. The chaplain may provide a spiritual perspective and a liturgical resource as a tangible adjunct to pastoral ministry.[387]

Apart from being practised in a holistic, caring context, as well as having regard for the spirituality of all people, pastoral care does not principally seek to impose an agenda on the individual. The agenda for the pastoral care offered is based on what the pastoral carer hears and discerns through careful listening to speech and/or non-verbal cues, as well as past information gleaned about the individual from previous pastoral engagement. The notion of pastoral care as journey indicates an ongoing relationship that seeks pastoral engagement in an 'all of life' context. Here, individually generated issues for pastoral engagement may include the gamut of joys, sorrows and ordinary, incidental experiences that are the content of human life. All such experiences can be points of necessary and needful pastoral engagement. The pastoral carer engages with the individual as a vulnerable fellow human being. This serves to indicate that the shared sense of humanity between pastoral carer and individual is a necessary ingredient in a

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[386] ibid., sec.2.

[387] ibid., sec.3. Bracketed word is that of author.

relationship which, although still of a professional type, nonetheless seeks regard from a mutually caring perspective.

4.1.5 The Capacity of Professionalism to Shape an Understanding of Pastoral Care

Pastoral carers seek to claim a unique caring role within the institutional context in which they exercise their care, but when they assume a role such as that of a professionally-employed chaplain, the question can be raised as to the capacity of such pastoral care to maintain its uniqueness and effectiveness. It could be argued that such pastoral care places the pastoral carer in a similar professional/client relationship to that which defines the relationship of medical professionals to the institutional clients to whom they offer their specialist care. After all chaplains and medical professionals are both employed in the institutional context on the basis of suitable academic qualifications and appropriate financial reimbursement. In principle this immediately distinguishes the care which chaplains can offer to the institutional individuals from that which can be offered by pastoral volunteers who can engage in institutional personal, pastoral relationships, not on the basis of financial motivation, but of wholehearted unconditional love that simply wants to be with the accommodated individual in the institutional environment for the sake of wanting to be in relationship with a fellow human being and child of God.

At the same time professionally-offered pastoral care cannot be principally understood in terms of whole-hearted friendship. As pastoral theologian John Swinton points out, such friendship includes a fundamental voluntary component with the associated freedom that is derived from an uninhibited, yet respectful, desire to engage in a caring relationship with a fellow human being.[388] This relationship is uninhibited by institutional criteria for caring that include accredited qualifications and appropriate financial remuneration.

There cannot be, as pastoral theologian Don Browning indicates in citing Kant, a relationship of truly equal regard, because “equal regard is limited by the specific socio-economic and ecological constraints that it confronts in specific

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[388] Swinton, John. *From Bedlam to Shalom: Towards a Practical Theology of Human Nature, Interpersonal Relationships, and Mental Health Care*. (New York: Peter Lang Publishing Inc, 2000), 79.

situations."[389] Therefore, institutional care, with its criteria-based conceptualisation of care, imposes such constraints on the nature of relationships between its professional staff and those for whom they bear responsibility.

As McKnight argues, an institutional conceptualisation of care regards the people served as clients, and therefore as deficient people in need of constant professional intervention. The giving of such care inevitably results in the recipients becoming dependent on the care providers.[390] This inextricably leads to the exercising of power within the institutional environment by professional staff towards their clients. The use of power relates back to the conceptualisation of care as requiring accredited expertise. People with specific professional categorizations of expertise are required to appropriately implement their role with those who are seen to be in need. These people are regarded as not having the expertise to maintain or restore their own care-related requirements. Such an exercising of power maintains clients in a position of care dependency and thus, as Barton describes, situated in a "syndrome of submissiveness."[391]

Given the professional status of pastoral carers such as chaplains and the accredited nature of the care they offer to those accommodated in the institutional context it needs to be acknowledged that chaplains too have the capacity to exercise their specific area of care expertise in such a way as to create dependency. This can occur when the professional pastoral carer fails to acknowledge and address issues concerning their own need for care, as well as when the professional carer fails to respect the need of the other to be nurtured as an autonomous human being.

The question then asked is what shape professional pastoral care should take. Given the diversity of care offered by carers ranging from family care to the care of doctors and psychologists, what is the unique and distinguishing contribution that professionally-offered pastoral care can provide to those accommodated in the institutional context?

Such a question calls for reconsideration of what it means to be a professional pastoral carer. Disability educator and advocate Bill Gaventa stakes a claim for the professional carer to reconsider the nature of their role with those

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[389] Browning, A Fundamental Practical Theology, 189.
[390] McKnight, The Careless Society, 122-23.
[391] Barton, Institutional Neurosis, 3.

with whom they engage in caring relationships. He questions the level of detachment created between carer and cared generated by means of the accredited role of the carer, which tends to negate the individual receiving that which they may well value from the professional more than anything else, that is, friendship. Whilst still affirming the importance of recognising and implementing professional/client boundaries in the caregiving relationship he calls for a reconfiguring of what it means to be considered ‘professional.’ He argues that the term has become too closely equated with the notion of ‘expert’ and ‘problem solver’ by dint of the role’s alignment with appropriate qualifications. This then generates an understanding of the professional caregiver’s role that heightens the detachment between carer and cared and the potential for a mutually-enriching relationship. [392] From an etymological perspective he calls for the term ‘professional’ to be reconsidered from the perspective of ‘to profess’ as in its original sense of commitment to a religious order. This is a notion that has been lost over time with it becoming more closely aligned with a commitment to more secular bodies of knowledge such as science and medicine. Consequently, the notion of profession has lost its sense of commitment to community and has been replaced by commitment to a body of knowledge, hence increasing detachment.

‘To profess’ also initially meant a permanent commitment ‘to follow,’ to act out of a sense of call from God, to use one’s gifts, to establish “a covenant of new bonds other than family or civic status, and a willingness to ‘stand with’ others in shared community.”[393] Professional pastoral detachment minimises the role of the professional carer in advocating for and assisting community networking with those for whom they care.

Educationist Zana Lutfiyya similarly questions the notion that ‘paid relationships’ negate the possibility of personal friendship. She asserts that occasionally there is a need for the professional carer to move “beyond the staff role in order to champion the interests of the individual with a disability.”[394]

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[392] Gaventa, Bill. "Gift and Call: Recovering the Spiritual Foundations of Friendships." In *Friendships and Community Connections between People with and without Developmental Disabilities*, edited by Angela Amado, 41-66. (Baltimore: Paul H. Brookes Publishing Co., 1993)

[393] ibid., 57.

[394] Lutfiyya, Z. (1993). When "Staff" and "Clients" Become Friends. Friendships and Community Connections between People with and Without Developmental Disabilities. A. Amado. (Baltimore, Paul H. Brookes Publishing Co.), 100.

Both Gaventa and Lutfiyya are arguing for a notion of caregiving and friendship that takes account of the socio-political circumstances in which the person with intellectual disability resides, along with the community relationships that emerge from such circumstances. This friendship bears the marks of a relationship of solidarity that may come to be regarded by the institution as insubordination. A justice-oriented relationship that may question institutional policy could be regarded with suspicion. Also, the person with the intellectual disability may find themselves placed in a particularly vulnerable situation because of their dependence upon the institution for services. As Lutfiyya states, "the nature and extent of such friendship is shaped and defined through such tests of interest and loyalty."[395]

From a Judeo-Christian perspective this understanding of friendship between professional caregiver and the person with an intellectual disability redefines the earlier-mentioned and classically-derived notion of pastoral care as 'cure of souls.' The 'cure' moves from a purely one-to-one relationship focusing on individual salvation, to one that incorporates the way in which the person's lived circumstances justly or unjustly affect their quality of life. It reinforces the biblical notion of the Christ who is 'on the side of the poor,' and the Christian disciple who defines his or her discipleship to the needy in terms of the biblical tradition of "care for orphans and widows in their distress ..." (James 1:27).[396]

Campbell describes the type of understanding of the pastoral relationship in which detachment is maintained, but not to the detriment of the need for the person being cared for to receive love and to have their concerns addressed. He speaks of the professional carer exercising what he refers to as 'moderated love.'[397] Here we have an expression of love which, unlike the potentially more erratic and inconsistent attempts to care which can emanate from family and friends, seeks, as a professional, to maintain a balance between reason and emotion. Along with the emotional investment in the life of the person with whom they exercise care, a measure of rational hard-headedness is also

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[395] ibid., 105.

[396] National Council of the Churches of Christ in the United States of America. *The Holy Bible*, New Testament, 229.

[397] Campbell, Alastair. *Moderated Love: A Theology of Professional Care*. (London: SPCK, 1984).

required.[398] This allows for injustices created by dint of socio-politically constituted disadvantage and vulnerability to be redressed.

This sense of balanced pastoral posture works in concert with a moderated sense of detachment which Campbell describes in terms of ‘critical distance.’ Here, an appropriate professional and personal relational distance between carer and cared is maintained in order for appropriate care to be offered; “too great a distance prevents the helper from responding to the other’s need: too little distance disables the helper from seeing the problem objectively and offering support from outside the situation.”[399]

It is from this moderated sense of detachment that a professional pastoral carer can function with integrity and advocate to the institution for the needs of those for whom they care. From the stance of moderated detachment a measure of more personal agape-oriented love recognises the personal need and human worth of the other, whilst respecting the boundaries of the professional relationship.

4.1.6 Towards a Meaningful and Effective Understanding of Pastoral Care

In the aforementioned pastoral care sections pastoral care history, post-modernist conceptualisations of pastoral care, and details of broad principles which form the basis of institutional pastoral care have been outlined. There has also been the outlining of a pastoral care organisational stance that takes account of the professional pastoral carer/individual relationship. This description serves to outline the broad parameters in which pastoral care in its theoretical design and implementation in the institutional context may be meaningfully and effectively interpreted.

However, in order for a liberating pastoral care model to specifically address the lives and circumstances of those who are the focus of this reflection the institutional narrative of these people needs to be articulated and given careful reflection. It is in the light of this first-hand account of institutional life, through the voices and experiences of those who live in such an environment, that an understanding of authentic pastoral care will come into sharpest relief. As Newell states, “... if we listen to the voices of people with disabilities, our theological

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[398] ibid., 79-80.

[399] ibid., 81.

understandings will be challenged and our pastoral responses sharpened and made more fruitful."[400]

Such reflection will be undertaken in the following chapter.

4.2 Summary

Historic consideration of the development of the notion of pastoral care significantly grounds the term within the teaching and ethos of the Judeo-Christian church. Here the term was often generically understood in terms of individual care for troubled souls. Such care came to be oft-defined in terms of spiritually bolstering the individual soul in response to the perceived threat provided by prevailing socio-political institutions and movements. The practice of pastoral care could be seen as an outcome of the church's regard for temporal institutions in terms of suspicion and menace.

As opposed to this fundamentally antagonistic ecclesial stance the concept of pastoral care today, in terms of both theoretical design and pastoral application, is positively understood amidst a pluralist context that requires ongoing redefinition. This is in order to maintain relevance to the institutional context in which pastoral care is located. Pastoral faith and practice need to work in concert, not only with each other, but also in a cooperative sense with the institution where pastoral ministry seeks a meaningful authentic presence within the broader caring ethos.

Also, the professional nature of contemporary pastoral care needs to be described in terms of a form of moderated love. This approach involves adherence to appropriate professional staff/individual relational boundaries, whilst also developing sufficient pastoral closeness to the individual. This can be understood as a form of friendship. It is this friendship that enables the professional pastoral carer to clearly understand the nature of the individual's socio-politically constituted circumstances and, where necessary, to advocate for their needs within the institution.

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[400] Newell, Christopher, and Fran Gillespie. "Narrative, Psychiatric Disability, and Pastoral Care: Towards a Richer Theology of Disability." Paper presented at the 3rd National Conference on Spirituality and Disability – Exclusion and Embrace: Conversations about Spirituality and Disability, (Melbourne 2001), 101.

4.3 How Do I Regard the One Before Me?

And I am challenged to see the ones before me as they who bear the marks of a Slave, but not in terms of some form of generic classification applicable to all contexts but as specific to the nature of the oppression they have experienced and do experience in this place. I see their oppression in terms of the ways in which they are regarded and treated by those who bear responsibility for them in this place. I begin to see their marks of enslavement as unique to those who live here.

And as I move away from the realm of generalised assumptions I am challenged to move closer to these enslaved people so that I may see their identity with greater clarity, to see the marks that are not only unique to those who live in this place, but to each person according to their specific human identity and formation. And in considering the issue of human identity I am challenged to see each Slave not purely as such but as a human being. I need to see those marks of their being in which I can claim a shared human identity. In moving close, I am invited to see not just difference but commonality, not just problem but giftedness, not just service to another but mutual regard and benefit.

To see such identity-defining marks means I can no longer stand back with others and observe with dispassionate glances, and categorize and care in generic form.

I can no longer be the detached observer. I need to be involved with this context and this human being. I need to truly engage with this realm of limited horizons. I need to see with clarity the inhumanity and humanity from a closer, more personal perspective. I need to move from outside to in, from uninvolved to involved, from detached to truly committed and engaged, engaged enough to want to make a worthy difference!

I need to care, pastorally, personally. I need to care, not amidst the precious closeness of a nearest and dearest, but nonetheless as a friend who is immanent enough to see both the inhumanity and humanity and thus, to act justly.

PART 2

EXTENDED REFLECTION DESIGN

CHAPTER FIVE

EXTENDED REFLECTION DESIGN

"Practical theology is theological interpretation of the unheard voices of personal and community life for the purpose of continual transformation of faith in the true God of love and power toward renewed ministry practice."[401]

(The) "only thing that can maintain the liberative character of any theology is not its content but its methodology."[402]

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[401] Poling, *The Abuse of Power*, 187.
[402] Segundo, *The Liberation of Theology*, 40.
Bracketed word is that of thesis author.

Plate 5.1

‘Crossed-leg Slave’

by

Michelangelo Buonarotti

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[403] Ruehring, Lauren. *Crossed-Leg Slave by Michelangelo* HowStuffWorks, Inc., 2011 [cited 30/12/2011]. Available from http://entertainment.howstuffworks.com/arts/artwork/michelangelo-sculptures13.htm

5.1 Introduction

As a professional chaplain exercising a pastoral care role in two Adelaide institutions that accommodate people with intellectual disabilities I regularly reflect upon the most effective way of exercising my pastoral role given the specific nature of the lived context. If this reflection is not carefully considered and intentional in nature the pastoral care offered will become reactive and haphazard in nature, lacking thought and respect for the quality of life of those for whom care is exercised.

There are two questions that form the basis of the pastoral care offered. Firstly, how do I best develop a meaningful understanding of this lived context and the people who live here for whom I hold a pastoral responsibility? Secondly, how do I most authentically and meaningfully give expression to a model of pastoral care that offers a measure of liberation to these people?

Answering these questions requires careful consideration of an effective mode of reflection upon action that describes those criteria that will best validate this pastoral process of engagement. Such criteria need to be methodical, coherent, respectful, well-structured, repeatable, transparent and collegial. The detailing of the hermeneutical process to be utilized in this reflection will verify the use of these criteria.

The careful answering of these questions needs to be suitably embedded in the most appropriate form of qualitative methodology. This pastoral carer will therefore argue for an action/reflection model of pastoral responsiveness that can be effectively embedded in a hermeneutical methodology.

There are two key features of the action/reflection model of pastoral responsiveness that make it particularly compatible with a hermeneutical methodology. Firstly, it offers an authentic means of pastoral response to the vagaries and changeability inherent in the development of knowledge and understanding of people and their lived contexts over time. Secondly, the qualitative nature of the action/reflection model makes possible a response to context significantly based upon the artistic and intuitive characteristics of the pastoral practitioner, that is, his or her internal frame of reference.[404] These and related points will be articulated as this chapter develops.

5.2 A Hermeneutical Methodology

There are various methodological approaches that bear application to elements of this extended reflection. The Revised Correlational approach highlights the need for constructive dialogue between the Pastoral and Social Science contexts of this reflection.[405] The Ethnomethodological approach acknowledges the need for careful and thorough description of the extended reflection narratives and the context in which they occur.[406] Action-Based methodology takes considered account of the specific environment under consideration and the qualitative elements to be considered in order to acquire authentic understanding.[407] However, I would argue that it is the Hermeneutical perspective that most thoroughly accounts for the methodological components requisite for this extended reflection.

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[404] Schon, Donald. *Educating the Reflective Practitioner, The Jossey-Bass Higher Education Series*. (San Francisco: Jossey-Bass, Inc., 1988), 31-35.

[405] See, for example,
Browning, Religious Ethics and Pastoral Care, 50.
Browning , A Fundamental Practical Theology, 44-70.
Tracy, David. "Some Concluding Reflections on the Conference: Unity Amidst Diversity and Conflict." In *Paradigm Change in Theology: A Symposium for the Future*, edited by Hans Kung and David Tracy, 461-71. (Edinburgh: T & T Clark Ltd, 1989), 461.

[406] See, for example,
Garfinkel, Harold. *Studies in Ethnomethodology*. Englewood Cliffs: Prentice-Hall, Inc., 1967.
Ruler, Amanda. "The Culture of Nursing Homes: An Ethnomethodological Study." qualitative, University of Adelaide, 2000. 361.
Wareing, David, and Christopher Newell. "Responsible Choice: The Choice between No Choice." *Disability and Society* 17, no. 4 (2002): 419-34, 420-431.
Wareing, David, and Christopher Newell. "Commonsense and the Doing of Supported Care: A Case Study." *Journal of Intellectual and Developmental Disability* 30, no. 2 (2005): 104-14, 105-106.

[407] See, for example,
Kemmis, Stephen, and Robin McTaggart. "Participatory Action Research." In *Handbook of Qualitative Research*, edited by Norman Denzin and Yvonna Lincoln, 567-605. (Thousand Oaks: Sage Publications, Inc., 2000).
Lewin, Kurt. "Action Research and Minority Problems." *Journal of Social Issues* 2 (1948): 34-46.
Denzin, Norman, and Yvonna Lincoln. "Introduction: Entering the Field of Qualitative Research." In *Handbook of Qualitative Research*, edited by Norman Denzin and Yvonna Lincoln, 1-17. (California: SAGE Publications, 1994).
McTaggart, Robin. "Principles for Participatory Action Research." *The Journal of the Participatory Action Research Network* 1, no. April (1991): 29-44.
Robinson, Viviane. "Current Controversies in Action Research." *PAQ* unknown, no. 4 (1993): 263-90.
Stringer, Ernest. *Action Research*. 3rd ed. (Thousand Oaks: Sage Publications, Inc., 2007).

5.2.1 The Hermeneutical Perspective

It is the hermeneutical perspective that, by dint of the pastoral necessities of this extended reflection, meets the need for a dialogue between a pastoral practitioner's historically-derived theological assumptions, and the understanding of the Word of God that emerges from the specific pastoral context. It is the Hermeneutical approach that best acknowledges the need for authentic dialogue between theological and social science modes of interpretation. Thus a holistic approach to the interpretation and understanding of the people concerned, their stories, and the context under consideration, can be developed. It is hermeneutics that permits the development of a valid process of pastoral reflection upon textualised narrative, either secular or scriptural, [408] while developing an understanding of the context.

Within a generalised consideration of a hermeneutical methodology, this pastoral practitioner will be proposing a design structure commonly referred to as the hermeneutical circle or spiral. The hermeneutical circle is defined as "a process of analysis in which interpreters seek the historical and social dynamics that shape textual interpretation."[409]

In relation to this extended reflection the concept of 'textual interpretation' can be understood to include the interpretation of the narratives of those with intellectual disability who are accommodated in the institutional context under consideration.

5.2.2 Constructivism as the Pathway to an Effective and Meaningful Hermeneutical Methodology

It is incumbent upon this practitioner to develop a hermeneutical methodology that takes careful account of key design factors. Essential to this mode of enquiry is that, due to its qualitative nature, it takes careful note of the people and context in question and of pastoral practice. Lived reality needs to be

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[408] Regarding the fundamental hermeneutical focus on textual analysis see, for example,
Babbie, Earl. *The Practice of Social Research*. 8th ed. (Belmont: Wadsworth Publishing Company, 1998), 81.
Regarding the hermeneutical focus on textual analysis in terms of the Word of God see, for example, Segundo, *The Liberation of Theology*.
Lartey, Emmanuel. *In Living Colour: An Intercultural Approach to Pastoral Care and Counselling*. (London: Cassell, 1997), 91-93.

[409] Kincheloe, Joe, and Peter McLaren. "Rethinking Critical Theory and Qualitative Research." In *Handbook of Qualitative Research*, edited by Norman Denzin and Yvonna Lincoln. (Thousand Oaks: Sage Publications, Inc., 2000), 286.

interpreted by means of the most appropriate literary tool available. In the case of this extended reflection that qualitative tool is narrative analysis which will be used to describe the people and context in question. It will be further employed as the primary means of developing an authentic understanding that can be used to create appropriate pastoral models and actions applicable to the pastoral context. The purpose of this is to achieve more liberating forms of pastoral relationship for those who live in the context under consideration. It is the contention of this pastoral practitioner that the most appropriate mode of enquiry for achieving this end is constructivism.

Social worker and researcher Mary Rodwell broadly defines the constructivist mode of inquiry as "the process of reality construction."[410] Constructivism is to be understood as an ongoing process of knowledge acquisition leading to constantly evolving and maturing understanding. It is based upon an internal representation of knowledge acquisition. This representation takes careful account of the context and the narratives intrinsic to that environment.[411]

Whilst this approach will be elaborated upon in greater detail as the methodology is further described, the value of constructivism to a hermeneutical approach can already be discerned in general terms. As Rodwell states,

> The hermeneutic process and the products of the dialectic within that process provide a mechanism for the enquirer to tease out the various constructions being held at the time of the enquiry, and bring them together into a coherent whole that also includes whatever other information is found to be salient to the process.[412]

The validity of this statement will come into sharp relief when a hermeneutical process/circle pertinent to this extended reflection is illustrated. The hermeneutical circle will be shown to give due priority to the institutional context and its constructed reality. It will also afford recognition to the various narratives that comprise the stories of those who live in this setting. The circle will also provide an appropriate action/reflection structure in which the a priori

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[410] Rodwell, Mary. *Social Work Constructivist Research*. (New York: Garland Publishing, Inc., 1998), 3.

[411] Bednar, Anne, Donald Cunningham, Thomas Duffy, and David Perry. "Theory into Practice: How Do We Link?" In *Constructivism and the Technology of Instruction*, edited by Thomas Duffy and David Jonassen, 17-34. (Hillsdale: Lawrence Erlbaum Associates, 1992), 26-30.

[412] Rodwell, Social Work, 215.

assumptions and internal frame-of-reference of the pastoral practitioner can be most appropriately brought to bear on the task of authentic analysis. With appropriate reflective processes this analysis will lead to valid pastoral understanding and action.

5.3 Key Constructivist Characteristics

For the purposes of this extended reflection the most relevant constructivist characteristics are to be understood from an incarnational perspective. This is because the constructed reality under consideration, that is, the institutions in question, is thoroughly concerned with incarnational matters, namely humanly-constituted relationships, personal and structural, and the struggle for liberation.

5.3.1 Contextualised Understanding

An essential component of a constructivist design is that lived context is the fundamental source for information gathering, analysis and understanding. Outside of this, information becomes speculative, second-hand and, in relation to more scientific forms of data gathering, generic in application. As Bednar et al. assert in describing the constructivist viewpoint, “[t]he environmental context is critical ... Learning always takes place in a context and the context forms an inexorable link with the knowledge embedded within it.”[413]

In reference to this extended reflection, it is the institutions that form the context in which the lives of the people in question are described and understood. The narrative that these people proffer can only be understood within their lived environment because their story, both personal and collective, is fundamentally shaped by their immediate lived context.

In terms of this qualitatively-based extended reflection, knowledge acquisition and learning are understood not primarily in terms of systematised knowledge derived from outside the context and generically applied to various settings. Instead, they are principally understood as being acquired from the unique institutional context under consideration.[414]

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[413] Bednar, Anne, Donald Cunningham, Thomas Duffy, and David Perry, Theory into Practice, 26.

[414] ibid., 30.

This is not to say that systematised knowledge acquisition and learning, along with learning derived from experience in other contexts, cannot contribute to the knowledge acquisition, reflective process and understanding under consideration.[415] What it is saying is that it is not the primary contribution because by itself alone it cannot address the unique circumstances of the particular context.

Contextualised understanding also implies an ongoing commitment to the context in question. As Bednar asserts, "in-depth understanding of the content arises from, and is essential to, understanding disciplinary thinking."[416] This implies a commitment to and deep familiarity with the ongoing methodological process required to acquire and maintain relevant and developing understanding. It also implies the importance of the one seeking knowledge and understanding having the time and commitment to become intimately familiar with the context so as to develop authentic, respectful and trusted relationships. Such rapport is necessary for the purpose of acquiring authentic narrative-based knowledge and understanding.

The contextualised character of constructivist study is linked to the concept of grounded theory. Grounded theory

> ..... is an approach that develops theory from data systematically obtained and analyzed through research. In effect, the theory is grounded in reality as detailed in informal and formal observations. The theory-building process in this approach is cyclical. Observations about practice are used to develop the constructs and propositions of the theory. Research is then designed to *verify* elements of the theory as well as *generate* new theory.[417]

Whilst overlap can be observed here with the circular or spiral nature of the hermeneutical process and its pursuit of improved theory, its empirical, technical approach to knowledge acquisition makes it of limited value in an epistemological approach that will soon be primarily described in qualitative, intuitive terms.

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[415] The contribution of knowledge and learning derived from outside of the context in question will be detailed later in this chapter amidst Hans-Georg Gadamer's historic considerations and the tabling of a hermeneutic circle/spiral that indicates the place in which such knowledge and learning inform the ongoing methodological and action/reflection process that is unique to this extended reflection.

[416] ibid.

[417] Shulman, Lawrence. *Interactional Social Work Practice: Toward an Empirical Theory*. (Itasca: F.E. Peacock Publishers, Inc., 1991), 2.
Italics are those of the author.

In relation to this extended reflection models of pastoral care are applied to the relationship between pastoral practitioner and the persons with intellectual disability, and are then reviewed with a view to fresh and improved application. Incarnational pastoral theology is found in the reality of humanly constructed institutions and the people who live in them. It is a Christian faith and theology based in the incarnational life of Jesus that serve as the foundation for the institutionally-based pastoral practice of this pastoral practitioner.

In relation to this extended reflection it is of great significance to develop a carefully considered system of knowledge acquisition. This is gleaned from the narratives of the lives being considered. Crucial factors to be carefully considered concern the socio-politically constituted conditions in which the narrative occurs; the nature of the interaction between those who are central to the narrative description; tacit assumptions; types of behaviour, observed strategies or tactics applicable to the context; and consequences observed to occur as a result of these specific behaviours, assumptions, strategies or tactics. These factors need to be carefully and rigorously applied.[418] From a pastoral, theological perspective, the incarnational nature of institutional living and pastoral relationships also need to be considered in a thoroughly disciplined manner.

Also of importance is the careful application of the core theory of interpretation. The core theory is the theory around which many other theoretical constructs pertinent to the extended reflection bear application. It is that which most readily applies to other theoretical categories. Through the regular application of the core theory, and as more knowledge is collated and carefully considered, the core theory develops and takes on a shape that maintains its relevance and ongoing application to new data and levels of analysis and understanding. However, it essentially remains the same theory, hence contributing necessary reliability and stability to the pastoral methodology and the process of reflection.[419]

In relation to this extended reflection the core theory concerns the metaphorical concept of the *Slave* from which stems the dual notions of oppression and liberation. These concepts are pivotal to the analysis,

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[418] Alston, Margaret, and Wendy Bowles. *Research for Social Workers: An Introduction to Methods*. (Crows Nest: Allen & Unwin, 1998), 196.

[419] ibid., 204.

Here, the authors refer to *core theory* as the core or central category.

interpretation and understanding of the institutional life being described, along with the effect of institutional practice on those living in this setting. Furthermore, these concepts fundamentally affect and determine the appropriate nature of the contextualised pastoral response.

5.3.2 Inductive Data Analysis and Theologising

An inductive data form of analysis begins with a specific thought, question or experience, that is, a specific piece of information, and through thorough and careful analysis builds overarching theories or models that encompass the multiple realities that comprise the context in question.[420]

From a pastoral perspective the initial thought, question or experience is expressed in metaphorical language as opposed to more conceptualised linguistic forms.[421] It is the metaphorical image that describes life and relationships in the context in question, along with the pastoral practitioner's role and relationships. It is from this starting point, and with the discipline afforded by conceptual linguistic forms, that a body of knowledge begins to emerge. The methodological process that will eventually lead to careful analysis, interpretation, understanding and pastoral action can be applied. It is from careful reflection upon the key metaphorical image pertinent to this extended reflection, that is, the *Slave*, that a pastoral theology, cognisant of the articulated and understood oppression and liberation, can emerge.

From a pastoral theological perspective Doehring describes inductive theology as beginning with the particular experience and moving then to ask broad-based questions about where God is and who God is in the pastoral context.[422] This pastoral practitioner seeks to move thoughts and experiences generated from description of the lived, communal context and the personal, pastoral narrative to pastorally-based conclusions and models of pastoral care that offer a measure of liberation to the people with intellectual disability living in the institutional setting.[423]

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[420] Rodwell, Social Work, 58-59.

[421] Doehring, "Developing Models," 27.

[422] ibid., 28.

[423] A helpful and relevant example of this inductive form of data collection, analysis and pastoral theologising is to be found in,
O'Connor, Thomas, Kathleen O'Neill, Victoria Rao, Elizabeth Meakes, Tracy Van de Laar, Sherry McKinnon, Mirella van der Zyl, and Jan Roadhouse. "Horse of a Different Color: Ethnography of Faith and Disability." *The Journal of Pastoral Care* 53, no. 3 (1999): 269-84.

This form of analysis requires the pastoral practitioner to be a careful and disciplined observer and analyst of context.[424] This issue will be considered in greater detail later in this chapter. However, apart from careful consideration of context and its effect on those who live there, the pastoral observer must carefully and systematically reflect upon pertinent pastoral, theological issues. Such issues will include the incarnate presence of God, along with an incarnately-derived model of pastoral relationship that most authentically offers a measure of liberation. In other words, theological understanding that leads to effective and relevant pastoral action takes place within the lived context and not separate from it. This ensures authentic pastoral meaning and conclusions.

5.3.3 A Multiplicity of Perspectives

In contradistinction to more empirical forms of enquiry where a generic mode of understanding is imposed upon a context from without, the constructivist approach builds reality from within the context under consideration amidst its complexity and multiplicity of perspectives. As Rodwell indicates in relation to the pursuit of situation-based understanding, it “involves coming to an understanding of the view of the world held by those people involved in the situation (an emic perspective) rather than adopting a ‘stranger’ or outsider perspective (an etic perspective).”[425] Those living and interrelating within the context in question provide the narratives that create the reality being sought. Different people fulfilling different roles within that context will, through faithful description and analysis, posit their unique understanding according to their particular situational perspective. It is the careful consideration of a multiplicity of perspectives that contributes significantly to the analytical rigor necessary to

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The goal of this ethnographically-based research is to discern the meanings and perceptions that wheelchair-bound nursing home residents attach to their faith and disability, and the relationship between the two (269). Data collection begins with careful and detailed description of the nursing home context in question. Against this primary lived context. phenomenonologically-based interviewing of the participants, along with field notes and relevant documents, are utilized to gain the relevant data. From the initial perspective of individual comments, an inductive process of analysis and pastoral reflection is employed to eventually draw broad-based conclusions concerning the faith and disability of the institutionalised people in question.

[424] Merriam, Sharan. *Qualitative Research and Case Study Applications in Education*. 2nd ed. (San Francisco: Jossey-Bass Publishers, 199), 95-99.

[425] Rodwell, Social Work , 27.
Bracketed words are those of author.

achieve the required measure of knowledge and understanding of the people and context in question.[426]

It is such consideration that points to the inclusivity of the constructivist approach. By dint of embracing a multiplicity of perspectives there develops an acceptance of a diversity of individual and collective value systems, and the practices and behaviours that emanate from them. At the same time such acceptance causes the enquirer to acknowledge the limitations of their own value system and practice, and to challenge personal prejudices. Ultimately, the embracing of a multiplicity of perspectives causes this practitioner to develop an enhanced pastoral practice. It will be one that more fully and comprehensively accounts for the reality in which the caring role is exercised, and that most effectively offers liberation to those who are the focus of reflection.

It stands to reason that the more perspectives on understanding, and the more thorough these perspectives are in description and analysis, the more authentic and holistic will be the understanding of the sourced reality. In relation to this extended reflection, that involves careful consideration of various narrative sources related to the people with intellectual disability who live in the institutional setting. Consideration also needs to be given to the unique circumstances of the institution in question, its traditions, values and history, and the ways in which it subsequently influences the lives of those for whom it bears responsibility. Attention also needs to be given to outside institutional influences such as prevailing disability philosophies for these can have a substantial effect on institutional practice.

5.3.4 The Internal Frame-of-Reference

Purely scientific modes of enquiry rely on rational forms of epistemological enquiry and outcomes in order to prove their validity. However, a constructivist approach is required when the focus of enquiry is concerned with human beings and relationships, as is the case with this extended reflection. It is in this context that responses and reactions are observed as altering according to internal variables such as personality, mood and health, and socio-politically derived variables such as social location, status, resources and power. In such a

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[426] Issues of careful observation and collegial analysis, and their contribution to rigorous analysis, will be considered later in this chapter. Rigor contributes significantly to the trustworthiness and authenticity of the reflection. See,
ibid., 36, 54.

situation, the internally-derived qualities of the one who is undertaking the extended reflection become primary tools of narrative analysis and understanding.

One of the primary issues with constructivist reflection concerns when an acceptable conceptualisation of the reality in question has been constructed. The response relies upon the analytical and interpretive skills, and internal frame-of-reference of the one seeking understanding. As Rodwell asserts, the search for understanding "... can only be undertaken in an interpretive paradigm where values and intersubjective shaping are acceptable research issues."[427] Within this environment reality is regarded as having been constructed in an appropriate form when the reality of the people and context under consideration is perceived to be reasonable and to make sense.[428]

In a specifically pastoral context consideration of the interior interpretive framework raises the issue of the qualities of this pastoral practitioner that would be of benefit in constructing the reality under consideration. Whilst this matter will become more self-evident as issues of methodology and method are discussed later in this chapter this practitioner advocates for the prioritization of the following pastoral qualities:

- awareness of relevant theological and socio-politically derived traditions
- clear understanding of disability models and the nature of institutions, and their effect on people with intellectual disability
- commitment to respectful and mutual pastoral relationship[429]
- capacity to reflect analytically and imaginatively amidst pastoral action[430]
- capacity to reflect pastorally and theologically amidst pastoral action[431]

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[427] ibid., 33.

[428] ibid., 27.

[429] ibid., 9. In social science terms the author here refers to 'mutuality of relationship' as 'respectful egalitarianism'. See also,
Sunderland, Ronald. "The Dignity of Servanthood in Pastoral Care." *The Journal of Pastoral Care Counseling* 57, no. 3 (2003): 269-79, 274.
In contradistinction to medical or charitable models of care where the focus is on helping the one who is in need, here the author speaks pastorally of a mutuality of care in which the focus shifts to what each brings and offers to the other in the relationship. Each enters the interpersonal relationship on an equal footing, upholding the dignity of the other, and regarding the other as a full participant in the relationship. The term will be more fully described in the following chapter.

[430] Riessman, Catherine. *Narrative Analysis*. Edited by Judith Hunter. Vol. 30, *Qualitative Research Methods Series*. (Newbury Park: Sage Publications, Inc., 1993).

- capacity for honest self-awareness and self-assessment[432]
- ability to work cooperatively in a collegial environment[433]
- capacity for metaphorical interpretation of the lived reality and pastoral practice[434]
- openness to change in the exercising of pastoral practice.

5.3.5 Tentative Applications

In taking account of the constructed reality this pastoral practitioner will apply his skills of interpretation, meaning and sense-making to the sourced narratives in order to develop a comprehensive understanding. The development of a thorough understanding will then form the basis of a model of pastoral care that will most effectively offer a measure of liberation.[435]

Further to this, understanding and meaning can only be regarded as valid in an impermanent sense. Those whose conceptualisations of understanding have been sourced will, over time, change their understandings according to personal factors such as experience.[436]

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[431] Dunlap, "Discourse Theory and Pastoral Theology."

[432] Moustakas, Clark. *Heuristic Research: Design, Methodology, and Applications*. (Newbury Park: Sage Publications, Inc., 1990), 9-16.
Liamputtong, Pranee. *Researching the Vulnerable: A Guide to Sensitive Research Methods*. (London: Sage Publications Ltd., 2007), 17.

[433] Participatory action researchers particularly emphasise the significance of collegial-based interpretation and understanding. See,
Kemmis, Stephen, and Robin McTaggart. *The Action Research Planner*. (Melbourne: Deakin University, 1988).
Robinson, "Current Controversies," 267, 284.

[434] Various pastoral theologians and researchers advocate, either implicitly or explicitly, for the role of metaphor in defining theoretical understanding, and practical, pastoral action. For example,
Doehring, "Developing Models," 27.
Lane, Belden. "The Tree as a Giver of Life: A Metaphor in Pastoral Care." *The Journal of Pastoral Care* 45, no. 1 (1991): 15-22, 21.
Mair, Miller. *Kelly, Bannister and a Story Telling Psychology* 2007 [cited 27/03/2007. Available from http://www.oikos.org/mairstory.htm
McFague, Sallie. *Metaphorical Theology: Models of God in Religious Language*. London: SCM Press Ltd, 1983.
Niven, Alan. "Pastoral Rituals, Ageing and New Paths into Meaning." In *Ageing, Disability and Spirituality: Addressing the Challenge of Disability in Later Life*, edited by Elizabeth MacKinlay, 217-32. (London & Philadelphia: Jessica Kingsley Publishers, 2008), 221.
Rappmann, Susanne. "The Disabled Body of Christ as a Critical Metaphor – Towards a Theory." *Journal of Religion, Disability & Health* 7, no. 4 (2003): 25-40, 25.
Schmidt, William. "Power as Theological Problem." *The Journal of Pastoral Care* 46, no. 1 (1992): 71-77.

[435] The tacit nature of the data gathered through the constructivist approach will be considered in further detail later in this chapter.

[436] Bednar, Anne, Donald Cunningham, Thomas Duffy, and David Perry, Theory into Practice, 21.

In paying reference to Heidegger, Hans-Georg Gadamer describes what he refers to as ‘rival projects’ or what can alternatively be thought of as competing classifications of knowledge or understanding that challenge prior conceptions and assumptions generating more suitable conceptions on an ongoing basis. He states,

> ... every revision of the fore-project is capable of projecting before itself a new project of meaning, that rival projects can emerge side by side until it becomes clearer what the unity of meaning is, that interpretation begins with fore-conceptions that are replaced by more suitable ones. This constant process of new projection is the movement of understanding and interpretation.[437]

Hence, the application of new understandings and new actions assumes a tentative character. This implies that the discerning of meaning and its application to context is not set in concrete but requires constant revision and improvement.

In terms of this extended reflection, this means taking into account factors such as changes in health, accommodation and staff morale. It also means maintaining accounts of the narratives of new people to the institutional setting and their unique perspective.

5.4 The Emergence of the Hermeneutical Circle

In light of the tentative character of the extended reflection design, meaning-making and understanding take on an evolutionary and ongoing form. This also implies an ongoing commitment by the pastoral practitioner to seeking ever more developed conceptualisations of meaning and understanding. This issue comes into sharper relief when considered in the context of a hermeneutical pastoral methodology, particularly where the cyclical nature of analysis and understanding is perceived of as a spiral. Under this design, pastoral applications assume a tentative and ever-maturing nature in which various and relevant sources of contextualised information, or “created realities,” are sourced on an

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[437] Gadamer, Han-Georg. *Truth and Method*. (New York: The Seabury Press, 1975), 236.

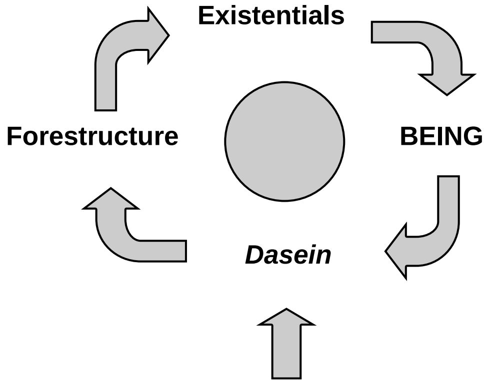
ongoing basis.[438] Action researcher Ernest Stringer refers to this as the pursuit of a “higher level synthesis.”[439]

5.4.1 The Historic Emergence of the Hermeneutical Circle

The concept of the hermeneutical circle can be traced to pre-Enlightenment religious contexts. One interpretation of this hermeneutical form conceived of the hermeneutical task involved beginning with text-based ideas that could lead to an understanding of the religious subject under consideration. The ideas presupposed at least a rudimentary understanding of that for which a more thorough understanding was sought. Thus, “understanding turns out to be a development of what is already understood, with the more developed understanding returning to illuminate and enlarge one’s starting point.”[440]

Some more contemporary forms of this hermeneutical structure are based on the conceptualisation of scholar Martin Heidegger who saw the hermeneutical circle as a means of conceptualising, from a phenomenological perspective,[441] the notion of human being, which he refers to as *Dasein*.[442]

Figure 5.1 Heidegger’s Hermeneutical Circle [443]



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[438] Guba, Egon, and Yvonna Lincoln. *Fourth Generation Evaluation*. (Newbury Park: Sage Publications, Inc., 1989), 143.

[439] Stringer, Action Research, 42.

[440] Crotty, The Foundations of Social Research, 92.

[441] See,
Heidegger, Martin. "Being and Time." In *Basic Writings*, edited by David Krell, 37-114. London: Routledge, 1996.
Heidegger interprets the concept of phenomenology as “the science of the Being of beings – ontology.” 84. It seeks “… to let what shows itself be seen from itself …” 81.

[442] The word *Dasein* is derived from the German word *Existenz* meaning *existence*. Heidegger refers to the term in the sense of “a being that has the possibility of existence ...” See,
ibid., 85.

[443] Crotty, The Foundations of Social Research, 98.

Through this circle understanding is sought; however, it is not concerned with presenting a means of interpreting and understanding randomly chosen pieces of knowledge but with that which emanates from the essential forestructure of *Dasein*, that is, existence itself. In later discussions of the circle emphasis was placed on dialogue with ancient Greek scholars and poets. Classical thinking is regarded as providing an historical grounding for understanding. Creative expression is seen as offering insight into the nature of Being, and a revelation of hitherto undisclosed layers of insight. In other words there is dialogue between the understood existential nature of Being and beings.[444]

Such hermeneutical conceptualisation lays the groundwork for moving away from systematised, detached modes of understanding of persons and contexts that inherently adopt generic philosophical understandings.[445] The alternative becomes a movement to a structure that invites engagement with people and their lived context with a view to developing more insightful understandings.

In pastoral terms it is the philosophical dimension of the hermeneutical process that enables the layers of understanding to emerge from the stories that result from the interpersonal communication, personal experiences and application of historic traditions to the contemporary context.[446]

5.4.2 A Commitment to the Oppressed

It is the contention of this extended reflection that the starting point of the hermeneutic endeavour is located in the socio-politically constituted reality of people’s contemporary lived experience. The lived experience incorporates the pastoral and theological perspective of this pastoral practitioner. As feminist theologian Sallie TeSelle asserts, it is the task of the hermeneutical process and of theological enquiry, “[t]o start with the ordinary and the everyday, with personal life, with corporate stories, with ‘our times’ in their political and social agony ...”[447] Or, as Segundo states from his emancipatory theological perspective, “… one cannot recognise Christ, and therefore come to know God, unless he or she is

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[444] ibid., 98-99.
[445] Pattison, Pastoral Care, 34.
[446] Gadamer, Hans-Georg. "On the Problem of Self-Understanding." In *Philosophical Hermeneutics*, edited by David Linge, 44-58. (Berkeley: University of California Press, 1962), 18.
[447] TeSelle, Speaking in Parables, 180.

willing to start with a personal commitment to the oppressed."[448] In terms of this extended reflection that translates to a commitment to those oppressed by the institutional context in which they live. That commitment is derived from the assertion by this pastoral practitioner of the orthodox theological position of God who, through Christ, displays a commitment to the poor and oppressed.

Hermeneutical and theological scholarship reveals cogent arguments for various starting points.[449] Nonetheless, it is the assertion of this extended reflection that, from a pastoral perspective, it is this contemporary context and its imperatives that are the activating agent, and thus the practical starting point, of the hermeneutical process.

However, the activating agent works in concert with what, in terms of Heidegger's hermeneutic circle, is referrred to as a 'forestructure' (see figure 1), and which Capps refers to as a 'pre-understanding.'[450] This is based on a fundamental understanding of that which is before us that is suspected of requiring greater levels of understanding.

The process of developing a new understanding, built upon a pre-understanding, gains substantial credence through reflection upon and application of those historic traditions intrinsic to the pastoral practitioner as a unique human being. It is the application of such traditions that allows personal and negatively-impacting practitioner prejudices to be challenged as new undertanding begins to emerge. It is the openness to such powerful traditions that leads to what Gadamer refers to as a "loss of self."[451] This implies a casting to one side of previously-held theological and pastoral prejudices, and understandings as more enlightened prejudices and understandings emerge. This loss includes a commitment to moving beyond purely rational forms of understanding to including a total giving of oneself to the ultimate being. Gadamer, in reference to Martin Buber,

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[448] Segundo, *The Liberation of Theology,* 81.

[449] For example, pastoral theologian Clodovis Boff claims the starting point as occurring in the dynamic relationship that occurs between "the letter of Scripture" and the hearing and reading of Scripture in community.
Boff, Clodovis. *Theology and Praxis: Epistemological Foundations*. (New York: Orbis Books, 1987), 136. Han-Georg Gadamer argues for the primacy of history over Scripture alone, because of the need to view biblical enquiry as an outcome of historical reflection which is commensurate with one's faith traditions.
Gadamer, On the Problem, 47.

[450] Capps, Pastoral Care, 40.

[451] Gadamer, On the Problem, 47.

omnipotently refers to this as the 'Thou.'[452] Boff and Boff refer to this in incarnational terms as God the Son who "assumed unto himself the totality of human life."[453]

Such understandings of God are generally understood as a commitment to and faith in an absolute entity. As Segundo claims,

> ... in and through faith, we absolutize one concrete pedagogical process in history, placing it above and before any other such process. We entrust ourselves to it in a free act that cannot help but be an absolutization, since we give our all to it. And to absolutize this process is to say that God, the Absolute, is guiding it in some special way.[454]

Tracy claims that a commitment to the cause of liberation requires a departure from both relativist and absolutist tendencies in favour of a universalist ethical appeal to justice.[455] However, it can be argued, in the case of the biblical God for example, that a commitment to an absolute being can include allegiance to an omnipotent being who is "[a] faithful God ... just and upright ..." (Deuteronomy 32:4);[456] implores the followers of Yahweh, through the Old Testament prophets, "... to do justice, and to love kindness ..." (Micah 6:8);[457] and through Jesus, proclaims a justice ethic by bestowing blessedness upon the poor (Luke 6:20),[458] and calling for the hungry to be fed (Matthew 25:35).[459] In other words, the liberationist appeal to justice can be regarded as intrinsic to the character and proclamation of an absolute entity, such as the Old Testament and Christian conceptualisations of God.

The appeal to an absolute being may suggest unalterable and eternal edicts of omnipotent origins that lead to unalterable understandings of truth. However, it can be argued that absolute truth does not refer to truth being infinite and unalterable but, instead, refers to "no truth more absolute to which it is

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[452] Gadamer, Truth and Method, xxiii.
[453] Boff, Leonardo, and Clodovis Boff. *Salvation and Liberation: In Search of a Balance between Faith and Politics*. (Melbourne: Orbis/Dove, 1985), 54.
[454] Segundo, The Liberation of Theology, 179.
[455] Tracy, On Naming the Present, 136.
[456] National Council of the Churches of Christ in the United States of America, Holy Bible, Old Testament, 187.
[457] ibid., 866.
[458] ibid., 64.
[459] ibid., 29.

relative.” [460] Therefore, the truths attributed to an absolute being can be reinterpreted, pointing to new understanding, whilst maintaining the essence of the truth in question.

For the one who regards themselves from the perspective of a finite historical being it is this appeal to such an historic theologically-derived tradition that allows dialogue with one’s presently-held beliefs and behaviours. The historic perspective provides the lens through which we experience the integral and dynamic interplay of human relationships, as well as “the natural givenness of our existence and of our world.”[461]

Gadamer maintains that this interplay or dialogue is predicated upon the development of a language compatible to both the historic and contemporary perspectives which can challenge and alter these perspectives.[462] He refers to this as the merging of historic and present horizons to produce a new horizon that points to new understanding, a higher universality, based on appropriate historic consciousness that supersedes our own previously-held understandings of truth.[463] Such new understandings can serve the purpose of positive change in terms of how the present context is to be regarded.

With truth being predicated upon constant changes to present-day socio-political and personal realities, which of themselves prompt fresh theological and pastoral reflection and interpretations, there is a need to keep revising and reinterpreting the understanding of truth to keep it as relevant as possible. As Segundo states in reference to the interplay between biblical and present-day ‘horizons’,

> ... the continuing change in our interpretation of the Bible ... is dictated by the continuing changes in our present-day reality, both individual and societal ... And the circular motion of this interpretation stems from the fact that each new reality obliges us to interpret the word of God afresh, to change reality accordingly, and then go back and reinterpret the word of God again, and so on.[464]

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[460] Weinsheimer, Joel. *Gadamer's Hermeneutics: A Reading of Truth and Method*. (New Haven: Yale University Press, 1985), 155.
[461] Gadamer, Truth and Method, xiv.
[462] Weinsheimer, Gadamer's Hermeneutics, 211-212.
[463] Gadamer, Truth and Method, 272-274.
[464] Segundo, The Liberation of Theology, 8.

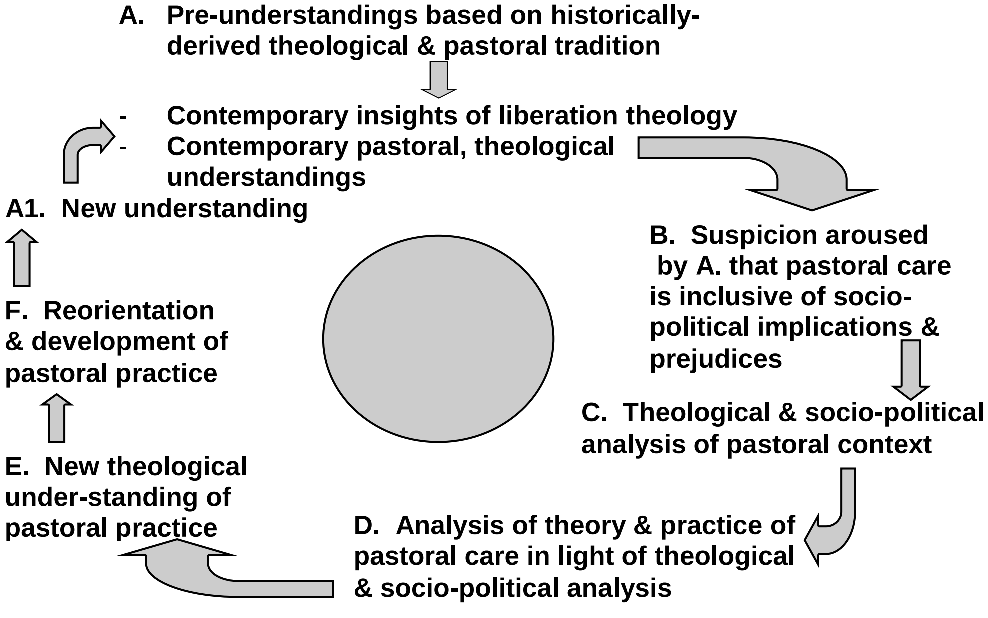
Segundo's perspective as a liberation theologian is based upon a commitment to the socially marginalized, and a desire for just and liberating outcomes for those who are socio-politically and systemically oppressed within the South American context. Theological and socio-political responsiveness to those oppressed is ongoing and changing in response to changes in understanding of biblical interpretation, and changes in the nature and understanding of the oppression experienced by the marginalised.

From both an historic and practical pastoral perspective, it is the claim of this pastoral practitioner that an authentic understanding of the life situation of institutionalised people with disability should include an understanding of these people as both human beings and those who are socio-politically oppressed by dint of institutionalisation. Based on new understandings pastoral models are sought that, when enacted in the context of pastoral relationship, reflect a form of liberation from institutionalised oppression.

5.4.3 A Contemporary Hermeneutical Spiral

In light of the above methodological commentary, it is the intention to propose a hermeneutical perspective compatible with Gadamer's historic orientation and with liberation theology, whilst maintaining a pastoral perspective.

Figure 5.2 A Contemporary Hermeneutical Spiral [465]



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[465] Adapted from a diagrammatic representation of a hermeneutical spiral, integrating some insights and methods of liberation theology with pastoral care. See,
Pattison, Pastoral Care, 61.

In terms of this extended reflection, the pastoral practitioner’s pre-understandings, represented by the pastoral and theological traditions of the church, are brought to bear upon the pastoral context as a pre-condition of pastoral commitment to the context. Also incorporated into this commitment are the practitioner’s contemporary theological understandings, including insights into liberation theology, as well as contemporary pastoral understandings.

In the midst of pastoral commitment to the context and people under consideration, pre-understandings and contemporary understandings generate suspicions[466] concerning the nature of the implications of pastoral care being exercised in a specific socio-politically constituted context. This commitment also leads to suspicions concerning the nature of practitioner prejudices towards both the overall pastoral context as well as those who live in that context.

The pastoral context is analysed in a holistic manner. Traditional and contemporary theological perspectives, as well as socio-political perspectives, are applied to the pastoral context with a view to analyzing the authenticity or otherwise of recently-formulated suspicions. Such analysis also generates consideration of the authenticity of previously-held theological and pastoral understandings.

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[466] The concept of suspicion in the hermeneutical process refers to an openness to the querying and critiquing of that which is a source of analysis. It could refer to text, systems or personal narrative. See,
Tracy, “Some Concluding Reflections”, 466.
Here Tracy describes a hermeneutics of suspicion expressed in terms of calling into question the privatising and silencing elements contained in traditional elements of Western Christian theology. See also,
Clapton, A Transformatory Ethic of Inclusion, 308.
Here, the author speaks of a hermeneutics of suspicion “exposing the hidden assumptions and legitimacy of a hegemonic socio-symbolic order.” A similar tone is adopted by,
Hollinger, Robert. "Introduction: Hermeneutics and Pragmatism." In *Hermeneutics and Praxis*, edited by Robert Hollinger, ix-xx. (Notre Dame: University of Notre Dame Press, 1985), xviii.
as well as,
Karaban, Roslyn. "Always an Outsider? Feminist, Female, Lay, and Roman Catholic." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie Miller-McLemore and Brita Gill-Austern, 65-76. (Nashville: Abingdon Press, 1999), 71.
Here the author, from a feminist theological perspective, applies this hermeneutic to a critique of patriarchal structures and clericalism that influenced the writing of the Scriptures and the development of the Church.
The works of Tracy make consistent reference to the term amidst hermeneutical critical theory considerations. For example,
Tracy, David. "Hermeneutical Reflections in the New Paradigm." In *Paradigm Change in Theology*, edited by Hans Kung and David Tracy, 34-62. (Edinburgh: T & T Clark Ltd, 1989), 45.

Analysis moves from the pastoral context to the nature of the pastoral care exercised within that context. The issue concerns how pastoral care can most authentically reflect the latest analysis and thus be as relevant as possible from a pastoral theological and socio-political perspective.

Analysis leads to new socio-political and theological interpretations. These interpretations lead to new understandings of the nature of pastoral practice. The new understandings are applied generating a reorientated and newly relevant form of pastoral practice. The reorientation applies to the pastoral carer's pastoral theological and socio-politically constituted relationship with the context in question, and the people who live in that environment.

The new pastoral theological understanding derived from the new pastoral practice, along with the pastoral carer's pre-understandings and insights from liberation theology, are reapplied to the pastoral context. This is as a fundamental component in the carer's ongoing commitment to contextualised caring in a continually relevant and authentic form.

The new understandings of 'A1' merge with the pre-understandings and contemporary understandings of 'A' to create an advanced, or 'new horizon,' of understanding. This new horizon forms the basis for further suspicion of the pastoral context and of new analysis of that context.

The two-dimensional form of figure 2 suggests that new understanding leads back to the starting point of the hermeneutical process. This is an incorrect assumption, one that could be reinforced by thinking of the process as being essentially circular or cyclical in form which is how it is sometimes described by pastoral theologians.[467] Whilst the circular form rightly suggests an ongoing commitment to the hermeneutical process it can also imply an ongoing return to the same starting point. In doing so it negates the notion that fresh analysis, interpretation and understanding lead to a developing and ever-growing maturity in terms of engagement with the hermeneutical process and the pastoral context.

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[467] See, for example,
Boff, Theology and Praxis, 136-47.
Lartey, Emmanuel. "Practical Theology as a Theological Form." In *The Blackwell Reader in Pastoral and Practical Theology*, edited by James Woodward and Stephen Pattison, 128-34. (Oxford: Blackwell Publishers Ltd, 2000). See diagram of hermeneutical circle, 132.
Segundo, The Liberation of Theology.
Browning, A Fundamental Practical Theology.

This maturity is better reflected by thinking of the process in terms of a spiral. As Forrester states,

> … if you move around a circle you come again and again to the point from which you started. It is rather a spiral, in the process of which we ascend to higher levels of understanding and more appropriate and faithful practice through a constantly moving process of radical questioning.[468]

5.5 Reflection–in-Action

Nonetheless, in one broad sense, the starting point always returns to familiar territory, although always viewed through the lens of new understanding. The day-to-day reality of the pastoral context, its storied structures, behaviours and activities always remain the basis for reinterpretation and new understanding. As TeSelle points out, "[l]anguage and belief are hammered out in action; they arise from and must return to the social and political worlds in which we find ourselves."[469] This means that the ongoing search for new understanding, and thus new practice, means an ongoing commitment to people with intellectual disability who live in the institutional context. It is this type of liberatory and pastoral orientation that is required for the pastoral practitioner to gain an appropriate understanding of context.

5.5.1 A Balancing of Epistemological Perspectives

The disability institutions under consideration are structured around an epistemological model that educator Donald Schon refers to as Technical Rationality.[470] From a European perspective this model can be traced back to the rise of technology since the Reformation, and thus to an understanding that true technical knowledge was primarily and normatively derived from the theories and techniques of basic and applied science. It was this rationalistic belief that shaped prevailing socio-political thinking through the Industrial Revolution and the Age of Reason, [471] and was influential in the development of asylums for the mad and institutions for the feeble-minded. The last couple of generations have

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[468] Forrester, Duncan. *Truthful Action: Explorations in Practical Theology*. (Edinburgh: T & T Clark Ltd, 2000), 28.

[469] TeSelle, *Speaking in Parables*, 175.

[470] Schon, Donald. *The Reflective Practitioner: How Professionals Think in Action*. (New York: Basic Books, Inc., 1983), 27-50.
Schon, *Educating the Reflective Practitioner*, 36.

[471] Schon, The Reflective Practitioner, 31-35.

seen a questioning of what can be regarded as an over-reliance on technique-driven professionalism and scientific method,[472] and the recognition of what social researcher Michael Polanyi refers to as the tacit dimension of knowing, understood as "the pursuit of a hidden truth."[473] This epistemological perspective, whilst acknowledging the value of scientifically-derived propositions, gives weight to the practitioner's internal frame-of-reference. It values qualities such as personal perception, intuition and sense[474] in the pursuit of what qualitative researchers Greg Neimeyer and Arthur Resnikoff refer to as "private meaning structures."[475] Such structures are concerned with the internal derivations of language, behaviour, values and attitudes.

This epistemological perspective also acknowledges the vagaries and changeability of context and people which cannot be fully accounted for by purely empirical pursuits, and which can have a significant influence on the internal perspective of the individual. This raises the issue of the influence of the institution on the private meaning structures and attendant language, behaviour, attitudes and values of the people with intellectual disability who live there.

It can be argued that the qualitative form of this type of epistemology is compatible with the nuanced nature of the human pastoral interaction being considered in this extended reflection. As Schon implores, "Let us search … for an epistemology of practice implicit in the artistic, intuitive processes which some practitioners do bring to situations of uncertainty, instability, uniqueness, and value conflicts …"[476] The incarnational context of the pastoral care being considered in this extended reflection, which equates with Schon's "swampy lowlands,"[477] describes a setting in which relationships cannot be wholly explained by scientific propositions but which require a form of pastoral artistry.[478] Such artistry employs skills such as intuition and imagination to more

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[472] ibid., 11.

[473] Polanyi, Thomas. *The Tacit Dimension*. (London: Routledge & Kagan Paul Ltd, 1967), 25.

[474] Moustakas, Heuristic Research, 10.

[475] Neimeyer, Greg, and Arthur Resnikoff. "Qualitative Strategies in Counseling Research." *The Counseling Psychologist* 10, no. 4 (1980): 75-85.76.

[476] Schon, The Reflective Practitioner, 15.

[477] ibid., 43.

[478] The concept of the professional as an artisan is asserted in,
Couture, Pamela. "Pastoral Theology as Art." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie Miller-McLemore and Brita Gill-Austern, 169-87. (Nashville: Abingdon Press, 1999).
Schon, The Reflective Practitioner, 50, 62.

fully understand the institutional context under consideration and the people with intellectual disability who are engaged in pastoral relationships.

5.5.2 Praxis as the Foundation for Reflection-in-Action

The word ‘praxis’ is derived from the term ‘othopraxy’ which refers to right action. It takes the notion of truth beyond the mere notion of that which is the product of detached academic thinking, that is, ‘orthodoxy,’ to the notion of truth as that which is acted upon and reflected upon simultaneously.[479]

In broad liberationist terms, espoused by radical South American educationist Oscar Freire, the concept is firmly grounded in the struggle for the oppressed of the Third World to be given voice. The goal is to discover an avenue to freedom through a transformed sense of social awareness. Through educational programs those who have been silenced by their oppressors learn to develop a level of autonomy. This enables them to perceive the socio-historically developed structures that have served to entrench notions of individual and class inferiority and to challenge the culture-laden myth of oppression as a form of expected social norm. Thus praxis, the touchstone between reflection and action, and action and reflection, provides the basis for liberating social awareness and transformatory action.[480] It provides a framework for justice-making which can be referred to as an act of humanisation.[481]

Freire embeds such praxis in a dialectical process compatible with a mode of analysis, interpretation and understanding characteristic of the hermeneutical methodology proposed in this extended reflection. As he states in reference to the act of critical analysis,

> ... it is also true that action upon an object must be critically analysed in order to understand both the object itself and the understanding one has of it. The act of knowing involves a dialectical movement which goes from action to reflection and from reflection upon action to a new action. For the learner to know what he (sic) did not know before, he must engage in an authentic process of abstraction by means of which he can reflect

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and,
Schon, Educating the Reflective Practitioner,22, 35, 68.

[479] Bevans, Stephen. *Models of Contextual Theology*. Edited by Robert Schreiter, *Faith and Culture*. (New York: Orbis Books, 1992), 65.
Here, the author refers to it as " ... reflected-upon action and acted-upon reflection – both rolled into one."

[480] Freire, Paolo. *Cultural Action for Freedom*. (Harmondsworth: Penguin, 1972), 13, 30.

[481] ibid., 30-31.

> on the action-object whole, or, more generally, on forms of orientation in the world.[482]

This statement suggests an ongoing dialectic between analysis and action that leads to the evolved hermeneutical understanding suggested earlier in this chapter. This of itself implies a newly-developed praxis every time analysis and action interconnect.[483] The image of the hermeneutic spiral comes to mind which, of itself, is in contradistinction to the more fixed understanding of truth that Freire elsewhere refers to as the "circle of certainty."[484] Such a circle proffers truth and reality as static constructs designed to maintain those oppressed in a normative state of oppression.

In relation to this extended reflection, discussion of praxis within the liberationist South American context needs to have its major contextually-based limitations acknowledged. Firstly, Freire speaks primarily with a socio-political voice, whereas I speak primarily with a pastoral voice. Freire defines oppression in terms of silence or loss of voice. I speak pastorally of lost identity. Freire describes the need for education programs to enable awareness and literacy. I speak of pastoral models that offer a measure of liberation. Freire describes the impoverished of South America as those with the capacity to be freed to act as autonomous human beings. I speak of people who by dint of their intellectual impairment are generally limited in their capacity to act as autonomous human beings, and who can be seen to need others to advocate for them, to articulate the words they may not be able to utter.

Nonetheless, the cause for which Freire advocates closely parallels that presented in this extended reflection. The South American struggle for literacy and voice closely parallels, from a pastoral theological perspective, the South Australian struggle for the liberation, through an appropriate model of pastoral care, of institutionalised people living with intellectual disability. Praxis that provides a forum for critical reflection upon oppressive institutional structures and practices, and ever more liberating models of living as human beings is fundamental to both contexts.

5.5.3 Pastorally-Based Praxis

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[482] ibid., 13.

[483] ibid., p.17.

[484] Freire, Pedagogy of the Oppressed, 23

The pastorally-based praxis of this extended reflection is inextricably linked to the fundamental connection of faith and words to action in the Old Testament prophetic tradition (see particularly Isaiah and Amos), along with the New Testament edict to “do the truth in love” (Ephesians 4:15) whereby appropriate ethical behaviour is connected to the outworking of theological thought.[485]

In terms of this extended reflection it is through the prism of liberation theology that praxis is understood as providing a forum for understanding oppressive influences. It also affords the opportunity to regard the complexity of relationships formed as offering the possibility of transformation for all. A reading of pastorally-based liberation theology indicates that while liberation is there to be experienced by the individual the focus is upon the collective marginalised and oppressed people.[486] Likewise, the narratives to be detailed in the following chapter are to be understood as being representative of people rather than individuals.

The individual needs to be understood in terms of the collective call for justice. As feminist theologian Rebecca Chopp indicates, praxis in liberation theology is “... first the web of relations in which the individual doing and being is enabled and contained.”[487] It is this perspective that will be expressed in this hermeneutical process.

5.5.4 The Nature of Action and Reflection

Within the overall hermeneutical process, action and reflection are to be regarded from a creative relational perspective. As Freire asserts, when action and reflection act in union, they “constantly and mutually illuminate each

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[485] Bevans, Models of Contextual Theology. 64.

[486] See, for example,
Boff and Boff, Salvation and Liberation.
Gutierrez, A Theology of Liberation.
Segundo, The Liberation of Theology.
In the Asian context liberation theology finds its equivalent in Minjung theology which emanated from South Korea in the early 1980s. The word *minjung* means “the multitude of the people” and is closely related to notions of those oppressed, exploited and marginalised. See,
Yim, Taesoo. *Minjung Theology Towards a Second Reformation*. (Chiangmai: Christian Conference of Asia, 2006), 5.
Chopp, "Practical Theology and Liberation,” 134.
See also,
Anderson, In Search of the Disabled Human Body, 35.
Here the author refers to the disabled human body living and gaining meaning within the context of their society.

other."[488] The ultimate result of such creative dialogue is transformative; the silenced narrative of the oppressed is interpreted and given voice.[489] The pastoral goal of the ongoing action and reflection process upon the institutional disability narrative is to offer a model of pastoral action that liberates and reveals the identity of those concerned.

The crucial function of what Schon refers to as 'reflection-in-action' is to critique the scientific and dogmatic forms of knowledge acquisition referred to as 'knowing-in-action,'[490] where scientific systems of knowledge are applied in a generic manner to a context irrespective of the narrative derived from that context. In relation to this extended reflection this means that the creative capacities of the pastoral practitioner are applied to a problematic situation. The situation is reflected upon amidst the arena of pastoral activity with the practitioner applying artistic skills such as intuition, understanding of context, and sense. The pastoral practitioner, whilst taking significant account of issues concerned with their socio-politically constituted setting, will principally reflect a pastoral theological perspective, applying the principles of liberation theology to the context under consideration. This involves discerning the voice of the marginalised who are the focus of this extended reflection, in the light of the Word of God.[491]

As a consequence, problems are addressed with restructured strategies of pastoral action and new understandings of the phenomena in question, based on fresh interpretation of the pastoral narrative.[492]

5.6 Pastoral Reflection Method: Pastoral Visitation and Narrative Analysis

The two methods that will be employed to elicit and interpret the required reflection-in-action data are pastoral visitation and narrative analysis. These methods are consistent with the pre-existing pastoral role of this pastoral practitioner where visitation is a core pastoral activity, and where narrative reflection and analysis discerned from that visitation is necessary in order to nurture and improve the quality of ongoing pastoral engagement.

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[488] Freire, Pedagogy of the Oppressed, 151.
[489] Freire, Cultural Action for Freedom, 30.
[490] Schon, Educating the Reflective Practitioner, 28.
[491] Gutierrez, A Theology of Liberation, introduction.
[492] Schon, Educating the Reflective Practitioner, 28.

5.6.1 Pastoral Visitation and Unobtrusive Observation

For reasons to be articulated these methods are well-suited to the qualitative nature of the hermeneutical methodological process previously described. This pastoral practitioner will gather knowledge and contribute tacit assumptions.[493] These will pertain to those with intellectual disability who live in institutions, by means of unstructured pastoral visitations, as part of his regular pastoral and visitational role as chaplain. Subsequently, the narratives that will form the basis of collaborative analysis will be recorded.

The observations to be considered are concerned with the chaplain's interaction with those with whom he engages in pastoral relationship. This requires detailed description of the interpersonal engagement.

In terms of the observer perspective this pastoral practitioner will assume an unobtrusive posture with those who are the focus of this extended reflection by dint of always assuming the role of chaplain when with the people with intellectual disabilities with whom he engages in pastoral relationships.

From an ethnographic perspective the pastoral practitioner seeks to describe how everyday activities concerning individual people and groups of people are influenced by the institution of which they are a part. This is achieved by investigating how people respond to and make sense of each other's behaviour in the contemporary context amidst the gamut of experiences that comprise a normal daily routine within that setting. As social researchers David Wareing and Christopher Newell state, "[s]uch analysis makes visible the machinery for producing social phenomena, by explicating the social order that it produces." [494]

The usual routines of pastoral visitation and care within the institutional settings with which this pastoral practitioner functions provide a comprehensive range of experiences that form the basis for the collation of narratives to be interpreted. These experiences include engaging with those with intellectual disabilities amidst their usual daily activities, including social activities such as arts and crafts, concerts, movies, exercise classes and community outings. It may also include time spent in their shared dining areas where they may watch

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[493] Polanyi, The Tacit Dimension, 22-23.
Here, the author refers to tacit knowledge in intuitive terms as "… the intimation of something hidden, which we may yet discover." See also,
Schon, Educating the Reflective Practitioner, 21.
Here the author refers to Polanyi's *intimation* in terms of "professional artistry".

[494] Wareing and Newell, "Commonsense and the Doing of Supported Care," 105.

television, play private games such as jigsaw puzzles, listen to music, spend time in their shared garden, sleep, or simply sit while seemingly staying with their own thoughts. Sometimes pastoral visitation will include being with individuals amidst visits from the various medical professionals who tend to their diverse disability-derived medical needs. Routine visitation may be intentional in terms of planning to catch up with certain individuals from a particular accommodation or activity area. It may also be ad hoc in terms of the chaplain engaging with an individual in an informal manner whilst moving around the institution.

Pastoral visitation may also include engaging with individuals or groups of people on special occasions that may be celebratory, traumatic or critical in nature. The celebratory occasion could include being present with an individual at a birthday or Christmas party. The traumatic event could be concerned with engaging with someone at a time of bereavement for a friend who has recently died or at some other time of emotional unrest such as a dispute with a colleague or staff member. The critical occasion may include spending time with a frail individual, whose death is imminent, and their family members.

5.6.2 Narrative Status

The form of narrative to be discerned, described and reflected upon will be constructed from a thorough, congregate perspective. The narratives represent the ‘strong threads’ of institutional life and of persons accommodated therein. As such, the behaviours, experiences, conversations, described presence and articulated voices are those which are representative of various types of pastoral observations and encounters, intentional and ad hoc.

No narrative represents the telling of a literal recounting of any particular personal, pastoral encounter in the institutional context.

No narrative represents the telling of a first-hand story by a person living in the institution at the time.

No narrative is the result of consultation or negotiation with any person or persons whatsoever.

The diversity of pastoral visitation experiences and observations leads to the recording of a range of narratives that reflect the nature of institutional life for the community of people with intellectual disability who live in this environment. It is through these multiple observations and, subsequently, the typological narratives that emerge, that the truth revealed in any one observation and narrative can be tested against a broader range of experiences.

It is the purpose of this extended reflection to develop a pastoral approach that offers a measure of liberation to those with intellectual disability who engage in pastoral relationship within the institutional context. Therefore, it is the intention of this pastoral practitioner to reflect upon narratives that are of a representative type derived from those who live in the institutional context. This is in contradistinction to narratives that focus on personal, literal truth, concerned as they are with verbatim recording of personal pastoral and institutional engagements and context. It is argued that this latter form of narrative reflection requires a pastoral response that accords with the nuances of each particular narrative. It is argued that a comprehensive and representative pastoral model cannot authentically emerge from the individual narrative even if the literal personal story is reasonably representative of the institutional situation. Such a pastoral model could always be claimed to be more responsive to personal nuances than the congregate perspective.

The discerning of narratives of institutional type acknowledges the common threads of those stories that represent the nature of life for the community of people with intellectual disability living in the institutional context. As Rodwell states in relation to constructivist research practices,

> [t]he ... researcher is duty bound to collect information relevant to all stakeholders; to collect information in ways that expose 'facts' useful to all sides; and to release findings continuously and openly so their credibility can be examined by all.[495]

This pastoral practitioner would argue that such broad-based ‘fact finding’ is best discerned through the analysis and reflection upon narratives of institutional type. It is from this perspective that a pastoral model pertinent to all can be developed.

Such narratives will be discerned from the multitude of pastoral encounters in which this pastoral practitioner has engaged since beginning this ministry in March 2001. The collation of and reflection upon narratives over this length of time has ensued since the commencement of this ministry. It has enabled the development of a mature understanding of what is meant by the

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[495] Rodwell, Social Work, 10.

notion of ‘narratives of institutional type.’ The narratives that thus emerge will faithfully reflect the common strong threads of life for people with intellectual disability who live in this environment.

The narrative description of such experiences needs to be cognisant of a broad range of detail that serves to fully illustrate and assist in the process of interpreting the meaning behind the narrative. The type of detail being sought is derived from what social researcher Raymond Lee refers to as simple observations, noting behaviours, postures and social descriptors in detail.[496]

It is through a rich diversity of perceptions that this pastoral practitioner can understand the context and reality under consideration and its people. This is understood in terms of history, primary relationships and collegial support. Understanding emerges from the application of traditional and pastoral theological knowledge to the narratives being reflected upon. It also emerges through a socio-political understanding of the contextual basis to issues of culture, gender, majority/minority relationships and the exercising of power.[497] It is this rich diversity of perceptions that provides the material for pastoral reflection and modelling.

The task of reflection upon the institutional narratives was undertaken with the support of this chaplain’s employer, the Uniting Church in Australia, Presbytery and Synod of South Australia, and of the institutions in which he exercises his pastoral ministry.

5.6.2.1 The Purpose and Value of Narrative Description to a Pastoral Practitioner

The purpose and value of narrative description is that it can lead to legitimate description and understanding of life in the institutional setting. Such experiences need to be recorded whilst also giving appropriate description of the lived context in which they occur. This is necessary so as to gain an understanding of the interplay and influence that occurs between institution and those who live in that environment. The recording of such experiences needs to include the response of the pastoral carer. This response requires careful analysis

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[496] Lee, Raymond. *Unobtrusive Methods in Social Research*. Edited by Alan Bryman, *Understanding Social Research*. (Buckingham: Open University Press, 2000), 34-42.

[497] Poling, James, and Donald Miller. *Foundations for a Practical Theology of Ministry*. (Nashville: Abingdon Press, 1985), 75-76.

so that the quality of pastoral engagement can be part of the spiral of ongoing improvement.

A conceptual approach alone cannot reveal the reality of the lived and nuanced experiences of those with intellectual disability living in the institutional context. It cannot do so at either a structural or personal level of enquiry. As theological educator Robert Anderson asserts,

> We need the voice and presence of people with disabilities to realize a richer revelation of God and ourselves … Because methodology and theories are often (at least) one step removed from human experience … [These narratives] must not only be said about disability; they must include people with disabilities …[498]

Without the specifics of a narrative that give first-hand clear pastoral description of institutional life, we are left with the generalisations of a meta-narrative. This is because its lack of specificity to the context being considered means that a first-hand narrative cannot be articulated. As theologian and ethicist Miroslav Volf asserts, "the universality of grand narratives is the main reason for their failure."[499]

It is through narrative devices such as familiar plot lines, archetypal characters and significant remembered incidents that a coherent narrative can emerge that enables a person to derive meaning from, and knowledge about, their life.[500] It is through such devices that a pastoral practitioner exercises the reasoning, perception and imagination that make effective narrative analysis and critical reflection possible.[501] As psychologist George Rosenwald indicates in describing the relationship between life stories (his term) and identity formation, the capacity for such stories to reveal repression and social perplexity might be "liberated by critical insight and engagement."[502] Such narrative understanding is

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[498] Anderson, "In Search of the Disabled Human Body," 36.
First bracketed words are those of author.
Second bracketed words are those of thesis author.

[499] Volf, *Exclusion and Embrace,* 196.

[500] Singer, Jefferson, and Susan Bluck. "New Perspectives on Autobiographical Memory: The Integration of Narrative Processing and Autobiographical Reasoning." *Review of General Psychology* 5, no. 2 (2001): 91-99, 93.

[501] See ,
Lester, Andrew. *Hope in Pastoral Care and Counselling*. (Louisville: Westminster John Knox Press, 1995), 28.

[502] Rosenwald, George. "Conclusion: Reflections on Narrative Self-Understanding." In *Storied Lives: The Cultural Politics of Self-Understanding*, edited by George Rosenwald and Richard Ochberg, 265-89. (New Haven: Yale University Press, 1992), 262 & 286.

crucial to the development of liberating pastoral response that meets the people in question at their point of pastoral need.

Human behaviour can only be clearly understood and articulated when narrative describing the individual is understood amidst the wider context in which that narrative is embedded. The personal narratives of those individuals living in the institution need to be heard amidst the accounts of the other selves within that lived environment. The common threads that bind these narratives, namely a shared lived context, a shared humanity and a shared love by God, are discerned and articulated so that a contextualised pastoral response can be tendered. As Lester states in reference to systems theory, "[t]he narrative process of any individual (including the language, images, and symbols) is affected by the narrative structuring of the larger culture and the meanings that are attached to life by gender, politics, and ethnic heritage."[503] In relation to the specifics of this extended reflection it is appropriate to add to Lester’s list of attachments those of disability, institutional and pastoral theological heritage, all of which imply an appreciation of the influence of the historical context upon the present-day institutional and pastoral narrative.

Such narratives are interpreted and understood by the pastoral practitioner amidst dominating institutional discourses such as the wielding of power.[504] Hence the importance of authentically hearing and responding appropriately to the narratives of those who find themselves in an institutional context where their identity struggles to be revealed amidst dominant service delivery identities and discourses.

Amidst the institutional setting there is a compelling need for those with disregarded identities to be revealed. Such revelation serves as a fitting biography that articulately and truthfully describes the identity of those who live in an environment so defined by prevailing discourses concerned with power, image and medical relationship. As Campbell, Jones and Gillett assert, in relation to health care and people with disability, “[w]e must give permission for things to

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[503] Lester, *Hope in Pastoral Care,* 38.
Bracketed words are those of author.

[504] McAdams, Dan. "The Psychology of Life Stories." *Review of General Psychology* 5, no. 2 (2001): 100-22, 114.

be said that otherwise remain hidden ...”[505] It is the role of the pastoral practitioner to allow for such revelation to occur through the considered disclosure of those personal and collective narratives that would otherwise remain unidentified.

Such revelation needs to be understood from a pastoral theological perspective. It is the claim of this pastoral practitioner that God is present with all human beings who are all imprinted with God’s image through the act of creation (Genesis 1:26).[506] This God is present with that creation, both individually and collectively, amidst the contexts in which they live their lives. As such, the Word of God and its truth are to be perceived through the utterances, actions and the being of God’s people, including those who live with disabilities in the institutional context. It is the voice of God speaking in and through the institutional, communal and personal narrative that informs, challenges and develops the pastoral response by the pastoral practitioner to their ongoing relationship with the institution and its people.

This disability voice, through whom God speaks, requires intentional and careful listening. As disability chaplain Andy Calder asserts,

> Honoring and respecting a person’s lived experience are of paramount importance. Rather than offering a thoughtless and dismissive cliché, pastoral care best begins by listening intently to the person’s story: to their struggles, hopes and fears.[507]

Whilst endorsing this call to listen to the voice of those with disabilities the broader revelation of their identity takes on an oft under-acknowledged and complicating dimension when we specifically consider those living with intellectual disabilities. There are many whose voice is difficult to interpret. This is because of diminished levels of cognitive awareness and reduced communication capacities.

Campbell, Gillett, and Jones. *Medical Ethics*. 184. Here, the authors describe the privileging of certain narratives over others, which can serve to silence those discourses that shed light on outmoded and oppressive institutional practice.

[506] National Council of the Churches of Christ in the United States of America. *The Holy Bible*, Old Testament, 1.

[507] Calder, Andy. ""God Has Chosen This for You" – "Really?" A Pastoral and Theological Appraisal of This and Some Other Well-Known Cliches Used in Australia to Support People with Disabilities." In *Voices in Disability and Spirituality from the Land Down Under*, edited by Christopher Newell and Andy Calder, 5-19. (New York: The Haworth Pastoral Press, 2004), 13.

In earlier discussion concerning disability models it was noted that even within that which can be described as the ‘disability movement,’ such as amongst those who have been active in claiming disability rights, there remains a diminution of the status of people with intellectual disability. This is due to the lack of autonomy which is the result, not only of the effects of the particular impairment, but also of cognitive dependence upon others. As Parmenter states in relation to the claiming of rights by people with intellectual disabilities,

> The emphasis on individualism ... presents quite a threat to a vulnerable population, such as those with intellectual disabilities. In our goal to encourage their independence we have overlooked the essential fact that the vast majority of this population will, in many aspects of their daily lives, remain dependent on supports. ... The challenge, then, is for us to create environments where the interdependence of individuals is a central feature and where individuals perceive their identity and conceptualization of self in the context of a mutually dependent society.[508]

With the concept of mutual dependence in mind comes the need to develop a means of enabling the identity of people with intellectual disability to be pastorally revealed. This occurs through the support of pastoral carers who can faithfully and authentically discern and describe the required narrative. It can also occur with the corrective support of colleagues from beyond the institutional setting. They can assist with interpretation and provide necessary objective narrative understanding. Beyond the primary role of the individual’s family in interpreting such narrative pastoral carers can claim relationships with institutionalised individuals in which narrative can be discerned and acted upon appropriately. The pastoral practitioner claims as his or her role the need for the institutionalised narrative to be articulated in a manner that reveals the collective identity of those for whom he or she cares. This is fulfilled in the context of the mutually-interdependent pastoral relationship.

5.6.2.2 Pastoral Collaboration

Whilst there can be no thoroughly objective observation and analysis of narrative this pastoral practitioner has sought to increase the authenticity of the analysis by reflecting collaboratively with qualified chaplains from outside the institutional context pertaining to this context. The collaborators in question are

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[508] Parmenter, “Intellectual Disabilities”, 289.

an Anglican hospital chaplain, a Uniting Church aged care chaplain, and a Uniting Church hospital chaplain.

Despite the emphasis in this extended reflection on the pastoral practitioner’s internal and creative frame-of-reference the act of collaboration adds essential rigor to the process of observation and analysis, which has been previously highlighted in reference to Rodwell’s constructivist approach to qualitative research. New meanings and greater understanding of narrative can emerge that may not be apparent to this pastoral practitioner. As social researcher Ernest Stringer asserts, “new meanings emerge as divergent views are compared and contrasted. The major purpose of the process is to achieve a higher level synthesis ... and to build an agenda for negotiating actions to be taken."[509] Similarly, Moustakas refers to the act of peer analysis as leading to a “mutual unveiling”[510] of insight.

A subsidiary role of such collaboration is to take account of any negatively-impacting prejudices by this pastoral practitioner in his narrative reflection. Such personal bias needs to be challenged in order that authentic pastoral outcomes can be achieved for those who live in the institutional environment. As social researcher Theodore Kisiel asserts, “true hermeneutic experience does not begin until we are sufficiently open to permit the text to question us, that is, to 'unhinge' our prejudices and to suggest its own."[511] It is argued that whilst self-reflection can assist with identifying and challenging negatively-impacting pastoral prejudices it is the act of collaboration with skilled and objectively-located others from outside the pastoral context in question that can most effectively unhinge such biases and replace them with more positively-weighted attitudes and practices.

5.6.2.3 The Process of Discernment and Analysis

The process of discernment and analysis will be based around two layers of questioning that will both be applied to the sourced narratives. Firstly, there is the discernment and analysis that will improve understanding for pastoral practitioners from a pastoral, theological perspective and contribute to improved

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[509] Stringer, Action Research., 41-42.

[510] Moustakas, Heuristic Research, 48.

[511] Kisiel, Theodore. "The Happening of Tradition: The Hermeneutics of Gadamer and Heidegger." In *Hermeneutics and Praxis*, edited by Robert Hollinger, 3-31. (Notre Dame: University of Notre Dame Press, 1985), 9.

pastoral models and behaviours. The issues and questions that will form the basis of this will, in the light of the pastoral theological perspective of this pastoral practitioner, be liberatory in nature. The issues and questions will be based on and adapted from the reflective theological questions of theological educator John Paver.[512] See table below.

The pastoral theological elements that contribute to an effective narrative analysis enable the pastoral practitioner to develop an understanding from a pastoral, faith-based perspective. This will enable pastoral responses to be made to people and context that are theologically liberatory in nature. This is based on the theological presupposition that God is expressed in incarnate form and seeks relationship with human beings.[513] This is commensurate with the core Christian conceptualisation of the love of God for humankind expressed through the sacrificial love of the incarnate Christ.

The pastoral theological questions are analysed with consideration for the social analysis so as to locate the pastoral reflection in its lived context.

Table 5.1. Pastoral Theological Questions Contributing to Narrative Discernment and Analysis

Foundational questions
• In what sense is life present in this situation? • How might the incarnate God be understood to be present in this situation? • In what sense is oppression present in this situation? • What biblically-based models of liberation bear application to the narrative? How? • What are the biblical principles present in the pastoral carer’s faith tradition and pastoral assumptions that assist understanding of this situation? What effect do they have on understanding?
Subsequent questions
• What can the pastoral carer do to bring theological forms of liberation to the described situation? • What model of pastoral ministry can the pastoral visitor offer that best responds to the pastoral needs expressed in this situation? • What pastoral actions will facilitate positive change based upon the theological conceptualisation of liberation?

Secondly, from a sociological perspective, questions will be derived and adapted from the work of qualitative researchers Sharan Merriam[514] and

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Paver, John. *Theological Reflection and Education for Ministry*. Edited by Leslie Francis and Jeff Astley, *Explorations in Practical, Pastoral and Empirical Theology*. (Aldershot: Ashgate Publishing Limited, 2006), 61.

[513] ibid.

[514] Merriam, *Qualitative Research,* 97-98.

Raymond Lee[515] that will be based on standardised contextual elements of each narrative. See table below.

Table 5.2. Contextual Questions Contributing to Narrative Discernment and Analysis

the physical setting
• What is the physical environment like? • What is the purpose of this physical setting? • Where are the people located within this setting? • What activities are occurring in this setting?
interactions
• What is occurring between people? • What norms or rules dictate the nature of the interactions?
exterior physical signs
• How would you describe the person’s physical appearance (e.g. neat, unkempt)?
non-verbal signs
• How would you describe the person’s facial expressions (e.g. calm, excited)? • Is this expression usual? If not, why? • How would you describe the person’s physical posture (e.g. erect, hunched)? • Is this posture usual for this person? If not, why? • What is the significance of silences in conversation?
subtle factors
• Are there symbolic meanings behind any of the words used? • What words or behaviours are not observed to occur that may be expected? Why?
emotional signs
• How would you describe the person’s emotional state (e.g. engaged, anxious)? • Is this emotional state typical or atypical? If atypical, why?
chaplain’s behaviour
• How has the chaplain’s’s presence and social interaction affected the behaviour? • How might this interaction be improved?
in situ conversation
• In what ways is the conversation relevant to this occasion or place? • What is the content of the conversation? • Is there conversation that seems out of place to this context? Why?
in situ behaviour
• In what ways is the behaviour relevant to this context? • Is there behaviour that seems out of place with this context? Why?
time-related behaviour
• To what extent do standardised routines indicate the time and length of time for this activity?

**above questions are examples only*

In light of the narrative discernment and analysis requiring both pastoral theological and contextual reflection understanding is reached that points to a

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[515] Lee, Unobtrusive Methods, 34-42.

course of pastoral action that is applied to the situation. In the case of this extended reflection the action assumes the form of a pastoral model. This model dictates the pastoral carer’s future relationship with those who are the focus of the reflection. This action then becomes the basis for further reflection, discernment and analysis, understanding and pastoral action.

5.7 Summary

Central to this extended reflection is the development of a model of pastoral engagement with people with intellectual disability who live in institutional contexts which is based on authentically discerning the revealed identity of these people. Therefore, it has been the principal aim of this chapter to detail a qualitatively-constructed design that gives best expression to that identity. It is an identity that cannot be described through quantitative research designs. They are not constructed to interpret and understand the nuances of non-empirical human behaviour. These nuances are highlighted through those with major levels of intellectual disability whose voice and behaviour require particularly stringent levels of listening and observation and then, interpretation and understanding.

The necessity is for a design that will be as responsive and adaptive as possible to the pastoral theological and socio-politically situated circumstances of those in question. Through appropriate description and understanding the narratives of these people can point towards the type of liberatory pastoral model that will most authentically engage with them.

What has been called for is a means of pastoral relationship that dignifies people with intellectual disability as those who merit due recognition of their unique life situation as well as their theological status as human beings created in the image of God.

As has been outlined earlier, the history of people who may have found themselves described as morons, idiots, feeble-minded or retarded is a history marked by silence, both for embodied, institutional and wider socio-political reasons. Even today, such influences maintain a measure of silence over institutionalised people with intellectual disability.

Such silence points emphatically to the need for this reflection to not seek to speak for or about people with disability. This is so even though this may seem necessary to some given the diminished capacity for people with intellectual disability to describe their story in a way that can be understood as the telling of a first-hand narrative. Such a prevailing loss of identity points all the more to the need to develop a reflective design that, through thorough listening to the voice of people with intellectual disability, will give authentic first-hand expression to that narrative.

5.8 How do I Regard the One Before Me?

And so, in the light of such an imperative, how do I regard the one before me, the one who can be observed as the Slave?

I strive to see someone whose personal voice and story needs to be heard. I see someone who has too often been talked about by those who think they know best or who believe that the voice of those they observe is not to be heard, or cannot be heard. Yet I know it is justice and human dignity that says that every human being has their own voice, and that that voice reveals a unique, God-given identity. Every human being has the right and need to have their identity described, understood and acted upon as required. It is an identity that needs to be authentically interpreted even if the embodied and socio-political circumstances in which they live demand that the observer and listener look and listen with all the commitment, skill and Christ-like compassion available to them. Human dignity, of a personal and collective kind, requires nothing less.

However, in discerning the identity of the Slave, I am aware of the gap between the one I observe and myself, a gap that has been generated by two crucial factors. Firstly, there is the need to acknowledge that the Slave and I live on opposite sides of both a socio-political and cultural divide. Even if I observe from within the constrained bounds of the Slave's lived context I can never presume to fully know what it means to be a Slave, either in terms of the lived circumstances which serve to oppress, or any embodied sense. Even though I may enter the Slave's world and observe and listen out for what goes on around me this is not my world. I do not live in an environment which purports to care for me, yet also oppresses me by dint of any socio-politically constituted and/or embodied label that may be attributed to me. I do not bear the marks of slavery.

To a significant extent, this is a culturally-imposed gap that cannot be fully bridged. It is arrogance to presume that I can walk in the shoes of the one I observe. However, I can reduce the space between us by observing and listening with all the commitment and resources I can harness. At least using such resources in this way can lead to an understanding that may offer a measure of positive identity. However, it can never be a fully first-hand identity for the Slave's world is not mine.

But there is a secondary cause for a divide that I can do something about and that concerns the gap that exists between theory and practice. Even if I observe and listen with acute commitment and skill a divide will remain if observations and understandings go no further, and compassion goes no further than a good intention. I need to confront the question of the limited worth of understanding that goes no further than contributing to the development of renewed frameworks for future observations. Such observations are of no practical benefit to the lived circumstances of the Slave. They do nothing to improve their lives either personally or systemically. If such benefit is to be afforded to the Slave then the time must come when my theoretical perspective must be applied to a mode of relationship with the Slave and their lived context which is, ultimately, of practical benefit to them.

This is a gap that must be bridged if a measure of liberation is to be attributed to the life of the one whom I observe, and if a measure of lived slavery is to be redressed by carefully-considered pastoral action. And as the life journey of the Slave proceeds it is a gap that must go on being bridged.

This is a gap that must be bridged through my seeing the one before me as a fellow human being created in God's image who deserves the benefits of human life on the basis of being human and loved by God. It comes from a passion for seeing injustice redressed and life restored. The Slave requires no less of a commitment.

PART 3

TOWARDS A LIBERATING PASTORAL MODEL

CHAPTER SIX

THE PASTORAL NARRATIVE

“If we cannot write new stories that imagine a new future for women and men, we will die still holding to old narratives that do not liberate, but bind."[516]

> At first I could see no meaning in this jumble of words, of images, thoughts, prayers, observations and emotions. … Eventually it came to me that here in these pages there was something I could only dimly perceive, some threads running through and holding it together like the veins that carry blood to the living heart.[517]

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[516] Chopp, Rebecca. *Saving Work: Feminist Practices of Theological Education*. (Louisville: Westminster/ John Know Press, 1995), 22.

[517] Keenan, Brian. *An Evil Cradling*. (London: Vintage, 1993), 81.

Plate 6.1

‘Rebellious Slave’

by

Michelangelo Buonarotti

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[518] Ruehring, Lauren. *Rebellious Slave by Michelangelo* HowStuffWorks, Inc, 2011 [cited 30/12/2011]. Available from http://entertainment.howstuffworks.com/arts/artwork/michelangelo-sculptures12.htm

6.1 Pre-understandings

Consistency with the hermeneutical design just described, and its importance to the pre-understandings or assumptions brought to bear on the process of narrative reflection and analysis, require due acknowledgement of the faith traditions that form the basis of my pastoral ministry as a Uniting Church Chaplain. Furthermore, I will affirm those principles of liberation theology that give appropriate pastoral focus to this extended reflection and narrative analysis. Finally, I will describe the personal pre-understandings I bring as a pastoral care chaplain and Christian to the process of analysis and understanding.

6.1.1 The Basis of Union and Supporting Historic Documents

Beyond the Bible itself the primary document on which the Uniting Church in Australia's faith and life is ordered is the Basis of Union. This document reflects the faith and witness of the three Reformed churches that merged in order to become the Uniting Church, that is, the Congregational, Methodist and Presbyterian churches. Apart from issues of contemporary ecclesial ordering and practice the Basis of Union was grounded in the historic documents that undergirded the faith and witness of these denominational traditions. These historic documents are The Apostles' Creed, The Nicene Creed, The Scots Confession of Faith (1560), The Heidelberg Catechism (1563), The Westminster Confession of Faith (1647) and The Savoy Declaration of Faith (1658), as well as a selection of John Wesley's sermons.[519]

This Basis of Union affirms the primacy of Scripture when it states,

> The Uniting Church acknowledges that the Church has received the books of the Old and New Testament as unique prophetic and apostolic testimony, in which she hears the Word of God and by which her faith and obedience are nourished and regulated. ... The Word of God on whom salvation depends is to be heard and known from Scripture appropriated in the worshipping and witnessing life of the Church.[520]

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[519] Owen, Witness of Faith.
The Creeds are specifically acknowledged in paragraph 9 of the Basis of Union, whilst the various Confessions and sermons are acknowledged in paragraph 10.

[520] Uniting Church in Australia. *Constitution and Regulations*. (Collingwood: Uniting Education, 1999), pars 5, 11.

Scripture is thus regarded as witnessing to Jesus Christ as the Word of God and is enacted and understood in its worshipping and witnessing life.

God is regarded as a giver of spiritual gifts to all members of Christ's Church. The Church:

> ... acknowledges with thanksgiving that the one Spirit has endowed the members of his Church with a diversity of gifts, and that there is no gift without its corresponding service: all ministries have a part in the ministry of Christ. The Uniting Church, at the time of union, will recognise and accept the ministries of those who have been called to any task or responsibility in the uniting Churches. The Uniting Church will thereafter provide for the exercise by men and women of the gifts God bestows upon them, and will order her life in response to his call to enter more fully into her mission.[521]

Implicit in this missional call is the honouring and ordering of the Church's witness in the community in response to those seeking pastoral ministry that is in accord with their pastorally-related gifts.

While regarded as primary, the scriptural witness to the incarnate Christ, who lived and died and rose again, is not to be interpreted and understood in isolation from the wider community of which it is a part. As the Basis of Union states, the Uniting Church,

> ..... lives within a world-wide fellowship of Churches in which she will learn to sharpen her understanding of the will and purpose of God by contact with contemporary thought. Within that fellowship she also stands in relation to contemporary societies in ways which will help her to understand her own nature and mission.[522]

In other words, the incarnate Word of God, understood in and through Scripture, develops a more informed status as it engages with the God who is intimately connected with all of humanity. The concept of modes of enquiry embraces the notion of reflective pastoral enquiry, and narrative interpretation and understanding inherent in this extended reflection.

The church understands her nature and mission all the better for engagement and dialogue with those contemporary cultural and institutional contexts in which church members are called to serve.

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[521] ibid., par. 13.

[522] ibid., pars. 11, 12.

The statement also affirms that greater understandings of truth occur through dialogue and interaction between ecclesial and wider societal contexts. It also highlights the dialogue that is embedded in the co-relational process of reflection detailed in the methodological process presented in the previous chapter. That process concerns the ongoing interaction between the pastoral theological and social science perspectives for the purposes of gaining the most comprehensive understanding of the narratives under consideration.

Thus, the Basis of Union, standing as it does within a Reformed scriptural tradition and undergirded by its historic documentation, can be regarded as endorsing, sustaining and informing a ministry that seeks Christ-centred pastoral engagement with contemporary, culturally-grounded institutions such as those that accommodate people with intellectual disabilities.

It is also this faith tradition that is consistent with the fundamental principles of liberation theology. Whilst there is differentiation based on socio-political context, there is a fundamental consistency between the theological and ecclesial ethos expressed in the Basis of Union and its supporting documents, and of liberation theology.

6.1.2 Liberation Theology

Amidst the range of positive influences that liberation theology can bring to bear on contemporary, pastoral theological thought the following considerations are the most pertinent to this extended reflection.

6.1.2.1 A Preferential Option for the Poor

Liberation theologians speak of a God who is on the side of those who are socially, economically or politically poor and who, as stated in relation to Freire in the previous chapter, are sustained in such poverty by those in positions of authority seeking to entrench their socio-politically derived status. Gutierrez speaks of this as God’s option or preference for the poor when he states,

> In the final analysis, an option for the poor is an option for the God of the kingdom whom Jesus proclaims to us. ... The entire Bible, beginning with the story of Cain and Abel, mirrors God's predilection for the weak and abused of human history. This preference brings out the gratuitous or unmerited character of God's love.[523]

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[523] Gutierrez, A Theology of Liberation, xxvii.

The Basis of Union speaks of the Incarnate Christ in terms of the “Jesus of Nazareth (who) announced the sovereign grace of God whereby the poor in spirit could receive the Father’s love.”[524] Whilst the emphasis here is on poverty of spirit, the principle is the same. The kingdom of God is accessed through poverty, through that life and spiritual perspective that strips one bare of material, socio-economic and philosophical understandings that separate one from God. This God is understood through the incarnate Jesus of Nazareth who modelled a commitment to the poor, and poor in spirit, through his earthly life.

It is this impoverished perspective that enables us to understand the poor as oppressed and marginalised, as an historically identifiable people who can validate their struggle to overthrow oppression and claim liberation. As Catholic Third World liberation theologians Leonardo and Clodovis Boff state,

> A preferential option for the poor enables us to pursue a rereading of history from the standpoint of ... marginalized groups ... The purpose of this endeavour is to give ... (oppressed people) ... a genuine historical consciousness, without which they will remain rootless and deprived of the support needed to nourish their struggle for liberation.[525]

Such historical identification and awareness is given credence through the earthly life of Jesus. As theologians Michele Taylor and Roy McCloughry state in relation to the historically-situated Jesus who they describe as the Disabled Christ, "the solidarity is there in the events of the Incarnation, the Crucifixion and the Resurrection.[526]

It is to be asserted that those with intellectual disability accommodated in institutions are an historically-situated oppressed people by dint of their institutional circumstances. Furthermore, it is Jesus of Nazareth who lays full claim to these marginalised, impoverished people, through his incarnate life, death and resurrection. The oppressed have an ally in the historically-situated Jesus.

Furthermore, whilst Jesus is regarded as coming to an oppressed, marginalised people, the nature of his life, death and resurrection is such that God

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[524] Uniting Church in Australia, Constitution and Regulations, pars. 3, 10.
Bracketed word that of thesis author.

[525] Boff and Boff, Salvation and Liberation, 29.
Bracketed words are those of thesis author.

[526] Taylor, Michele, and Roy McCloughry. *A Disabled God?* (October) Third Way, 1998 [cited 18/2/2008]. Previously available from http://www.thirdway.org.uk/, par.21.

does not regard these people as marginal. Instead, the message of liberation theology is that these people, through Christ, can lay full claim to the salvation God offers to all human beings. As Gutierrez asserts, through Christ the liberator, "... salvation embraces all persons and the whole person; the liberating action of Christ – made human in this history and not in a history marginal to real human life – is at the heart of the historical current of humanity ..."[527] It is this Christ who upholds the value and worth of these people who live with intellectual disability in an institutional context.

Thus, as Christ the liberator offers salvation that is unconditionally embracing of all humanity, Christ's followers regard others as central to their relational and philosophical focus. This is necessary if their need of liberation is to become a genuinely-perceived and understood concern of others. As Tracy asserts in respect to regard for the other,

> The others must become genuine others for us – not projections of our fears and desires. The others are not marginal to our centers or their own. Their conflicts and their liberationist self-namings demand the serious attention of our center on their own terms. [528]

It is to these people that the message of liberation comes through carers who witness to this faith perspective. These people become the whole-hearted focus of those who engage in pastoral relationship with them. This perspective brings dignity, value and liberation to those who receive it. It enables the other to recover something of their God-given identity. As pastoral theologian Donald Chinula asserts from a liberation perspective,

> ... the vocation of pastoral caregiving empowers the caregiver to empower the symptom bearer to reclaim the sense of "somebodiness" that issues from being a copy of God's own image and personality. ... Such prophetic, pastoral caregiving aids the sufferer to achieve ... a deeper adventure to reclaim God-valued, God-allied, God-dignified, and God-bequeathed personhood ... [529]

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[527] Gutierrez, A Theology of Liberation, 97.

[528] Tracy, On Naming the Present, 5.

[529] Chinula, Donald. "The Tasks of Oppression-Sensitive Pastoral Caregiving and Counseling." In *Injustice and the Care of Souls: Taking Oppression Seriously in Pastoral Care*, edited by Sheryl Kujawa-Holbrook and Karen Montago, 133-38. (Minneapolis: Fortress Press, 2009), 136.

It can be rightfully asserted that the claiming of liberationist rights by the poor is traditionally predicated on the capacity of the individual to claim those rights. This is the principle of individual autonomy. This clearly works to the benefit of those who are cognitively capable of claiming such rights, and against those whose cognitive limitations make the claiming of such rights highly problematic. However, as implied above, it is within the caregiver's role as advocate to assist the person with intellectual disability to articulate their rights. From a pastoral perspective this includes the right to be fully regarded as a human being of God-given worth. This point will be further asserted in the upcoming discussion of the incarnational, theological term 'God with Disability.'

6.1.2.2 Creating a Communal Context for Pastoral Care

The Basis of Union unambiguously speaks of the Uniting Church in Australia regarding its ecclesial identity from an historical, communal perspective. It speaks of living and working "within the faith and unity of the One Holy Catholic and Apostolic Church."[530] From an eschatological perspective, it speaks of a church "on the way", whose identity, through the influence of the Spirit, "will bring her into deeper unity with other Churches, and will use her worship, witness and service to his eternal glory through Jesus Christ the Lord."[531] To this end, the Uniting Church in Australia understands that its ecclesial identity is significantly influenced and shaped by its historic, ongoing and intimate interconnectedness with the Church Universal.

However, it needs to be acknowledged that there are, as Campbell asserts, individualist tendencies in contemporary ecclesial expression,[532] such as in relation to personal evangelisation. While the one-to-one relationship may imply a personal, pastoral agenda,[533] such engagement can also suggest, as was mentioned in chapter 3, a corporeality or mutuality of relationship in which the love of God can have a transformative effect on both pastoral carer and the other.

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[530] Uniting Church in Australia, (1999). Constitution and Regulations, pars. 2, 9. See pars. 1, 3, 9, 10, 11, 12.

[531] Uniting Church in Australia, Constitution and Regulations, pars. 17 & 18.

[532] Campbell, Professionalism and Pastoral Care, 92-93.

[533] Jacobs, Alan. *What Narrative Theology Forgot* (August-September 2003) Institute on Religion and Public Life, 2003 [cited 9.1.05, 2.

The biblical and faith-based concept of ‘love of neighbour’ or, as Volf from a liberationist perspective uniquely describes it, ‘Embrace’, [534] is undergirded by the suffering and crucified God. This God’s own intrinsic nature calls us into community and unity with the excluded and oppressed by the giving of one’s self to the other.[535] From this theological perspective the act of genuine pastoral engagement with those who live with intellectual disabilities in institutions can be regarded as an act of community-making. Through the being and the action of the giving of pastoral care to these people, expressed through the God-given love of neighbour, a sense of community, albeit imperfectly expressed, is present.

Such an action of community-making requires commitment which of itself derives from Jesus’ giving of himself to humanity expressed through his incarnation, death and resurrection. Indeed the action of offering care to another reveals the incarnate reality of Jesus. As Segundo asserts, “Jesus seems to go so far as to suggest that one cannot recognise Christ, and therefore come to know God, unless he or she is willing to start with a personal commitment to the oppressed."[536] This is essential to a pastorally-based theological understanding. The Word of God is revealed through lived, contextualised experience.

In advocating for the force of a liberationist understanding of community being absorbed into the Western ecclesial context Campbell asserts the need for a radically impartial interpretation of the Christian ethic of ‘love of neighbour.’ He asserts,

> The truly unsettling aspects of this dimension of formation for pastoral care are as yet only to be guessed at, but they will be found when pastoral care rediscovers its communal identity and its ethical challenge to all human institutions.[537]

For Campbell, the ‘unsettling aspects’ referred to concern a fearless pastoral vulnerability in which there is an unambiguous commitment to engaging in the fragility of life, including in the institutional context.[538]

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[534] Volf, Exclusion and Embrace.
[535] ibid., 47.
[536] Segundo, The Liberation of Theology, 81.
[537] Campbell, Professionalism and Pastoral Care, 94.
[538] ibid., 89.

Ultimately, the pastoral care model proposed at the culmination of the hermeneutical process needs to bear radical application not only to isolated individuals but to an institution of oppressed, vulnerable people living with intellectual disabilities.

6.1.3 Personal Pre-understandings

As a final significant component in the detailing of pre-understandings two core personal pre-understandings brought to the process of reflection and analysis will be described.

6.1.3.1 People with Disability

Firstly, since early in my pastoral ministry I have sought to regard the people with disability with whom I engage as ‘people with disability’ rather than ‘disabled people.’ While both ascriptions profoundly address the question of human identity there is a crucial divergence of emphasis.

While both terms link the concepts of personhood and disability the former term expresses my fundamental regard for the people I pastorally engage with as whole persons who live with disability as a component of their personhood. As influential as a disability, including intellectual disability, may be to a person’s human identity, there remains more to that person than their disability alone. I choose to see the person before their impairment.[539]

Like all people, they are created in the image of God and are to be regarded as whole persons, as expressed in the Old Testament concept of loving God with all one’s heart, soul, mind and strength.[540] Components of human identity and expression are integrated into a holistic conceptualisation of personhood.

Contrastingly, the term ‘disabled person’ describes personhood as being subsumed by a disability identity. All that a person is can be understood, as interpreted in the disability model proposed for this extended reflection, as that which socially and medically impacts upon their identity. The person is the sum total of that which defines their disability. Implicitly, all that a person is, including values, beliefs, morality, relationships and faith formation, can be

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[539] Swinton, John. *Resurrecting the Person: Friendship and the Care of People with Mental Health Problems*. (Nashville: Abingdon Press, 2000).

[540] National Council of the Churches of Christ in the United States of America. Holy Bible. See,
Deuteronomy 6:5; 10:12; 11:1, 13, 22; 19:9; 30:6, Old Testament, 163-185.

discounted by dint of the disability construct being accorded the status of the shaper of human identity.

When people with a disability are not regarded as whole, autonomous beings the implications, in terms of human value and regard, are profound from a moral, theological and socio-political perspective. As Clapton indicates, “some who fail to be full, autonomous persons are excluded from full moral consideration and significance, are unprotected by any theodic considerations, and can be at risk of vulnerability and disposability." [541]

In seeking to relate honestly with the people for whom I care and to reflect with integrity upon the narratives I bring an understanding that the people under consideration are whole persons who each subsequently live with their own socially and medically understood disability. It is from this perspective that I relate to the other as a whole, fellow human being and not as one who can be regarded as less than fully human.

I do not relate to the other as a medically-constituted problem in need of rehabilitation,[542] nor as a tragedy unable to attain some acceptable level of human fulfilment by dint of intellectual limitation.[543] I relate as a fellow human being, acknowledging that I am in the presence of one who can, in their unique way, give and receive love. I am in the presence of one who I can assist in their relationship with God and who, conversely, can assist me in my relationship with God because we are both created in the image of God, and are loved by God.

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[541] Clapton, “A Transformatory Ethic of Inclusion,” 57.

[542] There is a significant body of literature that critiques disability in terms of medically-perceived problem, or medically-regarded inferior being. Amongst more contemporary literature see,
Campbell, Gillett, et al. Medical Ethics.
Clapton and Fitzgerald, "The History of Disability," 2-4.
Goggin and Newell, Disability in Australia, 23-24, 56, 107.
Swinton, *Resurrecting the Person,* 106.
Titchkosky, "Disability in the News."

[543] The concept of disability as medically and bio-technologically constituted tragedy is considered in detail in,
Clapton, “A Transformatory Ethic of Inclusion”.
Clapton, "Irrelevance Personified."
Clapton, “Disability, Ethics, and Biotechnology”.
Clapton and Fitzgerald, "The History of Disability."
Goggin and Newell, Disability in Australia, 23-29.
Newell, Christopher. "Otherness, Virtue and Ethics Committees." *The Mix* 9, no. 6 (2004): 4-5.
Thomas, "How is Disability Understood?"
Common to such texts is the linking of *disability as tragedy* to the liberation theology concept of oppression and subsequently, liberation/emancipation.

6.1.3.2 God with Disability

The second core, personal pre-understanding brought to the process of reflection and analysis concerns how I understand the Christ who is present with the people with intellectual disability with whom I pastorally relate. This understanding is derived from the aforementioned pre-understanding concerning ‘people with disability,’ as well as my reinterpretation of the contemporary ascription of the Incarnate Christ as the Disabled God.

The term ‘Disabled God’ or ‘Disabled Christ’ is a theological term that various authors have articulated in recent decades so as to incarnationally describe God’s identity with people living with a disability.[544] In the 1990s it was popularly articulated by Nancy Eiesland, a person with her own disability, who sought a Christ figure who was in solidarity with her disabled self. She thus describes her realization of this Christ figure.

> I saw God in a sip-puff wheelchair, that is the chair used mostly by quadriplegics enabling them to manoeuvre by blowing and sucking on a straw-like device. Not an omnipotent self-sufficient God, but neither a pitiable suffering servant. In this moment I beheld God as a survivor, unpitying and forthright. I recognised the incarnate Christ in the image of those judged "not feasible", "unemployable", "with questionable quality of life". Here was God with me. [545]

Here God is seen as one who is ‘on the side’ of those socio-politically marginalised people who live with disability, offering hope through God’s own fully disabled being. Speaking as a liberation theologian Eiesland proceeds to detail a biblical focus of revelation that describes texts and interpretative

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[544] An early proposer of the term was,
Lewis, A. "God as Cripple: Disability, Personhood, and the Reign of God." *Pacific Theological Review* 16, no. 11 (1982): 13-18.
Others who have endorsed this theological designation, with its capacity for human identification, with the same or similar terminology, include,
Cooper, Burton. "The Disabled God." *Theology Today* 49, no. 2 (2006): 173-82.
Hauerwas, Stanley. "Suffering the Retarded: Should We Prevent Retardation?" In *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church*, edited by Stanley Hauerwas. Notre Dame: University of Notre Dame Press, 1996, 104.
Newell, Christopher, and Fran Gillespie. "Narrative, Psychiatric Disability, and Pastoral Care: Towards a Richer Theology of Disability." Paper presented at the 3rd National Conference on Spirituality and Disability – Exclusion and Embrace: Conversations about Spirituality and Disability, Melbourne 2001, 10.
Rappmann, "The Disabled Body of Christ.”
Swinton, *Resurrecting the Person*, 202.
Tan, Amanda. "The Disabled Christ." *Phronesis* 2 (1995): 47-48.
Taylor and McCloughry. *A Disabled God?*

[545] Eiesland, The Disabled God, 89.

frameworks that transcend able-bodied frames-of-reference that exclude people with disability. She proffers a biblical vision that includes people with disability as theological subjects and historic figures.[547] As she states, "... such revelation and truth is embodied in the image of Jesus Christ, the disabled God."[548] Whilst such a conceptualisation is to be commended for indicating the incarnate Christ's total solidarity with people with disability I would argue that by dint of describing God as disabled it promotes the image of a God whose total sense of incarnately-described identity is subsumed by a disabled status. Therefore, I advocate for the ascription of 'God with Disability.'

The ascription 'God with Disability' underpins my pastoral, theological understanding of the God who is incarnately present with the people with intellectual disability with whom I engage in pastoral relationship. It is this God who is in total solidarity with these people from the perspective of being people who are living with a disability. It is this God who has such regard from the perspective of seeing them as whole people, people living with a disability, but whose disability is integrated into their overall created identity.

However, the terms 'Person with a Disability' and 'God with Disability' can understandably be seen to conceal Disability behind all-encompassing conceptualisations of God and Personhood. This serves to discount the disability and its crucial role in shaping identity. Alternatively, phenomenologist Maurice Merleau-Ponty suggests that our embodied identities[549] are a location for epistemological development. In other words, bodies create knowledge. Therefore, the multitude of bodies that inhabit creation each contribute to the richness of our humanness and serve as revelations of the broad range of

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[547] It is to be pointed out that Eiesland, from a rights-based liberationist perspective, indicates that her book is concerned with those people with disabilities who have the cognitive capacity to claim their rights. This clearly excludes those with cognitive limitations. However, I would refer to the previous discussion concerning 'A Preferential Option for the Poor' where it is asserted that the incapacity of the person with intellectual disability to think autonomously and claim their liberationist-based rights is overcome by the role of pastoral carer as advocate. Here, the carer, through careful attention to the individual's narrative, including their socio-politically lived context, develops an awareness of the rights that are to be claimed, and speaks up for those rights where the person is unable to do so for themself. At this point, Pattison's liberationist discussion of the institutional advocacy role of the pastoral carer speaking up for those with mental illness bears careful noting. See,
Pattison, *Pastoral Care and Liberation Theology*, 176-80.

[548] Eiesland, The Disabled God, 90.

[549] Here I would include our cognitive capacities.

possibilities of what it can mean to be human. Therefore we need to look at disability in order to reveal disability as a legitimate shaper of human identity.[550]

I agree with such a perspective to the extent that disability as a shaper of knowledge and understanding regarding humanity should never be concealed but should be observed with acute clarity. However, I would argue that such clarity should not conceal concepts of God or Personhood because disability needs to be clearly described from within, and not autonomous from, these fundamental theological and philosophical constructs. We need to move beyond the language of concealment.

Rather than being hidden disability identity needs to be clearly viewed from within these overarching structures concerning God and Personhood. These structures frame but do not hide disability. I would argue that we still need to attend firstly to the overarching structures as defining parameters by which disability is appropriately understood. However, disability is easily observed.

For the pastoral carer this perspective suggests a clearly perceived conceptualisation of disability within a defining theological framework which suggests a God who is in solidarity with people with disability, including intellectual disability. It also accounts for disability as a part of a holistic, incarnate human identity rather than the sum total of incarnately perceived identity.

6.2 Institutional Narratives, with Individual Reflection and Analysis

The following narratives seek to comprehensively describe the context in which I as a pastoral practitioner exercise my pastoral ministry. They describe the people who live their lives in this socio-politically constituted context. They also serve to articulate my pastoral role and relationships, as well as my reflections upon and analysis of these storied lives. It does both in terms of my understanding of those with whom I engage in pastoral relationship, as well as in regard to critical reflection upon my own responses and behaviours as a pastoral practitioner.

6.2.1 Narrative #1: Communion[551]

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[550] Merleau-Ponty, Maurice. *Phenomenology of Perception*. London: Taylor & Francis Ltd, 2002.

I'd like to describe what amounts to a fairly typical worship scenario on a Holy Communion Sunday at this institution's chapel. 'Typical' is a word to be used advisedly given that some who attend are prone to fairly spontaneous physical and verbal gestures. Furthermore, there are those who attend who are simply not concerned with or cognisant of what your average worshipper may consider normal worship protocols.

So here this morning is Barry who likes to laugh at the most seemingly inopportune moments, such as during the sharing of a concern over a resident who is dying.

There is Angela who offers me a geranium she's pulled up from a large pot placed just outside the entrance to the chapel. She takes pleasure in seeing it placed on the Communion table.

There's Eileen who keeps singing loudly long after the song has finished, provoking Nicole to utter quite loudly, "Oh, shut up." But the singing continues.

There's Mario who may have an anxiety attack at a moment's notice.

There's Janet who needs to be woken in order to receive the communion elements.

There's Rodney, hearing and intellectually impaired, and one of the most committed up-front worshippers in this place.

And there's quiet undemonstrative Howard who sits erect in his wheelchair seemingly oblivious or unconcerned at whatever else may be going on around him.

All such folk and numerous others are present for this service of Holy Communion. The service follows a familiar liturgical form – bright, well-remembered hymns and songs; opportunities to share good news and concerns for those who can verbalise; and descriptive and familiar biblical stories, such as parables. Added to this, there is some laughter and spontaneous feedback. And so we proceed to Holy Communion.

A short, less verbal liturgy is intoned. The bread and cup are raised: the traditional Lord's Prayer is spoken with some who can speak joining in with this familiar prayer. The bread is raised again and broken as the words are uttered,

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[551] Apart from minor alterations, this narrative, and reflection and analysis, represents an extract taken almost verbatim from a self-penned journal article, namely,
Whitney, "Intellectual Disability."

Jesus is the Lamb of God,
who takes away the sin of the world.
Happy are those who are called to his supper.[552]

An invitation to all to receive the elements where they are seated is offered. I hand the chalice of grape juice to my assistant while I take hold of a small plate of wafers. We proceed to the congregation.[553]

The residents wait their turn as familiar hymns and songs are played on the piano. The dipped wafer is placed on the tongue and left to dissolve as the Words of Distribution are uttered.

The body and blood of Christ keep you in eternal life.[554]

Smiles may be shared. A gentle hand on the shoulder is offered. An occasional 'thank you' is mouthed by one who can speak.

A few, for reasons of denominational sensitivity, or because of problems with swallowing, do not receive the elements. Words of inclusion are still offered,

God bless you and keep you always.

With the distribution complete I return to the Communion table and, with arms outstretched, offer the Words of Peace.

The Peace of the Lord be always with you.
... And also with you.[555]

I invite those who are physically able to move to those less able and share with them a personal Word of Peace.

With the noise of this sharing subsiding a final familiar hymn is sung – "Jesus Loves Me." An old, familiar hymn such as this is much loved.

A Benediction is offered with arms stretched wide and those present are invited to say with me if able, at the top of their collective voice, an almighty *Amen!*

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[552] Uniting Church in Australia, Assembly Commission on and Liturgy. *Holy Communion: Three Orders of Service*. Edited by Uniting Church in Australia Assembly Commission on Liturgy, *Uniting Church Worship Services*. (Melbourne: The Joint Board of Christian Education of Australia and New Zealand, 1980), service three, 34.

[553] The method of distribution is *intinction* – soluble wafer dipped in juice and placed on the tongues of those who wish to receive – this being the most accessible form of distribution, especially for those who cannot hold the elements, or chew.

[554] adapted from,
ibid., 35.

[555] ibid., 31.

The service is complete. The pianist continues to play as worship participants are gradually returned to their dining rooms by church and institutional volunteers.

Reflection and Analysis

I reflect on the significance of what has just occurred. I think about the individuals of this community of faith who generally receive the communion elements with much intent and, on occasion, passion, despite most having levels of intellectual impairment that presumably inhibit them from attaching much significance to the more cerebral elements of the liturgy.

And I think to myself …

What of those who are literally deaf to the liturgical words I speak?

What of those who may hear my words as nothing more than an incoherent jumble?

What of those for whom the finely-honed theological sentiment of the communion liturgy is indistinguishable from the script of their favourite daytime soapie?

What of those who, amidst the communion call to eat and drink … *in remembrance of me,* struggle to remember, because their remembrances of people, places, events and key elements of their faith formation, including the actions of Christ in their life, now escape them?[556]

How can I make sense of their keen desire to participate in this sacrament when, for many here, the service seemingly communicates so little at a cerebral level?

What is going on in their being that, despite a lack of intellectual comprehension, still seems to make participation in the communion service a deeply significant component in their faith formation?

I speculate as to what may be going on …

Perhaps it has something to do with the presentation of the visual symbols -- the overt display of bread and juice denoting the presence of the crucified Christ.

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[556] Bryden, Christine. *Dancing with Dementia: My Story of Living Positively with Dementia*. (London & Philadelphia: Jessica Kingsley Publishers, 2005), 40.
From the personal perspective of living, in middle age, with the advancing and debilitating effects of Alzheimer's Disease, the author claims that despite increasing difficulty with memory, she can still understand through insight.

Perhaps there is some unconscious connection that those present make between the broken Christ depicted through the breaking of bread, and their own sense of brokenness -- a sense of being loved and accepted amidst brokenness, just as they are.[557]

Perhaps it's the physical movement that takes place during the distribution of the communion elements. The bread and juice are brought to each member and placed on their tongues, as if the broken Christ is coming to them and being absorbed into their being.[558]

Perhaps it has something to do with receiving these elements in an environment in which, through various visual depictions -- the cross, the banners, the murals -- people have Christ's sacrificial nature reinforced for them in a visual form which may stimulate the senses.[559]

Perhaps it has something to do with sharing in this sacrament with all those around them, thus offering them a sense of strength and solidarity through community, and with it, a sense of belonging to something worthwhile, beyond the institution.

Perhaps the regular celebration of communion speaks to those present of a constancy of love and acceptance amidst a world where their bodies and minds have failed them and where others treat them more as problems than acceptable and loved human beings.

Perhaps the sacrament speaks to them of a God-given value invested in them that is not dependent upon successes or failures of their minds and bodies.

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[557] Hull, John. "The Broken Body in a Broken World: A Contribution to a Christian Doctrine of the Person from a Disabled Point of View." *Journal of Religion, Disability & Health* 7, no. 4 (2003): 5-23.
Here the author asserts that the notion of the broken body of Christ, depicted in the broken bread of Holy Communion, generates a fundamental point of human connection between the Incarnate Jesus -- the Word made flesh -- and those with disability whose embodied human experience encompasses pain and vulnerability.
Moltmann-Wendell, Elisabeth. *I Am My Body*. Translated by John Bowden. (London: SCM Press Ltd, 1994).
Here, the author, from a feminist, theological perspective, affirms the God who, through embodiment, confirms the human, bodily nature. See especially, 103.

[558] Perske, Robert. "The Chaplain's Role in an Institution for the Mentally Retarded." In *The Pastoral Voice of Robert Perske*, edited by William Gaventa and David Coulter, 13-28. (New York: The Haworth Pastoral Press, 2003), 20.
The author, an institutional chaplain, describes the contribution of gesture and body posturing in developing an effective worship experience for people with intellectual disability.

[559] ibid., 18-19.

It may be all these things, or possibly something else altogether simpler, or more profound.

I simply do not know, and I never will. And perhaps if the likes of Barry, Angela, Eileen, Nicole, Mario, Janet, Rodney and Howard could articulate clearly they may not be able to tell me because their experience is beyond words, or too personal. But there are questions I feel compelled to consider.

Does my reliance on the value of words, their power to communicate, inhibit me from appreciating the power of communication through less cerebral forms? Am I thus limited in my capacity to accept the power of ritual action and symbol to speak deeply to one's soul and spirit?

To what extent has my Protestant faith tradition, which highly values the (spoken) Word of God and which historically has sometimes regarded physical symbols as idols, caused me to undermine the ritual means of worship that these people appear to value highly? I have been taught to preach, to convey a message that evokes a rationally-conceived response and outcome. This could well prevent me from valuing the experience of worship through symbol and ritual where meaning and value can be observed to act upon people at a spiritual level completely apart from rationally-preconceived outcomes.

And what of the God who reaches out to and expresses love to these people through the sacrament of communion, who defines worth in terms of unconditional acceptance, not intellectual achievement. Indeed, this sacrament and the God who is worshipped and received through it, define worth not in terms of human aspiration or merit, but in terms of a God who affirms their created value solely and wholly in terms of being made in the image of God.

I also see this sacrament and the nature of its reception, describing a holy God who is not received as proposition or dogma, but who is accepted as mystery, awe, beyond understanding.[560] The people with intellectual impairment who have received this sacrament this day are not concerned with the truths of the sacramental theology espoused through the Communion liturgy. They are here to embrace the import of the sacramental moment and to absorb the moment with the human faculties at their disposal.

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[560] Steere, David. *Spiritual Presence in Psychotherapy: A Guide for Caregivers*. (New York & London: Brunner-Routledge, 1997), 179-183.

Therefore, with their impaired intellectual understanding, the God who is present in this sacramental moment becomes one who is imagined, experienced and sensed more so than understood.

With this in mind Francis speaks of absorbing the meaning of the sacraments through a sense of symbolic knowing.[561] Fowler also contends that, at a more foundational level than our conceptual sense, most of our knowing is shaped by images, symbols and rituals, and that this sense of knowing has a determining effect on faith formation.[562] It is this sense of knowing that engages the person of faith at a greater level of mystery and ambiguity than can be discerned in more rational sacramental forms.

And so God, perhaps more readily than in the wider faith community, is accepted as beyond understanding, a mystery, by these people with whom I have shared the Communion host.

How might such experiences of worship inform my daily pastoral visitations? How much am I prepared to let the pastoral encounter be shaped in non-cerebral forms according to the wants and needs of the one I am with?

How much am I prepared to let the pastoral encounter remain ambiguous or incomprehensible to my pastoral reckoning?

Am I prepared to allow the pastoral encounter to be as imbued with as sacramental a spirit or form as may be perceived as being what the other person wants, and which speaks to their spirit at their point of need, material or spiritual?

Am I prepared to look like ‘Johnny out of step’ in order to be what the other person requires?

Am I prepared to fully let go of my preconceived pastoral outcomes?

How might the grace of the formal sacramental moment take shape in the daily pastoral visitation?

In different ways, all these questions challenge me to risk letting go of more rationally-formulated assumptions and to allow mystery and grace to dictate the pastoral agenda. They invite me to take the risk of both being, and appearing to be, different, perhaps foolish, within the context of my fellow professionals,

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[561] Francis, M. "Celebrating the Sacraments with Those with Developmental Disabilities: Sacramental/ Liturgical Reflections." In *Developmental Disabilities and Sacramental Access: New Paradigms for Sacramental Encounters*, edited by E Foley, 73-93. (Collegeville: The Liturgical Press, 1994).

[562] Fowler, James. *Stages of Faith: The Psychology of Human Development and the Quest for Meaning*. (San Francisco: HarperCollins Publishers, 1981).

medical and managerial, who understand professionalism as signifying the primacy of relating to residents more rationally.

As such, am I prepared to allow myself to be liberated from rationally-conceived notions of professionalism and collegial acceptance for the sake of being in solidarity with those with whom I am committed to offer care?

6.2.2 Narrative #2: Cross

On various Good Friday services, following the proclamation of Jesus' death, a colleague of mine and I have each taken a simple wooden cross to the individual members of the assembled number, most of whom live with an intellectual impairment, who have gathered in this institution's chapel. The action of taking the wooden crosses to each member of the congregation is to reinforce, if not by understanding, then by impression, Jesus' death. While there are those who offer little observable response to this action there have been reactions that have been very emotional and spontaneous.

Such as the one who just gently runs her fingers down the length of the cross in a quite sensual manner.

The one who holds the stem quite firmly for a while, looking at it with much intent.

The one whose permanently-clenched fingers struggle to take hold of the cross but who, with assistance, perseveres till it is within his grasp.

The one who takes hold of the cross and kisses it, as if kissing the body of Christ.

The one who grasps hold firmly of the figure, staring, then audibly sighing.

There are those elsewhere who have wheeled themselves to a configuration of the cross enmeshed with wire, who upon invitation, have, with much concentration, woven a long-stemmed flower into the frame, adding colour to the lifeless symbol.

And there are those without speech who, beyond the Easter season, may make a sign of the cross in the air, or point to the ceiling, symbolising heaven, or who may point to a scene from Christ's passion on a mural.

Reflection and Analysis

These are highly physical, emotional responses that move me deeply. They show a depth of faith and devotion that often shatters my expectations.

They are responses that challenge me because they are unplanned, or exceed my expectations. They take the worship in unforeseen directions. They invite me to ask, where is this service going? I am being challenged to take risks, to allow the worshippers to take hold of this worship, as some have insisted on taking hold of the crosses, and for me to let go. It means taking the risk of losing control and placing control in the hands of those who receive the wooden cross, the crucified Christ, the worship moment, with so much intent and passion. It means allowing the worship to become messy and I don't like mess. It means allowing God to speak to the hearts of these people through ritual and symbol in ways beyond my understanding and conceptualisation.

These people invite me to not only see worship in such an uncontained form, but to accept and respond to them pastorally in their daily living in ways that engage their faculties beyond just the rational. They challenge me to take the risk of losing control of the pastoral agenda and let the spirit in them reign.

They challenge me to regard the daily pastoral encounter as sacramental, mysterious, holy, risky and uncontained. They challenge me to be liberated as I seek liberation for them. They renew my consideration of the power of the cross to speak of liberation for all those present.[563] They invite me to bring symbol and ritual, religious or secular, to the pastoral encounter, whatever it is that engages with their spirit, their soul, their faith.

They invite me to let the pastoral encounter become messy, to move spontaneously in unplanned directions, at the behest of the one I am with. They invite me to consider pastoral care as that which can be conceived and expressed through all of my being and theirs. It can include expression through every fibre of their physical, sexual, emotional and mental being, and mine. It might involve pastoral boundaries being challenged. The path to liberation can be risky and messy.

6.2.3 Narrative #3: Normal

It's insightful listening to residents who have lived in the institution for many years, some since childhood. They've seen so much, experienced so much about which Johnny-come-latelies such as I have no idea. It's like I can see the tip, but they, through their long-held remembrances, reveal the extent of the

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[563] Moede, Gerald. "My Power Is Made Perfect in Weakness." Paper presented at the Symposium on Theology and Persons with Handicapping Conditions, Boston, 1981.

iceberg below. Their clearly-articulated memories enable me to understand their identity as so much more than that revealed through medical discourse. They help the person concerned to deepen and historicise their sense of identity. [564]

And so there's Bill who talks of his days as a youth when he worked on the farm. He remembers being called 'stupid' for not understanding an instruction. We're talking 50 years ago and, despite his age, he still clearly remembers.

There's John who remembers a friend being smacked for being 'lazy' when he was meant to be working.

There's Mary who has a keen memory for details of her younger life here but who is silent when it comes to details of family members, those deceased and those still alive. I am left wondering as to what is contained in that silence. Neglect? Indifference? Embarrassment?

There's Jimmy who never gets invited to family weddings or funerals. Sometimes he doesn't hear till it's over. Family excuses are offered. I wonder as to how exclusion from such significant life rituals can be justified if human worth is to be upheld.

Reflection and Analysis

As I listen to these people what strikes me with force is the institutionalised sense of normality with which such people speak. Often the stories are not told with bitterness about the labels applied to them; they don't get angry at the family rituals they've missed; and they don't question the absence of usual family relationships with staff members who've become akin to surrogate family. They just speak as if that's the way life is.

But these stories are raw for anyone who listens with honest ear. These are not the stories of a sugar-coated institutional narrative. This is harsh, wounding stuff. And like many wounds it needs to see the light of day.

The other detail that captures my attention is that sometimes these stories are told with considerable clarity and detail. Although the storytellers may speak with impaired cognition some stories are clearly articulated. People, places and

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[564] Hammond, Gaynor. "Rediscovering the Person through Shared Memories." In *Between Remembering and Forgetting: The Spiritual Dimensions of Dementia*, edited by James Woodward, 59-63. (London & NewYork: Mowbray), 2010.

impactful behaviours can be well remembered. These stories really mean something to the storytellers.

Following the telling of a story, the conversation may continue around seemingly more mundane matters but with little alteration in tone of voice or emotional content. Physical abuse appears to be regarded in a similar light to routine matters. It's all normal.

For a number of these institutionalised people who have lived here since childhood, they came to know and experience no other way of human behaviour and, since those days, they seemingly haven't had such behaviours challenged. For much of their lives, the institution alone has been their sole frame-of-reference in terms of relationships, rituals and behaviours. Therefore,

... it's normal to be hit by a staff member.
... it's normal to be called 'stupid'.
... it's normal to not be invited to family funerals and weddings, and
... it's normal to have someone only relate to you because they're paid to do so.

Normal as in … OK
… the way life is
… acceptable.

And who is present to challenge that sense of normality, both that with past and present frames-of-reference?

I speak of past and present abuse, neglect and standardised institutionalised routine, to make the point that despite changing times, evolving institutional and wider community philosophies and values, oppression, in various guises, has been and continues to be imposed upon people with intellectual disability who live in institutions.[565] Whether it's past physical abuse,

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[565] Tumeinski, Marc. "Adopting a Personalist Response within Impersonal Service Structures." Paper presented at the Many Faces of Abuse conference, Auckland, New Zealand , 2005.
Here, the author describes institutional abuse in the health care service delivery sector emanating from bureaucratisation, the prioritisation of systemic values, and an inequity of power between senior management and service workers.
Regarding institutional modes of abuse, see also,
McKnight, *The Careless Society,* and,
Wolfensberger, Wolf. *A Brief Introduction to Social Role Valorisation as a High-Order Concept for Structuring Human Services*. (Syracuse: Syracuse University, 1991).

or the present day imposition of client-based medicalised routines,[566] oppression still happens. Many, although not all, of those paid to work in this context are fulfilling medical, managerial or other paid roles, doing so with a pathologised view of service towards the needful, dependent other.[567] If such caring roles assume an overwhelming priority over all other care modes then we see oppression.

It's possible to justify the use of physical abuse in the treatment of people with intellectual disability living in institutions, just as it's possible to justify the primacy of medicalised and managerially-imposed routines. Both practices can be regarded as emerging from institutional philosophies and wider social values commensurate with their times. However, this doesn't justify that which can be observed to be an oppressively normal practice. Normal can be morally and socially wrong. Such forms of normality need to be understood and articulated as wrong.

As a pastoral carer how do I best challenge past and present oppressive behaviours dressed up as normality? How do I best engage with these people in a way that can be regarded as liberating, as opposed to abusive, threatening, neglectful and overpowering?

Normal ought not be automatically equated with acceptable or right. As Hauerwas states,

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[566] For a practical, contemporary description of this institutional and deficit-based model of care, see
Whitney, "Intellectual Disability," 254-256.
See also,
McKnight, *The Careless Society*.
Here the author is concerned with the medicalisation of relationships within the institutional environment which see those termed as clients, and as deficient, dependent persons, relying upon professional expertise for their requisite and constant medical care.

[567] There is a significant body of contemporary literature that links oppression, in terms of human regard and institutional practice, to regard for the person with a disability as the other who is to be feared or disregarded on the basis of otherness. See,
Clapton, Disability and Moral Constructions.
Newell, C. (2002). "Remembering and Memorialising Disability." Interaction **16**(1): 31-32.
Newell, Christopher. "Embracing Life: Ethical Challenges in Disability and Biotechnology"." *Interaction* 16, no. 2 (2003): 25-33.
Schmidt, "Power as Theological Problem."
Swinton, Resurrecting the Person.
For an historical perspective on this issue see,
Foucault, Madness and Civilization.
Porter, A Social History of Madness.
Roets, Griet, and Geert Van Hove. "The Story of Belle, Minnie, Louise and the Sovjets: Throwing Light on the Dark Side of an Institution." *Disability & Society* 18, no. 5 (2003): 599-624.

> ... to raise the question of the criteria of the human is not first an empirical question, but a conceptual-moral claim about how the nature of man (sic) should be understood. We wrongly assume that what our eyes perceive to be 'normal' is what we should morally understand men to be qua human. The presence of the retarded helps us feel the oddness and the problematic nature of this assumption and its attendant ethical implications.[568]

That being so, then what of those who suffered such abuse, both those still living and those who have died? What of those who witnessed such abuse and who can still describe it in detail, despite their impaired intellectual capacity? It is a pastoral perspective that says that past sins, whether they concern physical abuse, indifference or neglect, or contemporary transgressions concerning disempowerment, must be acknowledged. But beyond mere acknowledgement, where entrenched institutional sin has been committed, repentance by the perpetrators, or those representing the perpetrators, needs to be expressed.

The word 'sorry' needs to be uttered with intent. Part of that apology requires the institution to own up to its past and acknowledge its contribution to the hurt caused, articulating an institutional history that includes successes and failures, rights and wrongs. This implies the acknowledgment that normal was and is sometimes very wrong.

Institutional silence over such issues serves to suppress narratives of oppression that are a part of the fabric of the place, threads to be revealed, not hidden. The very act of silencing is oppressive. Institutional silence ought to be broken even if the stories that fill the silence cause considerable discomfort. It ought to be broken even if it reveals threads of ugly hue. It's to do with acknowledging the reality of the past in order to move forward with integrity. It's to do with naming the darkness and seeking the light.

6.2.4 Narrative #4: Invisible

I'm sitting with Graham on a sofa in the general living area. He is in his 60s but could pass for a few years younger. He has a significant intellectual impairment but it doesn't hamper his capacity to engage generously with those who pass his way. He loves to talk, especially about what he's done since I last saw him. It's all about family visits, outings and the footy, and a bit of gentle

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[568] Hauerwas, Stanley. "The Retarded and the Criteria for the Human." In *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology*, edited by John Swinton, 127-34. (New York: The Haworth Pastoral Press, 1977), 130.

‘goss’ about staff, usually offered with an impish smirk. He’s fun, engaging, good for a laugh. Staff like him. I like him.

Across from Graham on his sofa is Alice in her recliner chair. Alice is a frail, small woman living with Down Syndrome. She’s in her 50s but could pass for her 70s. Although I’m told she used to talk a little, she always was and is more so now, a very retiring lady. Time with her may well be spent in silence.

I visit Alice’s living area about once a week and she is almost always there in her recliner by the window. She seems to almost withdraw into her chair, enveloped by its arms, overshadowed by the headrest that lies above her head. Her toes barely touch the ground even with the chair in an upright position.

Staff rarely pay attention to Alice except to dress, feed, toilet and put her to bed at the end of the day. In all the years I’ve been here I’ve rarely seen anyone engage her in conversation beyond that required.

Whilst listening to Graham prattle on about his upcoming birthday and the expected celebration I see two therapists enter the living area. They approach one of the attendant carers and indicate that they need to see Alice for her weekly therapy. The carer approaches her and, yes, does actually talk to her, but only to say,

“Come on Alice, up you get.”

The therapists approach little Alice and escort her towards her room, one on each side of her. Alice is silently compliant, somewhat hunched and dwarfed.

The therapists talk to each other over the top of Alice’s head. They keep talking seriously until they disappear with their client into her room. And not a word is spoken to Alice.

As I said, most people like Graham. He offers colourful conversation, humour, an outgoing personality. He gives as much as he takes. But Alice seems invisible.

Reflection and Analysis

As I reflect upon Alice and her circumstances, I must begin by confessing that there are times when I have passed Alice by for the more engaging individuals who live in her accommodation area. Why is this so?

Most obviously it’s because the likes of Graham are more fun to be with. They make me laugh and there are times when working in this institution leaves me searching for a laugh. They are much more overt than Alice in communicating to me their cares and concerns, that is, telling me or showing me what they're thinking or feeling. Alice's withdrawn visage rarely changes at all and, as she can no longer talk, I find it much harder to discern her thoughts and feelings. Put simply, Alice is hard work.

There is also a sense in which it is safer to talk to Graham than Alice. By not talking to Alice I'm falling into line with the numerous staff who relate to Graham on the basis of his likeability.[569] Graham puts a smile on people's faces. In electoral terms, Graham is a popular vote. In contrast, few people vote for Alice as evidenced by her aloneness and apparent invisibility.[570] Hers is an invisibility understood in its literal sense, as well as in terms of a complete disregard, lack of understanding or antipathy towards those deeper values, thoughts and feelings that are not readily identified.[571] If I choose to spend time with her I'm choosing to stand out from the crowd, and there's a part of me that

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[569] This relates to the concept of the *attraction paradigm* whereby people are attracted, either consciously or subconsciously, to those who offer them an affective stimulus, generating positive regard for the other person. In the instance of Graham, his generally cheerful personality, and capacity to cause staff to smile or laugh, create a sense of positive regard towards him. See,

Byrne, Donn. *The Attraction Paradigm*. (New York: Academic Press, 1971), 371, 415.

Conversely, this notion of attraction can generate a dislike of those who foil attempts at getting desired rewards. See,

Berscheid, Ellen, and Elaine Walster. *Interpersonal Attraction*. Edited by Charles Kiesler, *Topics in Social Psychology*. (Reading: Addison-Wesley Publishing Company, 1969), 92.

Arguably then it can be suggested that the likes of Alice, through her vulnerability and frailty, create a dislike or disregard from others because, at the level of interpersonal relationship, she is observed as being unable to offer desirable interpersonal rewards.

[570] Block, Jennie. *Copious Hosting*. (New York and London: Continuum, 2002), 52.

The author speaks of people with a disability as being invisible, "as if they are not present, as if they do not exist."

Valle, Jan, and David Connor. *Rethinking Disability: A Disability Studies Approach to Inclusive Practices*. Edited by Alfred Posamentier, *The Practical Guide Series*. (New York: McGraw Hill, 2011).

The authors describe invisibility from historical and contemporary medical perspectives.

Lecomte, Jocelin, and Celine Mercier. "The Emergence of the Human Rights of Persons with Intellectual Disabilities in International Law: The Cases of the Montreal Declaration on Intellectual Disabilities and the United Nations Convention on the Rights of Persons with Disabilities." In *Challenges to the Human Rights of People with Intellectual Disabilities*, edited by Frances Owen and Dorothy Griffiths, 43-75. (London and Philadelphia: Jessica Kingsley Publishers, 2009).

Here, people with an intellectual disability, within the struggle for human rights in recent decades, are regarded as being denied rights because of their "invisible disability," 43-44.

[571] Killick, John. "Learning Love from People with Dementia." In *Between Remembering and Forgetting: The Spiritual Dimensions of Dementia*, edited by James Woodward, 52-58. (London & New York: Mowbray, 2010), 56.

Here, the author autobiographically recalls observing an elderly person with dementia in a nursing home who was identified by staff as " ... the happiest soul on the unit" because of the happy songs she was heard to sing. A more personal engagement with her gleaned the understanding that the songs were concerned with a sense of spiritual release to be found in death.

prefers to acquiesce with others rather than sit with Alice and risk people wondering why I'm apparently wasting my time.

I also wonder if I pass her by because there are aspects of Alice's frail vulnerable self that reflect my own frailty and vulnerability. Perhaps she puts my own mortality into such sharp relief that I rather spontaneously react by passing her by, thus avoiding seeing frail vulnerable Alice in me. It is a reminder of the role of pastoral carer as that of Wounded Healer, engaging in a shared pastoral relationship with the frail vulnerable other out of a recognition of one's own wounded identity.[572] It raises the issue as to my readiness to embrace my wounded self if I choose to embrace Alice. It means overcoming the fear aroused in me when confronting my own mortality.

But the outlined reasons for passing Alice by are palpably inadequate. They only reinforce the lack of human identity and worth she experiences from most who live or work in close proximity to her. This is exemplified by the therapists who talk over the top of her as if she was non-existent. It only compounds the lack of love and relationship she seems to experience.

When I do stop and sit with her I usually find myself saying only a little, often in terms of what is going on around her at that moment, or describing what can be seen in the garden close to where she sits. But I often find myself just sitting with her in prolonged silence looking into her face or looking with her out the window, trying to get a feel for her mood and level of comfort. When I can't easily discern what she may be feeling or thinking I try to reassure myself of the value of simply being present with her. I try to remain hopeful of communicating to her at some level of her being that her human worth is such that it is worth my time to spend time with her.

From a pastoral theological perspective I understand that God values those created in God's image on the basis of their being rather than anything they do. God's love is not won through achievement or through the magnetism of an attractive personality. It is simply offered on the basis of their God-given status. So 'being with' affirms the God-given value of the other.

I dearly hope that somehow Alice does feel valued through me or someone else taking the time to sit and be with her. However, I can't be sure. It

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[572] Nouwen, The Wounded Healer.

might be that she has become so accustomed to being ignored and only being attended to when there is a required therapy that she feels threatened by those who come close to her. Perhaps she feels I'm invading her personal space. I can't be sure.

And whilst there are those who live in this place whom I admire for their resilience, including Graham, when I look at the likes of Alice I see someone who, to my pastoral eye, shrivels up in her over-sized chair. She seems to be giving up on living and completely acquiescing to institutional relationships and requirements. And that makes me very sad because her life should be observed to mean a whole lot more than it does.

Alice has lived for so long here and when she dies this institution won't miss a beat. Except for the odd caring individual, she will be quickly forgotten. Following her funeral which too few will attend, her room will be quickly cleared and within perhaps a week a new person will be sleeping in her bed. That's the crushing oppressive and business-oriented nature of institutional routine. It sucks human value and worth from those for whom they purport to care, both in life and death.

How can the likes of Alice be more fully nurtured amidst her oppressive circumstances? How can I more fully offer a measure of liberation to her? How can I most authentically represent the love of God to her?

Alice deserves so much more.

6.2.5 Narrative #5: Names

I approach an administration suite of offices as an institutional executive manager and a manager are engaged in earnest conversation. Brief courtesies are exchanged between the executive manager and I. Sally approaches in her manual wheelchair. She recognises the executive manager and tries to tell him something that sounds important but she can only communicate verbally through groans.

"I'm sorry, I'm not sure what you're saying," says the executive manager to Sally with a somewhat benign tone to his voice.

Sally groans with some feeling. But the executive manager does not reply.

Sally mutters words to anyone around and to no one in particular, but gets no answer.

Disgruntled, Sally slowly moves on.

The administrators and I remain.

The executive manager says to the manager, “I wonder what that lady wanted.”

“Don’t know.”

I go on my way towards the café and the executive manager and manager head to the car park.

Reflection and Analysis

I wonder about the term *that lady*.

Sally has been living in this institution since the mid-1980s; the executive manager has worked here since the mid-1990s. The executive manager has his office only about 100 metres from Sally’s accommodation area. I wonder why it is that in the several years they have both shared in life here, not too far apart, Sally can remain so unfamiliar to this executive manager.

It’s not even as if Sally is anti-social. She joins in activities, can often be seen looking for people with whom she can talk. She’s no shrinking violet. And yet, whilst I know some administrators who may stop and talk to the people who live here, this executive manager not only does not know her name but also appears to know nothing of her. How can that be?

I don’t pretend to be above criticism when it comes to knowing or not knowing my neighbour. I’ve lived in my present house since 2001 and I barely know my neighbours, apart from the occasional “How ya goin?” and a brief conversation about rainwater tanks along fence lines.

But a part of me thinks, perhaps naively, that if not for friendship, at least in terms of effective decision-making, there would be merit in the executive manager learning the names of those who live here, as well as something about them. The lack of enthusiasm to discover what was concerning Sally suggests that the priorities of the executive staff lay elsewhere. The staff are employed to fulfil administrative roles that don’t specifically require personal liaison with or knowledge of accommodated people that denotes a measure of interpersonal identification.

Despite their spatial proximity to each other these staff and Sally are strangers to each other. The very term *that lady* suggests a remoteness from the other.

Speaking from the perspective of ethnic enmity Volf claims that we exclude others because we are uncomfortable with those we construct as strangers. They put us uncomfortably in touch with the strangeness within ourselves. “Others become scapegoats, concocted from our own shadows as repositories for our sins and weaknesses so we can relish the illusion of our sinlessness and strength.”[573] Thus, it can be argued that the staff may be excluding Sally because through her vulnerability and frailty she challenges the illusion of their human infallibility.

Social historian Susan Schweik speaks of identity as relational and of how forms of publicly-constructed group identities of people based on control and regulation can lead to victimhood and social exclusion.[574] It can well be argued that the exercising of detached institutional relationship with those for whom the institution bears responsibility, as well as regulations designed for mass control, serve to victimise and exclude the likes of Sally from the possibility of mutually-enriching and respectful relationship that can begin with the acknowledgement of a person’s name.

This simple incident provokes issues for me. It speaks of the worth that is afforded us when someone can actually call us by name. Conversely, it offers a glimpse into what it is like to not be known by those who occupy a space close to you and how that serves to describe the nature of the space into which you and the other are engaged in relationship. It thus points to the sense of relationship or disconnection between people as defined by those who manage that lived context.

As a pastoral carer I am challenged as to the nature of the relationships I seek to develop and maintain. I need to bridge the disconnections that exist between staff and those for whom the institution bears responsibility. However, I must also seek to build pastoral relationships that have full regard for them as whole human beings, offering a measure of liberation from the impersonal and regulatory nature of institutional routine.

I must also look to myself and address the issue concerning what more I could have done amidst the immediacy of the situation I’ve described. How could I have shown identification with and care for Sally? How could I have best responded to her need to be known and have her concerns met during that brief, shared moment? As Christ shows identification with the poor amidst the

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[573] Volf, Exclusion and Embrace,78.

[574] Schweik, The Ugly Laws, 290.

oppression they experience, how should I best show identification with the institutionally oppressed?

Amidst her anonymity and groans, how could I assist Sally to best be known as a human being of equal regard to all?

6.2.6 Narrative #6: Orchestration

When I visit this institution’s craft area I regularly find myself sitting next to Malcolm. I would estimate him to be in his late 40s although he looks older because of the ageing effects of Down Syndrome. He is living with the early effects of dementia, a familiar characteristic for someone living with his syndrome and of his age.

Malcolm dresses neatly in comfortable clothing. He carries himself in a gentle, dignified manner. He has a calm facial appearance and any physical movements are performed at a measured relaxed pace.

Although he works in close physical proximity to various other craft workers, and although those others seem quite comfortable with his company, Malcolm keeps largely to himself. He just seems happy being in his own space not far from others. I can’t say how he feels about those around him but at the very least he appears comfortable with the overall environment.

He gets on with his weaving whilst those around him keep up a steady banter of chat. He can’t communicate verbally. He may occasionally offer a small non-verbal acknowledgement of something you say, such as a brief smile. However, for the most part, he seems comfortable with his own silence and company.

He just gets on with his weaving at a slow steady pace operating on the basis of what seems to be a clearly-proscribed and regular internalised rhythm. And each time I visit the craft area I see silent Malcolm weaving away according to that sense of pace.

When I sit next to him he seems happy for me to be there. I ask him if he could slowly demonstrate his weaving technique so that I might learn how to do what he is doing. He is happy to oblige allowing me a chance to practise on his loom. He seems to trust me, or is just not cognisant or caring of my foibles.

I leave him, thankful that through his quiet gentle manner he has reminded me of the beauty of taking life at a calmer, slower pace. But I also briefly reflect on the sense in which Malcolm seems to live such a contained life.

He seems contained by the nature of his intellectual disability, as well as by the institutional practices and routines to which he has been subjected over many years. For he has experienced an institutionalism that primarily regards him and relates to him as a client, as one who is there to be served as a result of his impairment. He has experienced an institutionalisation that has severely restricted his interaction with the outside world and has limited his possibilities for a diversity of human relationships and nurturing experiences.

But now it is another day and Malcolm, along with a number of others, is attending a concert being put on by a local concert band. From a distance, I see silent Malcolm come and sit down in the middle of the institution’s hall, a large, fairly cavernous space with a few wall hangings, dirty carpet and minimal furnishings.

Despite the hustle and bustle of the assembling throng, Malcolm, in his own gentle way, quietly observes the band assemble. The band members find their seats and start to warm up their instruments. The trumpeters start blowing some random notes, the flautist plays a few scales, and the drummer bangs his drums. And Malcolm suddenly comes alive.

Amidst these sets of discordant notes Malcolm has sprung to his feet and he’s conducting the band like an impassioned maestro. Others around him are still settling down, chattering away, but Malcolm is there with imaginary baton in hand enthusiastically orchestrating the sounds of the unaware band members. It’s as if he’s bringing Handel’s “Hallelujah Chorus” to its tumultuous conclusion.

And I’m wondering what he’s going to be like when the real music gets underway. But it seems that Malcolm has heard the real music long before the rest of us. He’s hearing sounds that bring him to his feet, beg his rapturous gesticulations, inspire his passions.

The concert commences and Malcolm spends much of it continuing to conduct observing the varying tempos of the different tunes. All tunes, whether contemporary or classical, are embraced with fervour and joy.

The band proceeds for 45 minutes through its set of tunes before the program is brought to a bright conclusion with a familiar number. The band is greeted with applause as they have been for each number they’ve played. And with the conclusion of the last number, with the music over, Malcolm sits and resumes his silent posture whilst waiting to be escorted out of the hall and back to his accommodation area. The baton has been put away for the maestro has completed his performance. The quieter slower rhythm of his days resumes.

Reflection and Analysis

I think to myself WOW! I wasn't expecting this from Malcolm, this quiet gentle man who I pigeonholed as being seemingly limited to living his life in a very quiet undemonstrative manner. I realize that I've so misjudged him, unwilling to acknowledge his capacity to express himself with passion and creativity, limiting him to the slow quiet tempo of his weaving. And yet all along he was just a trumpet note and drum beat away from ecstasy. As long as the band played Malcolm was never going to be contained by dullness of routine or by my or anyone else's perceptions of his capacities.

As a pastoral carer I reflect on how this experience might affect the way I relate to Malcolm next time I catch up with him at his weaving. I suspect that the changes will be in me and not in Malcolm. I will regard him from a more whole perspective than previously. He is content to be who he is.

Perhaps I will see him as less contained by his environment than previously, along with others who seem to spend so much of their time acquiescing to institutional routine and regimen.

Perhaps I will be more willing and able to see a God-given spirit waiting for release, and a God that sits with him in his quiet times and rejoices with him in his moments of ecstasy.

I am also reminded that pastoral relationship is so rich when there is room for spontaneity and surprise, [575] when unplanned behaviours bring great joy, even laughter,[576] for the other person and for me. Moments of resurrection can be found in unlikely places. Amen to that.

6.2.7 Narrative #7: Creations

Christopher sits in his wheelchair by the window of the busy and airy activity room which is adorned with examples of artwork around the walls. Recreational staff come and go attending to the needs of various people -- helping with activities, making cups of tea, attending to administrative detail, making phone calls concerning an absent individual, assisting an unsettled soul, or attending to someone's toileting demands.

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[575] Pattison, "Some Objections to Aims and Objectives," 101.

[576] Pattison, *A Critique of Pastoral Care*, 170-190.

Christopher has a significant level of intellectual impairment. He would be about 50 and has lived about 25 years in this place. He can utter a few words, has a hearty, deep-throated laugh, and will sometimes peer at you through enquiring eyes. However, it would be fair to say that his verbal and non-verbal communication skills are confined to a limited array of responses. At least that is how he has presented himself to me over much of the time I have known him.

He dresses for comfort more than style -- jeans, tank tops and old sneakers. His priorities seem to lie elsewhere. His hair is thin, greying and straggly. To my eye Christopher's visual appearance is of someone who has grown into the role of the struggling artist.

Numerous other accommodated people have come to this room with Christopher to participate in the social activities on offer. Some are pondering jigsaws. Others are browsing through lifestyle magazines, while a couple of others are intent on separating strands of wool into colour groupings. But for Christopher it's all about the drawings.

While Christopher sometimes joins in with group activities, today, as often happens, he sits to one side preoccupied with his drawing. He proceeds to draw with considerable concentration. Despite a loud moment of panic and commotion from neighbouring Emily as she discovers that she's busting to go to the toilet, he continues his creative endeavours unabated, until the work is done. Then he will quite quickly set in place another piece of paper, check the sharpness of his pencils, and proceed with his next work of art.

Reflection and Analysis

Ever since I have known him Christopher has loved occupying his waking moments with drawing. Many of the people who live in this institution are to be found occupied in drawing. For many this involves having a child's colouring-in book placed in front of them along with a bunch of pencils or crayons. Whilst I can't be certain as to how stimulating the people in question find this activity, to my mind it takes on the appearance of staff-initiated babysitting.[577] But for Christopher drawing seems to be more of a self-initiated creative pursuit. When

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[577] It serves a similar purpose as to when residents are placed in front of afternoon television programs such as 'Judge Judy', 'The Bold and the Beautiful' and 'Days of our Lives'. It keeps people distracted while staff continue with other activities uninterrupted.

he isn’t engaged in another required activity, such as meal times or group recreation, he is often to be found assiduously involved in his drawing.

Christopher puts much careful consideration into the design and execution of his pictures. He carefully lays out the pencils he wishes to use and makes sure that a staff member has sharpened them all prior to beginning work. If you seek to engage him for a few moments of his time, you can easily find yourself helping him with his art in some way. You may be asked to sharpen oft-used pencils. You may be called on to secure his drawing paper to the board upon which he works. You may be required to pick up a pencil that he has inadvertently dropped to the floor. Generally he is grateful for your assistance, offering a laconic thumbs-up with a half-smile, or a “Good onya.” But he’s also quite happy to work away at his art on his own. For Christopher, art is an individually-absorbing exercise.

As with indigenous dot painting there is a distinctive geometric style to his work. He draws people as stick figures, usually solitary. The basis for his drawings is straight and curved lines usually of an umbrella shape. Whilst he will do some shading of space he will cover much spare space with star shapes or triangles. His work will not be complete until he has covered the entire sheet with his range of geometric shapes. The final result is, to my eye, abstract in nature, with an emphasis more on form and impression than understanding.

He works with a considerable degree of concentration. An art session may involve the completion of several A4-sized drawings over the one-hour duration.

Christopher works to a short and longer-term plan. Each drawing session seems to provide a sense of meaning and structure to that day but, given that he has pursued this art with considerable intent for many years, with no sign of abatement, it would seem that his art provides a meaning and structure to his life in this institution.

For Christopher, this is no randomly-selected activity generated to stave off the boredom of his institutional routine. There is a concerted well-considered plan and sustaining sense of meaning that he derives from this activity.

I cannot pretend to understand the significance of this activity for Christopher. Perhaps, as TeSelle suggests of the poem or autobiography, such a creative pursuit helps him describe the otherwise inexpressible.[578] Perhaps his commitment shows that he has found his own way of deriving meaning and purpose within the environment in which he lives. It's a task that gives rhythm and pace to his day, perhaps a little like a religious mantra, the repetition of the rosary.

And I think of Etty Hillesum who scrupulously diarised and monitored her thoughts and feelings amidst the chaos and ever-growing oppression of life under Nazi tyranny during World War II, both in her local Dutch community and in a concentration camp. She maintained correspondence with the outside world up to and including the moments when she was placed in a carriage with countless other Jews also destined for Auschwitz. Her writings brought inner order to her outer world.[579]

And although he lives in less dramatic and life-threatening circumstances, I see Christopher, in a creative way from behind institutional walls, applying his artistic resources to the task of maintaining rhythm and meaning in an environment where personal relationships for him are largely defined on the basis of his perceived physical and intellectual deficiencies. Perhaps it's a form of diarising for someone whose cognitive limitations inhibit the use of carefully transcribed words but permit the use of colour, shape and impression.

In the ongoing pursuit of his art, in the sense in which his art takes him into a creative place, away from institutional routine and regimen, away from embodied pain, Christopher is not contained. He is free.

As such, perhaps I can do nothing better in my pastoral moments with him than enthusiastically sharpen his pencils.

6.2.8 Narrative #8: Privacy

I sit with Madge in her small room, about three metres by five metres. She has invited me there for one of our regular conversations.

Madge is one of the more aware, articulate and less intellectually-impaired people of this institution. She is in her 70s and has lived in this place for over 50 years. She dresses well -- neat printed frocks, soft 'cardies', perhaps a necklace suggesting personal pride and dignity. To me she presents a

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[578] TeSelle, *Speaking in Parables*, 24.

[579] Hillesum, Etty. *An Interrupted Life: The Diaries and Letters of Etty Hillesum 1941-43*. Edited by Arnold Pomerans. (London: Persephone Books Ltd, 1999).

grandmotherly visage. She talks in a kindly, somewhat world-weary way. She always enquires about my children, offering gentle but firmly-held grandmotherly wisdom.

“Make sure they eat their vegetables. They should always eat their vegetables.”

“Indeed they should, Madge.”

Of herself, she likes to talk about familiar themes -- her childhood by the sea, picnics in the park, trips to the pictures, cats and dogs -- hers or the neighbours -- and her beloved Nana. They are childhood, filial, domestic themes. They’re pre-institutional themes and memories she seems to embrace like a well-worn, much-loved security blanket. Today as usual Madge has returned with clarity to that fondly-remembered era.

“Oh, Bobby was so cuddly. You’d wake up in the morning and he’d be there licking my hand. He was such a good puppy.”

“Oh I’m sorry. I didn’t know you had a visitor, Madge. I just need to put your towels back in your bathroom. Won’t be a minute.”

“OK love,” says Madge. And the carer hastily attends to her chore and leaves. Madge seems to accept this behaviour as normal.

A little later the visit ends with Madge’s perennial benediction, “Give my love to your family.” I leave, feeling annoyed.

Reflection and Analysis

Madge’s total private physical space consists of this one small room with an adjoining bathroom. In her room are displayed her entire range of worldly possessions. Hanging on the wall are various pictures of dogs. On her dresser is a picture of her brother, recently deceased, along with a few china ornaments, family hand-me-downs. Covering her bed is a hand-knitted blanket, quite brightly designed. At the top of her bed is a big teddy bear, the kind you might win in sideshow alley. On her bedside cupboard is a small photo album with pictures from recent outings.

It’s a simple neat room with simple belongings which Madge should claim as hers. And yet a carer can enter unannounced into this private space with a clichéd apology that does not prevent her from immediately fulfilling her required task.

“I didn’t know you had a visitor.”

Does it matter whether Madge had a visitor or not? Private space should be private space.

And I reflect on how I value my home as my sanctuary. What if someone, apart from one of my family, should enter my sanctuary unannounced. How would I feel? Certainly affronted, and perhaps scared, because it may well be a thief seeking to transgress my sanctuary and that which it contains.

And while it is well-intentioned and only ‘doing her job,’ the carer’s unannounced entry into Madge’s room feels like theft to me, for something of Madge’s claim to privacy has been stolen.[580] Not only has the peace and quietness of her room been transgressed, but her childhood memories, still richly and fondly remembered despite the onset of dementia, have been stolen from this quiet pastoral moment by the mundane need to return laundry.

It is in private spaces that Madge and all the others who live in this institution can claim a place where they can quietly remember, talk with others or to themselves, listen to music, sing, watch television, look out their window into the garden, or anything else they choose to do. It is in such private moments that a person can reaffirm or grow an identity that is not specifically shaped by institutional regimen or requirements. If staff feel so beholden to their institutionally-derived responsibilities that they have to interrupt such moments then something of an accommodated person’s identity is supplanted by the supposed higher priority of the business of being an institution. The freedom afforded by a respect for privacy is suppressed by the necessary continuance of institutional routine.

What can I do to uphold Madge’s identity fostered in the privacy of her room? Perhaps I should tell the ward assistant to come back later, advocating to the institution for the upholding of Madge’s identity. But it shouldn’t be necessary. We all need privacy. Whether it’s the backyard shed, the weekend shack, our study, or that sunset down at the beach, we accept it is as our

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[580] The fundamental right to privacy and the incapacity of institutions to ensure such a right is noted in Wolfensberger, *Normalization*, e.g. 66, 73.
The difficulty of contractually ensuring quality of life issues, such as privacy, in a service user environment, is highlighted in,
Cambridge, Paul. "Becoming Contractual: The Development of Contract and Social Care Markets in England." In *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, edited by Kelly Johnson and Rannveig Traustadottir, 240-50. (London and Philadelphia: Jessica Kingsley Publishers, 2006), 247-48.
Tressider, Virginia. "Cooper's Ailment." *Disparity* 3, no. 1 (2005): 4-7.

inalienable right. Most of us claim our right to be protected from invasions of privacy, whether it’s teatime phone sales people from India or garish unwanted pop-ups on the computer screen. Why can’t that awareness be translated into a respect for the privacy of others who live in the institutional context?

Do professional responsibilities override such rights? Do such rights get overridden because the ones served in the institution are viewed with lesser regard than what we would uphold for ourselves?

6.2.9 Narrative #9: Lifetimes

Henrietta is a lady in her 70s. I first met her several years ago in the craft room where she liked to occupy much of her time either joining in an activity such as basket weaving, or simply sitting back and enjoying the repartee engaged in amongst fellow artisans and staff.

Owing to the series of strokes she suffered some 20 or so years ago her verbal communication is limited, often indecipherable even to a trained ear. I most associate her communications with what I would describe as knowing, soft grunts. She is able to walk but needs the assistance of a walker to help her on her travels in and around the corridors and grounds of the institution. She can often be found sitting somewhat apart from the others. On this day in the craft room she sits somewhat apart from the main activity quietly thumbing through a magazine, sometimes offering a slightly amused smile at some of the jocularity happening nearby.

I move to sit adjacent to her at her table and talk with her. Apart from passing ‘hellos’ and shared smiles this is the first time I’ve actually sought to sit in close proximity to her. I feel I am overdue to build a relationship beyond the most superficial of pleasantries. I am curious to discern more of this person who seems to be a little distant to others. I also want her to get to know me, to discover more of me than the superficial impression she may have of a rather benign pastoral figure capable only of rather superficial interpersonal gestures.

I offer a few comments concerning others in the room and matters arising from the page she’s looking at in her magazine. She utters a few isolated words, nods and knowing grunts in response. She occasionally smiles in apparent agreement with a comment I make. There are times of silence but I don’t feel they are awkward moments. Henrietta seems comfortable with me just being there. I value her gentle acceptance of me.

The session draws towards a conclusion. Henrietta motions for me to follow her back to her room some distance away. I follow, wondering what’s behind the invitation.

We arrive at her gloriously cluttered little room and she invites me to sit on the edge of her bed. She places before me a book of news clippings and personal typed commentary that point to events, people and places that have been a part of her life in her far more active years prior to her strokes. The clippings and commentaries take me to faraway places like North America and Fiji, to former careers and callings such as teacher and writer. I see photos of family, colleagues and companions. She points to short stories that detail specific events from her pre-institutional, pre-impaired life. She wants me to read them.

I look up from these stories and she points me somewhat knowingly towards a large photo of a past pope, and to a nearby painting signed by herself, showing Jesus at the Last Supper. I turn to the opposite wall to observe a framed education degree, as well as a large certificate of appreciation from North America hanging above a large beautifully hand-crafted fruit bowl, with a plaque denoting best wishes from Fijian friends.

I sit with Henrietta a little longer in this place that for me, at least for the moment, has become less like her little room and more like the gallery of her life. I motion to leave, thanking Henrietta for the privilege of being offered such an insight into her rich life. She replies with a pleased nod and that knowing grunt.

Reflection and Analysis

As I leave her room I remind myself how until this day I have largely contained Henrietta to what I have seen of her in the present moment, this significantly-impaired lady who likes to slowly thumb through magazines in the craft room. I have observed a frail older woman losing her pallor and physical capacities. I have largely defined her intellectual capacity by the content of the magazines she flicks through. I have tended to regard the physical distance between herself and others in the craft room as evidence of a certain aloofness.

But I realize now that I have been observing and judging her on the basis of the tip of the iceberg; various of my observations have been superficial, and most of my judgements have either been limiting or completely wrong. Today she took me beneath the surface. She revealed parts of her lifetime of which she is clearly and justifiably proud, which continue to sustain her despite the restraints placed on her by body, mind and an environment that includes the limiting judgements of myself and others.

I wonder why Henrietta would want to invite me into her room and detail her accomplishments spread over a lifetime. Does she sense that I was only looking at the tip of the iceberg? Does she feel I was only looking at her in the present tense amidst her growing limitations? Was her pride and identity, forged over a lifetime, still sufficiently intact that she wanted to proclaim that there was more to what I might be seeing than a frail elderly woman now confined to a small room in an institution? Had she seen enough of me over previous months to gain the impression that her story was safe with me? I don’t know.

However, for me, this adventure into a fuller acquaintance with Henrietta and her life began with a simple commitment to sit beside her and a curiosity to know a little more of this seemingly guarded, mysterious person. I feel my curiosity was richly rewarded. Maybe Henrietta values such a pastoral quality. Maybe she appreciates presence that does not seek to overwhelm but prefers a more gentle form of hospitality.[581] I do tend to think that whatever the motivation for inviting me to her room it started with a desire by her for some form of meaningful relationship and understanding of who she saw herself to be as a human being, and who she wanted to be seen as by me.

Henrietta is symptomatic of those who have welcomed me into personal rooms that can be described as life galleries, autobiographies reflecting vividly upon life beyond disability and institution. Such invitations reveal people not contained by limited perceptions or judgements, nor by ageing bodies and minds. They are not contained by institutional routines and tiny rooms that, despite their limiting size and ubiquitous clinical surroundings, still manage to give description to lives proudly lived.

6.2.10 Narrative #10: Busy

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[581] There is a growing discourse on pastoral care as hospitality that specifically includes people with a disability. Later works include,
McNamara, "Ethics, Ageing and Disability."
Reynolds, Thomas. *Vulnerable Communion: A Theology of Disability and Hospitality*. (Grand Rapids: Brazos Press, 2008).
Yong, *Theology and Down Syndrome,* 155-292.

I’m in the midst of a busy day. I’ve just finished a palliative care meeting in the aged care complex and have only half an hour for lunch prior to a meeting with my supervisor where I will present her with my monthly report.

On the way back to my office I see Gladys walking around the front of her accommodation area. Gladys is a spritely 60 year old, born with a significant level of brain injury, who has lived here since her early 20s, when her parents decided they could no longer give her the level of care that her behaviours required. They made the agonising decision to place her in the care of this institution. Her father died a few years ago whilst her aging Mum keeps in regular contact with her only child.

Gladys is often on the look-out for someone to talk to. If she sees me she will urgently and repeatedly call out, “Hey there … ” like a mistress calling a servant, until I respond and give her the attention she demands.

She reminds me a little of my son when he was young. He would jump out of a tree believing that the passing parent was there to catch him. Usually he was right.

I know what to expect from Gladys. Her story usually follows similar themes -- Mum’s latest visit, the family dog Peggy, and an upcoming, real or imagined, holiday. It’s an oft-repeated chorus, not dramatic, but more of a report that needs to be validated by being repeated to another.

“Hey there, hey there.”

Today I’m really busy, busier than usual, and I just want some quiet moments before the next appointment.

“Hey there!”

I keep walking to my office. She might lose interest.

“Hey there!”

She’s persisting. I’ll have to stop.

“G’day Glad, how ya doin?”

“Mummy.”

“Yes Mum. How is she?”

“Mummy came to see me Saturday.” She shows excitement.

“Mum came to see you last Saturday. That’s great. But I … ”

“Mummy and Peggy.”

“Your beautiful little doggy.”

“Yeah … Peggy lick my face.”

“You love Peggy, don’t you?”

“Oh yeah.” With growing excitement she takes hold of my arm.

I feel spare lunchtime ebbing away and it isn’t until the themes are enthusiastically articulated three or four times that I feel able to prise my arm free, and bid Gladys goodbye.

Reflection and Analysis

As I proceed to my office I begin to realize how poorly I have treated Gladys. These random conversations are among the most natural conversations one can have in this place. They are not connected to any appointment. They’re outside of a clinical context required by the requisite health professional or me. The conversation is often initiated by the person with an intellectual disability, as opposed to the professional addressing a medical concern.

I feel they come closest, within this setting, to the amiable conversation you might have with your neighbour over the back fence. You know how it goes.

“G’day Frank, how’re ya roses goin? Mine are getting aphids. Damn beggars. You getting aphids?”

OK, so there’s no persistent “Hey there!” and there’s no grasping of arms, but there is the gravitation to familiar themes and the desire to share simple domestic details or enquiries with someone who will listen. And I only listened, albeit with an eye on my watch, after Gladys’s persistent “Hey there!” wore down my resistance.

I don’t feel proud of myself. I rail at myself regularly, and sometimes at others, over what I call the ‘five-minute therapies’ offered by the medicos, usually signifying little beyond required medical conversation and prescription. Yet here I am just as palpably showing a lack of genuine interest in the personal agenda of another who simply wants to be heard. And I reflect as to whether or not I was particularly disrespectful of her pleas because her intellectual disability veiled her capacity to discern my behaviour as disrespectful. And all she wanted of me was a genuine listening ear for a few minutes. I know I need to claim time for myself but would my day be ruined if my lunch is reduced from 30 to 20 minutes?

This story reminds me that as a professional pastoral carer working in this institutional setting I have to juggle my administrative responsibilities and more personal, pastoral priorities as represented in this story concerning Gladys. I am pleased that the institution includes me on committees such as on palliative care and ethics. I am also pleased that I can debrief with my supervisor, giving me cause to reflect purposively on the progress of my ministry in this place. These are institutional responsibilities which I willingly accept and which the institution expects of their chaplain. However, amidst such necessary responsibilities comes Gladys reminding me of my pastoral priorities.

Gladys reminds me that my core responsibility is to the people who live here. She also reminds me that part of that responsibility is to engage in relationships in which the people who live in this place have the right to relate to me on their terms and not just when it suits me. To only engage with the people here on my terms is to acquiesce with the medical concept of relationship which prevails in this place. A part of being human and caring in this place involves allowing the people who live here to have a say in when they might choose to relate to you. Sometimes this may take some negotiation; however, it must remain a priority in the definition of my pastoral relationships.

To allow the people who live here to have a say in when they may choose to relate to me offers them a measure of power, an opportunity to assert a relational agenda rather than having a medical agenda imposed upon them.

I am reminded of Volf's interrelational model of inclusion called 'Embrace',[582] whereby I as pastoral carer, seeking to offer generous hospitality and welcome, begin by throwing open my arms to the other in an act of self-emptying. In so doing a space is created in which the other may enter, an act described as "a gesture of invitation."[583] This invitation is followed by a willingness to wait for the response of the other and then, if the invitation to hospitality is reciprocated, a closing of the arms around the other, an embrace in which each enters the other's space and experiences the welcoming presence of the other.[584]

However, Gladys is turning the notion of 'Embrace' on its head. Rather than me reach out to her she is daring to take the initiative and seeks embrace

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[582] Volf, Exclusion and Embrace, 141-145.
The four-part process of Volf's model of 'Embrace' will be further articulated in the following chapter.

[583] ibid., 142.

[584] ibid., 143.

with me. With perseverance, she reaches out to me, urging me to enter into her world if just for a short time. Whilst being more impulsively physical than Volf envisioned, she 'waits' or maintains her pleas, until I stop and begrudgingly give her a little of my time. Then she embraces me with her stories, entrusting me with her familial narratives and the joy and enthusiasm with which they are told.

And finally, I am reminded that for every Gladys who confidently pursues her agenda with whomever she chooses, there are others sitting quietly in their rooms, or blankly watching television, who have had such self-confidence, perseverance and resilience overwhelmed by the force of expectation associated with institutional routine. There are those who lived here in the days when child-like uniformity was the expectation and autonomy was thwarted. They were taught compliance and adopted an acquired helplessness in the overriding interest of corporate cooperation. How might I pastorally encourage them to rediscover some self-confidence and persevere, to have their voice heard and their identity valued?

6.2.11 Narrative #11: Austria

As a child I was taken by my mother to see the musical 'The Sound of Music,' and I loved it -- the grand settings, the beautiful vistas, romance, lovely Julie Andrews and, of course, the music -- 'The Hills are Alive,' 'Edelweiss,' 'My Favourite Things,' and 'Do Re Me.'

It's hard to admit to loving the saccharine sweetness of those show tunes while also claiming to be a devotee of 'The Beatles,' 'Cold Chisel' and 'U2.' But that musical just got under my skin, and every year, when some television station churns it out yet again, I'm there watching it with rapt attention as the von Trapp family escape to Switzerland amidst the strains of 'Climb Every Mountain.'

And today I'm faced with ageing persons at this institution who also love this musical, who play it on their VCRs or DVDs with great regularity. Some must have watched it and absorbed the tunes over dozens of screenings. They don't seem to tire of it.

I think the staff are caught in a bind. They're glad that at least a few people have found such a regular source of entertainment, but they're sick to death of the von Trapps and probably wish Julie Andrews would lose her will to sing.

But the likes of Michael, Edna and Francesca just love it. It's seems like an old friend that helps them through the day. Perhaps it's the familiarity, perhaps it's a sense of constancy in a world of change, and it's certainly the music.

The other day I happened upon Francesca. She's about 50, has a significant level of intellectual impairment, and has very poor eyesight that requires the wearing of black-rimmed thick lenses. She was there in her dining area, sitting in her wheelchair, seemingly 'contemplating her navel.'

I got talking to her and it wasn't long before the conversation turned to that musical. Francesca seemed interested in it so I started talking about some of the songs. Before long I came to 'Do Re Me' and for some reason, probably because it's the only song for which I know most of the lyrics, I started singing in my inimitably discordant style.

"Do, a deer, a female deer,
Re, a drop of golden sun,
Me, a name I call myself,
Fa, a long, long way to run …"

Francesca smiled quite broadly and started completing each line that I started to sing. For a short time we were quite a duet.

Reflection and Analysis

Francesca is not tired of 'The Sound of Music.' It brings her joy, not to mention a smile to her face. It takes her to happy places in her heart. As much as it must drive some staff to distraction may it continue to bring her joy. As long as it brings a smile to her face, she is in a happier place than the one she lives in day to day. The hills of Austria and the strains of Julie Andrews are far more enriching than the routine and tedium of this institution and its medical ways.

As for me, although my singing is that which only a mother could love, I feel I should sing along, to validate the music, and affirm this woman who has been transported to a place where she, at least momentarily, is feeling joyful and free. She is experiencing a measure of release from embodied and institutional constraint.

For as long as Francesca hears the music and can still climb that mountain she is not contained.

6.2.12 Narrative #12: Blessing (integrated narrative and reflection/analysis)

I find myself sitting adjacent to Jim as he lays dozing in his bed. Jim is about 70 and, in his prime, would've cut a solid figure. He was talkative and enjoyed a joke. He was born with a significant intellectual disability and, whilst his Mum and Dad supported him as best they could eventually they felt their best wasn't enough. And so, he was transferred to this institution for people with intellectual disabilities at the age of 11.[585]

He has lived in various accommodation areas in this facility over the decades, but now finds himself in the aged care section living under palliative care orders. While he has endured many hospitalisations and operations over the years, which he has generally accepted with a pragmatic, resilient spirit, Jim is now close to death.

His pain is minimised due to constant doses of morphine enabling him to rest peacefully and drift into sleep on a regular basis. Nurses and other carers keep a regular vigil at his bedside checking his comfort and attending to medical and bodily needs. They ensure his favourite music is playing quietly in the background. They leave his door open so that he can hear the familiar reassuring sounds of staff and friends as they go about their daily routines.

I sit by his bed for some time stroking his arm, saying little. However, as I know him to have his own Christian faith, I hold his hand gently and utter a quiet pastoral prayer, finishing with the familiar Lord's Prayer. I then quietly drift into a couple of verses of the old hymn 'Jesus Loves Me' before resuming a quiet pose, searching his face for signs of response.

I think back over the nine years I have known him. I'm appreciative of his acceptance of me over that time, of his desire to tell me stories of his family and institution, some of which go back a long time. They are stories told with enough tone and description to suggest they are important wefts in the fabric of his life. He's let me sit with him in times of celebration, such as birthdays, and he's let me sit with him in times of pain. He is so gracious and hospitable towards me.

I think of his parents who trod a regular path to his institutional bedside over many years, and of other family who continued this nurturing and sustaining habit after Mum and Dad had died. I think of the sorrow that many parents have

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[585] Several decades ago it was policy in at least one South Australian institution that parents who sought institutional accommodation for their child had to have had their child accepted into the institution before their twelfth birthday.

had in handing their children over to the care of this institution in past generations, the understandable, yet unreasonable feelings of guilt and failure. I reflect on the desire, expressed through regular visitation, to maintain a modicum of familial normality.

Jim will die in the next few days. There will be a funeral attended by his family and community friends, as well as those grieving staff who are logistically able to get to the funeral amidst institutional routines and responsibilities. Following this there will be a Remembrance Service for him back at the institution in the accommodation area where he last lived. Words of affection will be shared, flowers offered and a good life will be celebrated. In the midst of conducting these important rituals I too will celebrate, and grieve, as I have already started to do. I love the guy. I will miss him.

But as much as I talk publically at funerals about all the ways that the likes of Jim have enriched the community life of this institution over the years, the reality is that, as with ‘invisible Alice,’ so with the more gregarious Jim, this place will methodically continue the business of being a disability institution. It won’t miss a beat. Following his death, his next of kin will be invited to come and lay claim to Jim’s personal effects; his bedroom will be thoroughly cleared and cleaned, and a new person will move into Jim’s old room, perhaps within 10 days. It’s an institutional routine that invites staff to suppress their grief for Jim and for others who live here by simply getting used to the new person occupying Jim’s old bed. But the grief will still be there. It’s called ‘unresolved grief’.

Eventually I feel it is time to leave Jim’s bedside. He is resting peacefully apparently unaware of my presence. Without expecting a response I rise and bid him farewell. But as I begin to move away he stirs a little, reaches up to hold my hand, and quietly but clearly says, “Thanks mate.” I momentarily stare at Jim from the side of his bed as he settles back into restful repose. This needful, dying man addresses me by name and offers me what I interpret as a blessing. I’m in disbelief.

I am truly humbled. Here I am, a Uniting Church chaplain, a professional carer, there to care for him and yet, through his two simple words and touch, my professional status melts away. I stand there not as a chaplain but as a fellow human being and child of God.

I feel vulnerable, wounded, the one who really needs care.[586] But through Jim's gentle blessing I also feel much loved and valued, Christ reaching out and accepting me as I am. I feel deeply blessed.

Caring in this place is about shared relationship, shared humanity, and shared spiritual resourcefulness that may have nothing specifically to do with religious identification. It's concerned with love, recognising and attending to the need of the other regardless of status, qualification or experience. It's about a mutuality of care that recognises the humanity of the other, that acknowledges that we all need each other because we are all needful people in need of loving communion. That need certainly transcends institutional roles and responsibilities.

Jim will soon die; the institution will move on, but I can honour his memory and those others who live and die in this place, by embracing the blessing it is to engage in caring relationship with these people, created as they are in the image of God.

6.3 Collective Narrative Analysis: The Strong Threads

In light of these 12 narratives it is necessary to look at the stories at a collective level and identify the strong narrative threads that most authentically and fully afford a valid portrait of the institutional context, the people with intellectual disability who live there, and my role as chaplain with them. It is this level of analysis that will form the foundation of an authentic understanding of the context and people in question. The task of gaining an effective understanding will be evidenced by the proffering of a pastoral model that most appropriately responds to the needs of those who live in this setting.

The strength of the narrative threads will be evaluated by both quantitative and qualitative means. The quantitative evaluation will be in terms of how many times a narrative theme recurs across various narratives. The qualitative evaluation will concern the judged level of influence that a particular narrative issue has on the development of a particular narrative, or narratives.

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[586] Regarding the pastoral carer finding a point of mutual vulnerability with the one in whom he or she shares in a caring relationship see, for example,
Nouwen, *The Wounded Healer*.
Webb-Mitchell, Brett. "The Place and Power of Acceptance in Pastoral Care with Persons Who Are Mentally Retarded." *The Journal of Pastoral Care* 42, no. 4 (1988): 351-60.

6.3.1 Institutional Character and Effect

In proffering a response to these narratives, initial comment needs to be made concerning the lived context from which these stories are derived. This concerns both institutional staff, and the objectifying medicalised nature of institutional routine that is so determinative of the nature of the lives of those who live in this context.

6.3.1.1 Caring Staff

In proffering a narrative-based account of the character of the institutions in question it should initially be noted that there are staff who work in these facilities who, within the bounds of their job description, genuinely seek to care and add quality to the lives of those people for whom they bear responsibility. These include those who allow the likes of Graham the space to ‘conduct the orchestra’ and who appear to understand the opportunity and need for him to creatively express himself in such a demonstrative, spontaneous and uncontained manner. It also includes those who, although not explicitly mentioned in the narratives, do respect the privacy of those for whom they care. It includes those who go out of their way to provide the space and resources that enable Graham to draw as much as possible, within institutional restraints. It also includes those who sensitively care for the likes of Jim in his final days of life. In their attention to his physical needs, in the offering of comfort, and in their attention to his familial, social and spiritual needs, they offer him as much of a sense of normality and dignity as is possible at a difficult time. It includes those who replicate such quality care in the less critical, more everyday moments of the lives of those for whom they care. The giving of such care offers to the other a sense of positive value and regard that enriches their sense of personal worth.

I also acknowledge the many staff who are genuinely welcoming of my pastoral need to have time and space with those with whom I seek pastoral engagement. The giving of such space enables those who live in the context in question to receive a more holistic model of care.

6.3.1.2 Institutional Routine

Because the institutions being considered in the aforementioned narratives offer a mass model of service delivery it is inevitable that, despite each individual having their own individual care and lifestyle plans, care is principally offered in a medical and administrative manner that militates against a more personalised, familial form of care.

People like Alice receive the requisite medical care from the appropriate health care professionals, and are fed, cleaned and toileted as required by trained professional carers. However, beyond these required tasks, she remains largely invisible as she sits silently by the window in her dining area, and is spoken over by therapists as she is taken to her room to receive the requisite five-minute health care intervention. She is, in effect, a non-person,[587] or, as Newell asserts of the medical discourse, the objectified other.[588] This is the one who is principally related to by paid professionals on the basis of his or her disability and deficiencies. As with Sally who is known ubiquitously as ‘that lady,’ Alice lacks personal identification and regard.

Such objectification is exacerbated by the inability of institutional staff to look beyond seeing the person, as stated in relation to Henrietta, as more than the ‘tip of the iceberg.’ Rather than seeing a whole person she is often seen purely in terms of her present intellectual impairment. Instead of being understood in terms of her entire life that has led to this point in time she is perceived presently as an elderly woman with failing health, including increasing levels of dementia. Such a narrow health care perspective means that a person such as Henrietta will not be treated as someone with an inherent worth and dignity, as someone deserving respect, understanding and kindness.

As social historian Rob Westcott states concerning the objectified non-personal care offered by Australian institutions to people with disabilities in the late twentieth century,

> There is little evidence that there was any more recognition late in the last century of the need to be kind, caring, helpful, friendly, tolerant, respectful, and personally connected to people with disability above all else, and to help people toward living an ordinary life, than there was a hundred years before. Conditions were immeasurably improved, but one cannot help feel that people with disability were and still are perceived as different, as somehow sub-species of the human race, with all the negative consequences of that benevolent, professionally determined distinction evident in their daily life.[589]

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[587] Goffman, *Stigma*, 18.

[588] Newell, "Disabling Health Systems," 13.

[589] Westcott, Rob. "Lives Unrealised: An Essay on Society's Responses to Disability – Part 2: The Australian Experience." *Interaction* 18, no. 2 (2004): 7-18, 15-16.

This lack of human regard is further exemplified by the chronic lack of private space afforded to those who live in the institutions under consideration. The only physical place which an institutionalised person can claim as their own private space is their bedroom. However, in the institutions in question, some still share their bed space, while many others such as Madge find the sanctity of their private spaces invaded by staff fulfilling work responsibilities such as cleaning bathrooms, replacing laundry items and replacing light bulbs.

All people have a right to privacy.[590] It is in private spaces that people who live in the institutions under consideration can rightfully claim the time and space to experience a measure of freedom from institutional routine. It is in private spaces that those who live in the institutional setting can rightfully nurture personal relationships and intimacy with another. As was stated in a past government report that considered the rights of people with intellectual disability who live in institutions,

> Institutions cannot provide the long term intimate relationships which families provide. Moreover, it is difficult for two or three persons to get away from others to play, talk, or just sit and hold hands. It is rare for residents to have privacy from staff or other residents in toilets, bathrooms and bedrooms, even when they are capable of looking after themselves.[591]

Although this comment was made in 1981 it still bears an alarming level of relevance. In the institutions under consideration it can still be difficult for intimate moments to be shared. Some bathing facilities remain shared and outdated in nature. Some bed spaces are still occupied by two or more persons. Furthermore, as mentioned in relation to Madge, staff can still demonstrate a lack of respect for the privacy of those in their care.

It is in private places, such as a person's bedroom, that an individual should be free to behave, relate, think and feel independent of communal routines, expectations, and institutionally-defined forms of relationship. However, when institutional routines disregard this right and space then such freedoms are denied. Where such space is denied personal identity becomes

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[590] General Assembly of the United Nations. *The Universal Declaration of Human Rights* United Nations, 1948 [cited January 1 2009].
Available from http://www.un.org/Overview/rights.html Article 12.

[591] Committee on the Rights of People with Handicaps. The Law and Persons with Handicaps , 118.

subsumed by an institutionally-defined identity. Such identity then becomes normative for those who live in such a context.

The institutional identity is fundamentally defined by the medicalised model of care in which medical professionals relate to those under their care from a position of power over those who are powerless and who are understood to be dependent, needful human beings. Where such a relationship is experienced over a significant period of time people such as Alice can develop a learnt sense of compliance and passivity towards those medical professionals who bear responsibility for them. Also, this model takes decision-making out of the hands of the individual as the perceived experts make decisions regarding the health and welfare of those dependent upon them for expertise and care. As social theorists Julie and David Smart state regarding the influence of this model upon individuals, it

> ... is often conceived to be a model of experts in control, therefore reducing individuals with disabilities to the role of passive and compliant patients. Because most individuals with disabilities do not possess the expertise, knowledge, education, and experience of physicians, they may not be accorded respect as decision-makers.[592]

Disability philosophies that began to be implemented by South Australian disability institutions during the first decade of the twenty-first century, such as person-centred planning and self-advocacy, place major emphasis on the right of those who live with disabilities to live with autonomy and personal choice.[593] Yet the lack of privacy experienced by those such as Madge, and the lack of personal identification experienced by those such as ‘invisible’ Alice and ‘that lady’ Sally, along with those who are generically ‘babysat’ with colouring-in books and pencils, would suggest that such philosophical values are far from realized.

It is also patently obvious that institutional life imposes a regimen and routine that generates a tacitly-understood set of values and behaviours that

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[592] Smart and Smart, “Models of Disability,” 76.

[593] Tarulli, Donato, and Carol Sales. "Self-Determination and the Emerging Role of Person-Centred Planning: A Dialogical Framework." In *Challenges to the Human Rights of People with Intellectual Disabilities*, edited by Frances Owen and Dorothy Griffiths, 102-23. (London and Philadelphia: Jessica Kingsley Publishers, 2009).
See also,
Owen, Griffiths, Tarulli, and Murphy. "Historical and Theoretical Foundations,”
Here, the philosophy of self-advocacy is seen as emerging as a response to past, oppressive disability philosophies such as eugenics.

becomes normatively and subconsciously absorbed by those who live in this environment. Many of the older people have been accommodated here for the majority of their lives, some since childhood. These include Bill who can recall the personal insults of his farm days, Jimmy who doesn't get invited to family gatherings, and Mary, who, despite having living relatives, is silent when asked about fundamental family details. To varying degrees, such people exhibit behaviours that suggest the largely unquestioned personal and corporate absorption of institutional values and practices. For example, those like Bill can recall demeaning attributions from staff but with little offence. And whilst such abuses can be attributed to previous generations the current generation of people with intellectual disability are principally related to as clients and do not question such labels. Nor do they question the staff-initiated mode of behaviours that accompany such language. This includes those like Alice who unquestioningly allows herself to be at the behest of therapists, and offers no compunction at being 'talked over' by those who barely acknowledge her presence despite physically escorting her to her room.[594]

Further to such institutional normalisation is the lack of identity that is afforded individuals. Various people struggle to have their name acknowledged, and to be afforded acknowledgement beyond the 'tip of the iceberg,' that is, that small part of their identity that presents itself to institutional staff in terms of health care and lifestyle needs. Alice is not identified by name and neither is Sally. Henrietta, it would seem, desires to be related to in terms of her whole life rather than purely as an elderly lady with an intellectual impairment and a growing level of frailty. And as much as his weaving seems to give contentment to his daily routine Malcolm's 'conducting of the orchestra' serves as a reminder to all, including myself, that there is so much more to his identity than that which can be attributed to him from his craftwork.

Poling speaks of a loving community as one that "understands experience in such a way that the fullest reality of all persons is engaged".[595] In pastoral terms this means identifying the other as fully created in the image of God and

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[594] Ruler, "The Culture of Nursing Homes," 259. Here, the author speaks of institutional staff *talking over* a cognitively-impaired, institutionalised individual because previous attempts at communication with the person have led to misunderstanding or misinterpretation. Therefore, staff have given up attempting to talk to the person in question.

[595] Poling, The Abuse of Power, 147.

not just in terms of their medicalised identity. It means regarding them as a whole, created being of God-given worth, as are all people, rather than attending to one component of their being which is viewed as deficient.

The types of oppressive practices outlined over recent pages point to the incapacity of institutions to develop the type of interpersonal, familial relationship that shows full human regard and holistic identification for those who come under their care. Swinton, speaking from both a psychic and structural perspective, describes such oppression as "... perhaps best understood as a power or force that prevents a person from becoming fully human and thus fully reflective of the image of God." [596] There comes a need for a mode of interpersonal friendship that acknowledges the full identity of institutionalised individuals, thus offering liberation to the one who has come to be regarded as a non-person. Such a restoration of identity is, as Swinton asserts, the work of rehumanization.[597]

Alongside this work of rehumanization Poling asserts that the "... stories of the oppressed must be heard for the full identity of a community to be understood."[598] In terms of this extended reflection that implies that a restoration to full identity of those who live with intellectual disabilities in the institutional setting requires the stories of oppression to be heard and honestly acknowledged. By the institutional setting acknowledging its past and present wrongs, including abuses, invasions of privacy, and lack of personal identification, those who live in this setting are enabled to understand that certain normatively-understood institutional values and practices were wrong. There is then the possibility of these individuals being enabled to deconstruct what Avery refers to as the "false-self cocoon,"[599] and to nurture the notion of being valued as whole persons.

The question that the pastoral carer thus needs to address concerns developing a model of pastoral care that affirms the notion of rehumanization, that best upholds these persons' whole created identity, and that affords them a God-given sense of regard and personal worth. To do so is to offer a measure of liberation to those who have been and remain oppressed by entrenched institutional values and practices.

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[596] Swinton, Resurrecting the Person, 17.
[597] ibid., 17-18.
[598] Poling, The Abuse of Power, 189.
[599] Avery, *The Pastoral Encounter*, 11.

6.3.2 Threads of Liberation

We thus turn to the narrative to not only describe the oppressive nature of institutional life but also to consider what glimpses of rehumanization, or liberation, are observable. The narrative invites us to discern those attitudes and behaviours not shaped or determined by traditional institutional philosophy or practice but by an influence of an altogether more enriching and life-affirming effect.

6.3.2.1 Pastoral Presence

One of the implicit or explicit assumptions that runs through a number of the narratives concerns those who live with an intellectual disability in the institutional context being regarded as deficient beings. This is the primary form of relationship for those who live in the institution.[600] Therefore, familial and filial modes of relationship are significantly supplanted by paid professional care. The institutional goals related to professional health care practice militate against priority being afforded to other more personal forms of caring. As Campbell claims, "the intensity of the one-to-one encounters of professional practice appears to create a blind spot with respect to the socio-political context of care."[601] Elsewhere, Annison, in reference to Maslow's hierarchy of needs, asserts the priority of a home environment as the most appropriate context in which care, amidst its physiological, creative, value-laden and relational identities, ought to be appropriated. As he asserts, "... the creation and experience of home is an important contributor to a person's humanity and their positive social perception by others."[602] The medical priorities of the institution, along with its social separation, work against a holistic caring for a person's humanity, as well as their spiritual identity.

The narratives described detail people with intellectual disabilities who do not experience home, or something that approximates a home environment, as a primary source of care. Instead, they primarily experience care as medical intervention. Apart from required therapy those like Alice are largely left to sit anonymously by the garden window. Those like Sally can remain lacking in

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[600] This is not to disregard those who receive a significant amount of contact and care from family members and others. Nonetheless, the primary contact, in terms of time and extent of health care intervention, is with medical and caring professionals.

[601] Campbell, Professionalism and Pastoral Care, 52.

[602] Annison, John. "Towards a Clearer Understanding of the Meaning Of Home"." *Journal of Intellectual & Developmental Disability* 25, no. 4 (2000): 251-62, 260.

personal identification as long as they are principally regarded as objectified, medical identities. Such institutionalised people are urgently lacking any significant, more personalised form of care.

At the same time Henrietta's invitation to view her galleried room and Madge's desire to tell stories that pre-date her institutional days are calls to be understood as much more than a medical identity.

Therefore, for as long as these people continue to live apart from the more nurturing and familial care that can be found in a home environment they are being denied a form of relationship that accords them their whole created status. It is in terms of pastoral presence that they can be afforded a value stemming from a liberating, holistic and God-given regard.

There is a growing body of pastoral literature that upholds the value of presence as intrinsic to a meaningful pastoral relationship. Presence can suggest the pastoral carer's whole-hearted giving of oneself to the other. It can point to the creation of a hospitable space in which the one being engaged with in care is unambiguously and non-judgementally welcomed and allowed to share their tacit or consciously-described story, whatever that story may be.[603] This hospitable space is a place of safety where the other person can find rest amidst their brokenness and the security of a loving God in the presence of the one who cares.[604] The assumption here is that the carer, in seeking to be the embodiment of a loving God, casts to one side personal concerns and pastoral agendas, and brings all of their personal, pastoral identity and resources to the task of being fully present.

A particularly pertinent form of Presence that has gained attention in recent years has been that of Non-Anxious Presence. This was first described by Bill Williams in 1997 in his autobiographical work, *Naked Before God: The*

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[603] Avery, William. "Toward an Understanding of Ministry of Presence." *The Journal of Pastoral Care* 40, no. 4 (1986): 342-53, 342-347.
Williams, Naked Before God, 33, 160.
Peterson, Sharyl. *The Indispensable Guide to Pastoral Care*. (Cleveland: The Pilgrim Press, 2008), 39-40. McGrath, Pam, and Christopher Newell. "The Human Connection: A Case Study of Spirituality and Disability." In *Voices in Disability and Spirituality from the Land Down Under*, edited by Christopher Newell and Andy Calder, 89-103. (New York: The Haworth Pastoral Press, 2004), 99.
Peterson, along with McGrath & Newell, here assent to Williams' concept of pastoral care as *non-anxious presence*.

[604] Peterson, The Indispensable Guide, 23-24.

Return of a Broken Disciple, in which he articulates a form of pastoral care that he describes as helpful amidst his disabled, dying state.

> 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 weeped (sic) when I heard it, it so defined what I needed. Engrave this upon your forehead, if you would wish to do good:
>
> *Ministry is a non-anxious presence.*
>
> 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.[605]

Here is a model of pastoral presence in which the carer seeks to divest himself or herself of all self-serving agenda items or anxieties for the sake of being whole-heartedly attentive to the needs of the other person. In serving the other at their point of need the carer is utterly sacrificial and committed to the other.

This understanding of presence involves vulnerability. Newell interprets this as the pastoral carer being willing to be a suffering presence with the one for whom he or she cares. Such human identity enables the broken God to be revealed to the other.[606] Janet Stokes speaks of this vulnerability in terms of servanthood characterised by suffering. Here, one adopts a posture of being alongside the other and experiencing the hurt resulting from their oppression. She states that, "ministry of presence in the pastoral office means vulnerability to and participation in the life-world of those served ... "[607] Campbell regards true openness to the life-world of the other requiring a "fearless vulnerability."[608] This suggests pastoral presence as risk-taking, an uninhibited engagement in the fragility of others that can reveal personal frailties to oneself.

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[605] Williams, Naked Before God, 33.
Italics are those of the author.
See also,
Calder, "God Has Chosen This for You," 15.
McGrath and Newell, "The Human Connection," 99.
Peterson, The Indispensable Guide, 39-40.

[606] Newell, Christopher. "Pastoral Care and Ethics: Some Reflections." *Ministry Society and Theology* 11, no. 2 (1997): 102-13, 104.

[607] Stokes, Janet. "Ministry of Presence and Presence of Spirit in Pastoral Visitation." *The Journal of Pastoral Care* 53, no. 2 (1999): 191-99, 192.

[608] Campbell, Professionalism and Pastoral Care, 89.

The narratives of this extended reflection reveal the necessity of this vulnerability of the pastoral carer for the other person. Engaging with Alice at a level where the extent of her invisibility and anonymity becomes apparent involves sitting alongside and seeking to feel something of her invisible and anonymous identity. Being with Madge in her room as she shares her pre-institutional stories necessarily involves feeling outrage in order to appropriately experience the loss of privacy that she has come to accept as a social norm. Sitting by Jim's bedside as he lives out his final days as his body succumbs to cancer involves doing all one can to imagine, albeit inadequately, one's own body, frail and institutionalised over a lifetime, finally surrendering to a terminal disease.

The importance of this pastoral posture assumes particular significance for this extended reflection given that the focus of the carer's attention is towards one who has diminished cognitive capacities beyond the present moment.[609] With the disintegration of cognitive capacities beyond the present people with intellectual disabilities are uniquely able to focus on the pastoral encounter in the present moment. It thus behoves the pastoral carer to cast to one side distractions from the present, such as past regrets, for the sake of heightened awareness in the here and now.[610]

Such a consideration leads to those who are the focus of the narratives being pastorally related to as those who are living in the present moment. Those who passionately embrace the wooden cross on Good Friday may be doing so with passions and instincts unencumbered by thoughts and feelings beyond that worship moment in the chapel. Those who are taken to a faraway place during their viewing of "The Sound of Music" may be doing so free from thoughts or feelings of tedium that others may experience on hearing the same songs for the umpteenth time. In response, the pastoral carer comes to the pastoral occasion

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[609] Lipinska, Danuta. *Person-Centred Counselling for People with Dementia*. (London and Philadelphia: Jessica Kingsley Publishers, 2009), 47-48.
See also,
Mearns, D, and B Thorne. *Person Centred Therapy Today: New Frontiers in Theory and Practice*. (London: Sage Publications, 2000).

[610] Matthiessen, Peter. *Nine-Headed Dragon River: Zen Journals 1969-1982*. (Boston: Shambhala Publications, Inc., 1998), for example, 21, 94, 97, 104.
Here, the author speaks of meditation that focuses on the present moment from a Zen Buddhist perspective.

with as much focus on the present moment as possible so as to honour the focus of the one with whom pastoral engagement is sought.

The question of presence also addresses the issue of human worth as that which is principally to be valued in terms of being, ahead of cognitive or other forms of human functioning or attachment.[611] As theologian Hans Reinders asserts, in a world in which the achievement of moral and social standing is vaunted God's providential care affirms human identity as deriving from a loving God, as opposed to being from commodified human endeavour.[612] That is, our worth is fundamentally estimated in terms of who we are as opposed to human achievement. Therefore, those institutionalised people who receive Holy Communion are being sacramentally affirmed as people who, according to orthodox Christian tradition, are loved by God in Christ for their being created in the image of God, as opposed to any sense of achievement. For those whose identity has been historically downplayed or disregarded owing to cognitive incapacity this theological reality is liberating.

From this pastoral posture the pastoral carer seeks regard from the other, not amidst the power inequity of a professional/client relationship, but as one who is regarded as a fellow human being and child of God.[613] More will be said of this in the following section.

6.3.2.2 A Mutuality of Care

Running through all the narratives in various ways is the notion that the pastoral relationship is of a shared nature in which both bring to the relationship qualities and resources that the other needs. In other words, the relationship concerns a mutuality of care.[614] It means that not only do I as chaplain regard

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[611] Regarding the priority of being over human attachment which can lead to god-like pride see,
Culliford, Larry. *The Psychology of Spirituality: An Introduction*. (London and Philadelphia: Jessica Kingsley Publishers, 2011), 173-74.

[612] Reinders, Hans. "Life's Goodness: On Disability, Genetics, and 'Choice'." In *Theology, Disability and the New Genetics: Why Science Needs the Church*, edited by John Swinton and Brian Brock, 163-81. (London and New York: T & T Clark, 2007), 173-74.

[613] Campbell, Professionalism and Pastoral Care, 89, 103.
Concerning the issue of sharing in vulnerability see also,
Lipinska, Person-Centred Counselling, 103 & 107.
Newell, "Pastoral Care and Ethics," 104.
Here, the author describes such pastoral vulnerability as "suffering presence."

[614] Sherwin, No Longer Patient.
In response to the assertion of the oppression of medical systems of care, the author claims that "... a feminist model would resist hierarchical structures and proclaim a commitment to egalitarian alternatives." 239.

myself as having needed qualities and resources to share with the other but the other person with an intellectual disability has needful qualities and resources to share with me. We both need each other. As we acknowledge these narratives the nature of those qualities and resources, both given and received, come into focus.

I acknowledge that I have much to offer these people. To those who worship, I offer signs of the journey of faith -- bread, juice, a sign of peace and the cross. To others I offer my time, and an attentive non-judgemental listening ear, allowing stories to be told or relationships to be valued as presence. To those rejoicing, I offer a celebratory heart and soul. To those in pain, I offer my empathy, compassion and tears. To all, I can open my arms wide in a gesture of hospitality, inviting embrace.

I also acknowledge that I seek not to give of myself out of a desire to receive for to do so would be to displace love with self-fulfilment. The other becomes a means to my ends. I seek to give of myself to the other out of a genuine desire to share with the other the love I have received from God. As Reinders states in reference to friendship with people with profound intellectual disability,

> The gift of friendship is received as a gift for the sake of our own person, as all true friendship is. God does not love us in order to get something from us. Likewise, we do not extend friendship in order to get something from the other, because the result would not be friendship but self-love. Therefore, as a sincere response to God, we extend friendship to the other person for its own sake. ... one cannot reap the fruits of friendship if one's friendship is a means to another. Friendship is its own reward.[615]

As this pertains to the narratives and persons of this extended reflection it means that I don't go to Jim's bedside out of a desire to receive a personal blessing from him. I don't sit alongside Henrietta in the craft room out of a

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Similarly, other pastoral theologians call for a mutuality of care,
Volf, Exclusion and Embrace, 152-155.
Swinton, John. "Friendship in Community: Creating a Space for Love." In *Spiritual Dimensions of Pastoral Care: Practical Theology in a Multidisciplinary Context*, edited by David Willows and John Swinton, 102-06. (London & New York: Jessica Kingsley Publishers Ltd, 1997), 106.
Moltmann, Jurgen. "Liberate Yourselves by Accepting One Another." In *Human Disability and the Service of God: Reassessing Religious Practice*, edited by Nancy Eiesland and Don Saliers, 105-22. (Nashville: Abingdon Press, 1998), 121-122.
Vanier, Jean. *Becoming Human*. 2nd ed. (London: Darton, Longman & Todd Ltd.), 2001.

[615] Reinders, *Receiving the Gift of Friendship,* 348-349.

preconceived desire to be invited to see her memorabilia, or any other form of pastoral contact that may lead to personal gratification. I give of myself to Jim and Henrietta because God loves me and has made friends with me, and I simply want to share that love and friendship with them.

Nonetheless, I acknowledge that which I interpret, and receive, as grace. As one appointed by my church to be a chaplain who engages in pastoral ministry with people with disabilities, I understand that it is at the level of their disabilities, and their attendant vulnerabilities, that I have been appointed to engage with these people in pastoral ministry. I acknowledge that, at this level of engagement, I receive much from these people which informs and nurtures my faith and pastoral ministry.

However, to understand the relationship as no more than this is to only regard the other in terms of their disability-related frailty, thus perceiving them as less than whole human beings. Here I return to my pre-understanding of God as ‘God with a Disability.’ I reaffirm the God who is at the core of my faith as one whose identity includes the notion of disability, and its attendant wounded, vulnerable meaning, but is not subsumed by this. Instead, I see a God who loves me wholly because I was created wholly in the image of God. It is this conceptualisation that I believe in before I pastorally engage with others. However, it is also this God who is affirmed for me as I see God revealed in the lives of those with whom I pastorally engage. As with myself, the one before me is created as a whole relational human being and child of God. As such, we both have a need to wholly love and be loved. In other words, we need each other so as to be whole human beings and children of God.

Therefore, I look to these people with intellectual disability to see what it is in their whole, God-given identity that I need. In the act of Holy Communion I am invited to consider life at a greater level of mystery and faith. On Good Friday I am invited to consider the Christ who is there to be valued with passion, worship and relationships that can shatter expectations. In the stories of normalised abuse, spatial privation and marginalisation, I better understand human spirit and dignity.

In my being personally identified and, conversely, being shown the lack of personal identification of others, I receive greater insight into what it means to be understood and valued at a personal level and, alternatively, to be regarded as an objectified identity. Through galleried bedrooms and well-remembered stories I accept the challenge to see people within the context of their whole lives and not just a portion of it. The passionate impresario invites me to expect the unexpected and not be quick with labels. Through the dextrous use of pencil and paint, wool and loom, I better value the power of the creative spirit, both theirs and mine.

However, through receiving all such insights, I fundamentally receive the love of God, not just through gestures of one to another but principally at the level of being. Those with whom I engage in pastoral ministry are created in the image of a loving God. The God who is at the core of their identity loves me before this is communicated to me through loving gestures and insights.

Nonetheless, all these incarnational points of human identification draw me closer to what priest and theologian Henri Nouwen, through caring for a profoundly intellectually and physically-impaired young man called Adam, recognised as “a sacred presence ... the face of God.”[616] In the faces and lived experiences of these people with intellectual disability who I have described God is there as sacred presence.

6.3.2.3 Of Lives Uncontained

Up to this point of the narrative analysis the institutions under consideration have been described in largely pathological terms. The people with intellectual disability are principally understood as medically-needful people by dint of their imposed dependence on medical care. It is within such narrow parameters that Clapton asserts that these people are understood as the central participants in a tragedy discourse which employs an illness mode of understanding.[617]

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[616] Nouwen, Henri. *Adam: God's Beloved*. (Blackburn: HarperCollins Publishers, 1997), 53. He further recognises the sanctity of this caring relationship as a ‘Christ event’ “where spirit greets spirit in the body,” thus conceiving of a relationship immersed in the sacramental nature of life, and the incarnational character of Christ. See 54.

[617] Clapton, “A Transformatory Ethic of Inclusion,” 86.
See also,
Clapton, "Irrelevance Personified," 4.
Clapton, “Disability, Ethics, and Biotechnology,” 25-27.
That is, tragedy from a bio-technological perspective.
Clapton, and Fitzgerald, "The History of Disability,” 3. Here, disability institutions are seen, from a historical perspective, as “agents of custody for social control and institutional segregation ... predicated on notions of tragedy.”
See also,
Goggin, and Newell, Disability in Australia.

This containment paradigm is not only to be understood as intrinsic to the philosophical foundation of institutional practice but also in terms of the lived reality of those described in narrative terms earlier in this chapter. By dint of observing Alice as one who is ignored and 'talked over,' of Madge having privacy ignored, of Sally's name being not known, of Malcolm's abilities being limited by others, and of others being 'babysat' by colouring-in books and daytime television, we see people denied their full personhood, their identity and abilities. They are made to live restricted, contained lives.

However, at the same time, there are strong signs of a number of people who evince certain personal qualities and behaviours that indicate they are not fully contained by narrowly and negatively-constructed institutional philosophy and regimen. This is a very strong weft in the narrative tapestry in terms of an alternative and positive response to institutional containment.

Various people in the narrative discourses give evidence of beliefs and behaviours that are resistant to strategies of containment, that suggest a fuller expression of personhood than that determined by institutional philosophy and practice.

Within the worship context we see responses by worshippers who, through committed eucharistic observance and through the sensual embracing of the Good Friday cross, verify imagination and life far beyond that afforded by oppressive institutional routine. Amidst his seemingly mundane daily regimen we see Malcolm ecstatically announce his presence as the conductor who hears a music that others have not heard, the author of which comes from a place far beyond institutional bounds. Less demonstrably, but with seemingly as much intent, we see Christopher with coloured pencil in hand pressed firm against his paper become the artist whose creatively-contrived shapes and forms belie the ongoing constraints imposed by wheelchair and medical expectation. We see Madge who, despite unthinking invasions of space, still finds regular room in her relationships for kindness and gently-recalled familial memories that extend back to pre-institutional, childhood days. Amidst her small room, which passes for a gallery depicting her life, we observe Henrietta point with intent to the pictures,

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Here, disability is not only regarded as tragic in the sense of a Greek tragedy (3), but also as catastrophic, particularly from a bio-technological perspective (107).

Newell, "Otherness, Virtue and Ethics Committees,"4.

Here, the author autobiographically describes disability as medicalised tragedy.

awards and artefacts that so generously describe her as so much more than institutional ascriptions of frailty and dementia. Within the context of a life long lived within institutional bounds we see Gladys maintain her persistence in getting her story heard against a socio-political regimen that insists on its story prevailing. To the strains of ‘Climb Every Mountain’ there can be found those who, for the moments whilst Julie Andrews sings, are transported to the mountains of Austria, far away from that place that assiduously monitors and records their movements and symptoms. And there is Jim, ailing, dying Jim, who, despite living the majority of his life behind institutional walls, despite living for decades at the behest of oppressive medicalised routine, despite countless hospitalisations and having a body fraught with cognitive and physical frailty and vulnerability, is still, in his final days, able to look beyond that which contains his dying physical body and find a spirit that enables him to offer a personal blessing to another.

Finkelstein speaks of the type of institution mentioned in this extended reflection as offering a context for living that leads to social death.[618] Much which offers life to people is denied or severely curtailed in this lived context including familial relationships and friendships, private spaces, broad-based cultural enrichment and community networking. So, whilst living in such a life-denying context, what is it that seems to enable some at least to show evidence of life that refuses to bow to institutional philosophy and practice?

I would argue that such a question cannot be definitively answered, just as institutionalised persons such as Barry, Angela, Eileen, Nicole, Mario, Janet, Rodney and Howard are probably unable to describe why it is they seem to gain value and meaning from the simple act of taking into themselves bread and juice signifying the body and blood of Christ. However, I would argue that when we look to twentieth century asylum narratives we find some instructive wisdom that sheds light on this issue.

Brian Keenan went to live in Beirut in 1985 as an alternative lifestyle to that afforded by his native Belfast. He soon found himself kidnapped by fundamentalist Shi'ite militiamen and held in the suburbs of Beirut for the next four and a half years. He was brutally incarcerated in his personal asylum.

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[618] Finkelstein, "Disability: An Administrative Challenge?” 21.

Amidst a de-humanising environment, in which he endured constant privations and death-threatening experiences, he found cause to maintain a personal diary. He describes the value of maintaining this ritual amidst such an oppressively containing environment.

> At first I could see no meaning in this jumble of words, of images, thoughts, prayers, observations and emotions. At times I thought I should tear it up and throw away my two-inch stub of pencil. But I couldn't do it, and as the pages filled up more and more, and I recorded more and more of this unexplored landscape, I felt myself become helplessly lost in it. But I could not stop, for to see what has previously been invisible is powerfully captivating. Eventually it came to me that here in these pages there was something I could only dimly perceive, some threads running through and holding it together like the veins that carry blood to the living heart. Here in all this confusion some veins of life held everything together. I don't fully know what it was, yet remember feeling that in these strange pages was a whole human being.[619]

I would argue that it may well be that the uncontained practices outlined in this chapter afford these people who live with intellectual disability in an institutional context what Keenan refers to as ‘veins that carry blood to the living heart.’ In doing so, they gain a glimpse, probably unconsciously, of a more fully human identity than that offered by the institution.

Elsewhere, Keenan also speaks of how in such a situation of extreme deprivation, where one is denied the simple pleasures that are otherwise taken for granted in more ordinary circumstances, these pleasures serve as life-sustaining metaphors when accessed in such a contained environment. As he states of a simple bowl of fruit,

> The fruits, the colours, mesmerize me in a quiet rapture that spins through my head. I am entranced by colour. I lift an orange into the flat filthy palm of my hand and feel and smell and lick it. The colour orange, the colour, the colour, my God the colour orange. Before me is a feast of colour. I feel myself begin to dance, slowly, intoxicated by colour. ... Such wonder, such absolute wonder in such an insignificant fruit. ... I cannot, I will not eat this fruit.[620]

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[619] Keenan, *An Evil Cradling,* 81.
As noted earlier in this chapter, in the face of concentration camp incarceration and imminent death Etty Hillesum also maintained a diary that afforded her opportunity for order and creative imagining that, in spiritual terms, took her to uncontained places beyond the camp, affording her a sense of freedom from her oppressive circumstances.
Hillesum, An Interrupted Life.

[620] Keenan, An Evil Cradling, 68.

I would contend that the uncontained behaviours of these institutionalised people are realizing a sense of uncontained meaning and purpose that goes beyond the pure mechanical meaning of that which they are doing. For Christopher, drawing shapes on paper with coloured pencils is more than artistic activity. For Gladys, her persistence in wanting to relay family details means more than simply relating news from one to another. For Malcolm, conducting the orchestra to the music that he alone hears is more than the need to stand up and joyously gesticulate. For Henrietta, the revealing of her life story is more than the articulation of personal life details to another. And the taking of bread and juice into oneself represents more than simple participation in a regularly-celebrated religious ritual, just as the embracing of a simple wooden cross on Good Friday represents more than the simple clasping of bits of wood. As with the light from beyond that shines through stained glass windows revealing colours otherwise dulled, each of these experiences serves as a sacrament, liturgical and everyday,[621] that points beyond themselves to a life that affords a

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[621] A theologically orthodox conceptualisation of sacrament describes Christ as the one, true sacrament. See, for example,

Barth, Karl. *Church Dogmatics, Volume 4: The Doctrine of Reconciliation, Part 2*. Edited by G Bromley and T Torrance, *Church Dogmatics*. (Edinburgh: T & T Clark Ltd, 1978), 55. Here, the author states that "there is no sacramental union and unity at all as distinct from the unity of God and man (sic) in their unity as it is grounded and achieved in Jesus Christ. ... the one and only sacrament." Elsewhere Barth elaborates upon such creaturely identity in revelatory terms. See,

Barth, Karl. *Church Dogmatics, Volume 2: The Doctrine of God, Part 1*. Edited by G Bromley and T Torrance, *Church Dogmatics*. (Edinburgh: T & T Clark Ltd, 1980), 52.

Here he states, "We can say quite simply that revelation means sacrament, i.e., the self-witness of God, the representation of His truth, and therefore of the truth in which He knows Himself, in the form of creaturely objectivity and therefore in a form which is adapted to our creaturely knowledge."

Whilst orthodox Christian theology most specifically locates this revelation of Christ in the context of liturgical ritual, there are those of a more progressive, liberal persuasion who describe sacrament in more universal terms. For example, see,

Schmemann, Alexander. *The World as Sacrament*. (London: Darton, Longman & Todd Ltd. 1974), 16.

Here the author speaks of the Eucharistic celebrant as one who stands "... in the centre of the world and unifies it in his act of blessing God, of both receiving the world from this eucharist, he transforms his life, the one that he receives from the world, into life in God, into communion. The world was created as the 'matter,' the material of one all-embracing eucharist, and man (sic) was created as the priest of this cosmic sacrament." 16. See also,

Weil, Simone. *The Notebooks of Simone Weil: Volume Two*. Translated by Arthur Wills. 3 vols. Vol. 2. (London: Routledge & Kegan Paul, 1956), 335.

Here, the author employs the concept of sacrament, in a secular sense, to refer to the capacity of material objects, such as a letter, ring or book, to point beyond itself (Plato) as a reminder of deceased or living lovers and friends. It is in this context that reference is made in the narrative analysis to that of an everyday nature that points beyond itself to a greater reality, beyond institutional conceptualisation.

richness and clarity and is described with its attendant meaning and a value that is far beyond institutional conceptualisation.

To speak of the uncontained behaviours of the people accounted for in these narratives is not to proclaim them as saints. Certainly they are not. Christopher can lash out, just as Henrietta can be mean-spirited. They are human and amidst their humanity they display a sense of resilience, a spirit, an inability to be completely restrained and contained by a system that regards them as deficient beings, as the objectified other.

And amidst the joy and sorrow of their very human lives, I, as a fellow human being and pastoral carer with these people, hold more fervently and realistically than ever to my reformed faith tradition that speaks of a God who, through Christ, comes in full humanity, and in the fullness of a God proclaimed as love to these people and to me.

But what of those who, to my pastoral observance, appear to show little spirit or signs of vitality, who anonymously shrink back in their chairs, who seem to have relinquished their story to the power of the institutional narrative? Are they fully contained? Where is God for them? Philosopher and mystic Simone Weil in speaking against the growing socio-political menace of 1930s' Nazi Germany, stated,

> In those who have suffered too many blows, in slaves for example, that place in the heart from which the infliction of evil evokes a cry of surprise may seem to be dead. But it is never quite dead; it is simply unable to cry out any more. It has sunk into a state of dumb and ceaseless lamentation.[622]

Elsewhere, Weil speaks of this oppression "pulverising the soul,"[623] but the soul cannot thus be defeated by the collective. That which maintains life is stronger than that which can oppress.

Weil can be understood as saying that the one who is ceaselessly made to suffer may reach the point where their capacity to communicate, to cry out against their injustice, becomes completely muted. One's human spirit may seem utterly crushed. Nonetheless, whilst that element of the soul that cries out has been silenced, the soul itself, although dormant, is still alive.

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[622] Weil, Simone. "Human Personality." In *The Simone Weil Reader,* edited by George Panichas, 313-39. (New York: Moyer Bell Limited, 1977), 316.

[623] ibid., 331.

In pastoral, theological terms, I would claim that Alice, as with all others, is created and lives as one made in the image of God and is loved by the One whose character it is to set free those contained and oppressed by socio-political circumstance. That is the One who, according to the Old Testament Exodus tradition, sets free the captives in Egypt and establishes nationhood and identity in a 'promised land.'[624] This is also the One who, according to Old Testament prophetic tradition, releases the imprisoned[625] and restores land, life and national identity to those held in exile as outlined, for example, in Deutero- and Trito-Isaiah.[626] This is the One who, in the person of Christ, proclaims "release to the captives and … [lets] the oppressed go free."[627] It is this God who graciously accepts people at the level of their being, ahead of any level of achievement. And so, amidst Alice's lack of responsiveness, it can be claimed there is God. And where there is God, there is life. Alice is not contained. Amidst her humanly-described anonymity, there is God.

The issue for me amidst my humanity and frailty, revealed so powerfully through Jim's eloquent blessing, is how to respond pastorally to these who have revealed so much of themselves through their stories. What model of pastoral care can most completely and authentically offer liberation to a people described as oppressed by institutional circumstance, although with uncontained wefts of pastoral presence, mutual relationship and spirit defiantly and vividly woven into the fabric of their lives. This is the task of the ensuing chapter.

6.4 Summary

As a Uniting Church chaplain I understand that I exercise a pastoral ministry with the valued resources of my faith tradition. The Basis of Union that undergirds the life and order of my church stands within a Reformed scriptural

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[624] National Council of the Churches of Christ in the United States of America, Holy Bible, Old Testament. See the Old Testament Pentateuchal books.

[625] ibid., 670, Isaiah 42:7; and 679, Isaiah 49:9-10.
National Council of the Churches of Christ in the United States of America, Holy Bible, Old Testament, 884, Zechariah 10:11-13.

[626] ibid., 667-698, Isaiah chapters 40–66.
Here the focus is upon the children of Israel as slaves in exile, as well as upon deliverance from slavery.

[627] National Council of the Churches of Christ in the United States of America, Holy Bible, The New Testament, 61, Luke 4:18.
Bracketed word is that of thesis author.

tradition. This is undergirded by its historic documentation which endorses, sustains and informs a ministry that seeks Christ-centred pastoral engagement with contemporary, culturally-grounded institutions such as the ones that accommodate people with intellectual disabilities.

This scriptural tradition also enables me to regard those with whom I pastorally engage as created fully in the image of God, along with myself and all humanity. This enables me to view the one before me, not as an objectified, medicalised identity, but as one with whom I can engage in mutually-enriching, loving relationship. The other person is a person with a disability, not a disabled person.

I belong to a church with a strong missional tradition. I exercise my pastoral ministry within, and not apart from, a contemporary society with its contemporaneously-constituted institutions. It is not for my church to approach ministry in the belief that she is equipped with all the faith-based resources required for fruitful ministry in the contemporary world. My church better understands her nature and mission through fruitful engagement with contemporary society. I better understand my God-given identity and the nature of my chaplaincy through honest engagement with those with whom I engage in pastoral ministry.

I better understand the nature of that ministry through seeking to faithfully understand the narratives of those with intellectual disability who live in institutions. It is these stories that help me understand the institutions in which they live and the ways in which institutional relationships and routines determine the lives of those therein.

They are stories that describe patterns of containment and oppression, but they are also stories that reveal uncontained lives. Threads of liberation are present. Oppression is challenged through unconditional presence and a mutuality of pastoral relationship that reveal the true worth of all God’s people. But they are also threads that reveal my own God-given identity and need of that other person. For in that other person there is God loving me.

The narratives thus analysed and understood invite careful consideration of the pastoral model that most fully and effectively affords liberation to these people with intellectual disability.

6.5 How Do I Regard the One Before Me?

And so, in the light of the revelation of these narrative wefts, how do I regard the one before me, the one who can be observed as the Slave?

I begin to see the one before me as so much more than a Slave. Yes, there are the marks of oppression, the stories of abuse, privation, disempowerment, neglect and acquiescence. These are clear and present. They are the visible wounds of the one who's been incarcerated. They are there to be seen. They should be seen, because for too long they have been wounds hidden from the light of day by those who inflict and harm. They should be seen because without that light the wounds will remain to fester; they cannot be treated and healed. Without honest revelation, the wounding, the oppression will continue unabated. The wounding will be seen as normal, and normal becomes acceptable and necessary. But as the one before me reveals something of their incarcerated story, I begin to see a fuller, more human identity.

I no longer sit as an observer but as one who needs to be fully present, not judging but accepting, not telling but listening, not quick to do but prepared to be. I begin to see someone who is more than an oppressed, wounded person. There is now one who describes a story of spirit and vitality, of attitudes and behaviours that transcend the ties that bind and harm. This person not only has a story that reveals their humanity to me, but a humanity that touches and wounds me, yet restores me to life.

It is also a story that radically challenges and changes my perspective. This person before me is no Slave, never has been, never will be, not to my eye. They are a fellow human being and child of God. I realize I am a mutual participant in life with this one with whom I now share in humanity as a wounded yet loved child of God. I realize my need of the child of God before me just as the one with whom I am fundamentally connected may have regard for the child of God in me. We need each other to experience love. We need each other to be whole. We need each other to see God, and experience the God whose image is impressed on all humanity.

CHAPTER SEVEN

TOWARDS A LIBERATING PASTORAL MODEL: IMMANENT THOU-NESS

> ‘Teacher, which commandment in the law is the greatest?’ He said to him, ‘You shall love the Lord your God with all your heart, and with all your soul, and with all your mind.’ This is the greatest and first commandment. And a second is like it: ‘You shall love your neighbour as yourself.’ (Matthew 22:36-39)[628]

> He sat in front of me in his chair, and I ‘saw’ the divine significance made visible in him. Adam, I believe, had a heart where the Word of God was dwelling in intimate silence. Adam, during our time together, led me to that intimate indwelling where the deepest significance of his and my humanity was unfolding.
>
> Adam’s humanity was not diminished by his disabilities. Adam’s humanity was a full humanity, in which the fullness of love became visible for me, and for others who grew to know him.[629]

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[628] National Council of the Churches of Christ in the United States of America, Holy Bible, New Testament, 25.

[629] Nouwen, *Adam,* 50-51.

Plate 7.1

‘Dying Slave’

by

Michelangelo Buonarotti

[630]

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[630] Ruehring, Lauren. *Dying Slave by Michelangelo* HowStuffWorks, Inc, 2011 [cited 30/12/2011]. Available from http://entertainment.howstuffworks.com/arts/artwork/michelangelo-sculptures11.htm

7.1 Laying the Foundation: Contributing Pastoral Models

The narrative analysis and the ensuing strong threads detailed in the previous chapter point to the development of a unique pastoral model specific to the people and context under consideration in this extended reflection. Nonetheless, due acknowledgement must be given to those pastoral models that most pointedly influence the development of an appropriate model through their inclusion of various of the outlined strong threads. Such pre-existing models articulate a liberating goal and in their own way provide inspiration for the development of a pastoral model appropriate to this extended reflection. Furthermore, these models contain points of intersection one with another.

7.1.1 The Wounded Healer

The notion of pastoral care as Wounded Healer is located within that contemporary paradoxical array of pastoral models that juxtapose seemingly contradictory images into a pastoral metaphor that seeks to address the varied and seemingly conflicting array of responsibilities and expectations of the pastoral carer.[631] Other such models include The Wise Fool, The Intimate Stranger and The Ascetic Witness.[632]

The Wounded Healer was first articulated in 1979 by Catholic priest Henri Nouwen. It seeks to generate an incarnately-described point of connection between the minister and the one who is pastorally served by seeing the world's woundedness transcribed in the minister's own heart.[633] Woundedness is most particularly understood in existentially-transcribed loneliness in which an all-pervasive sense of social competition and rivalry creates isolation of one from another.[634] The minister who serves such isolated people seeks to address such loneliness but is confronted by a coldness of heart and a church which has become peripheral to the needs of a rapidly-changing world.[635] Thus, the minister shares with others in an isolation generated by such a world. As competition

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[631] Dykstra, Robert. "Paradoxical Images of Care." In *Images of Pastoral Care: Classic Readings*, edited by Robert Dykstra, 69-75. (St. Louis: Chalice Press, 2005), 69.

[632] ibid., 94-149.

[633] Nouwen, The Wounded Healer.
See also,
Nouwen, Henri. "The Wounded Healer." In *Images of Pastoral Care: Classic Readings*, edited by Robert Dykstra, 76-84. (St. Louis: Chalice Press, 2005).

[634] Nouwen, The Wounded Healer, 83.

[635] ibid., 85-87.

disconnects people from those around them the minister experiences disconnection from the community which is there to be served. In the language of Pattison, this disconnected status places the pastoral carer into the thoroughly incarnate realm of failure and sin.[636]

The minister who can be accepting of such personal woundedness can become a source of hospitality to other wounded people who come to be regarded as guests. Access to the soul of the other becomes possible through gaining access to one's own soul.[637] The guests can be offered a friendly space in which the soul's loneliness can be shared. A sense of community is created and healing is thus offered to the otherwise isolated soul.[638]

Nouwen specifically regards this pastoral model from a just liberationist perspective when he states,

> In the middle of our convulsive world men and women raise their voices time and again to announce with incredible boldness that we are waiting for a Liberator. We are waiting, they announce, for a messiah who will free us from hatred and oppression, from racism and war – a messiah who will let peace and justice take their rightful place.[639]

McNamara specifically equates the carer, and those with disability for whom they care, with the wounded persons of Nouwen's pastoral model. The disabling effects of the ageing process generate isolation from the lionised, autonomous, rational individual who stands at the centre of liberal Western society. However, in their isolated position, they can gain a wisdom derivative of assuming the status of a Wounded Healer. As such, they are in a position to offer hospitality or friendship to the guest, no matter the disabled status or autonomy of the visitor.[640]

The contribution of this model to the understanding of a pastoral model pertinent to this extended reflection is that it understands the carer and the other person as those who are both wounded and receive healing through recognition of their shared wounded status. Particularly pertinent is the implicit notion that

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[636] Pattison, A Critique of Pastoral Care, 143-153.
[637] Capps, Pastoral Care and Hermeneutics, 110.
[638] Nouwen, The Wounded Healer, 92-94.
[639] ibid., 81.
[640] McNamara, "Ethics, Ageing and Disability", 36-38.

caring takes on a liberating aspect, not through notions of expertise, power or authority but through a shared sense of incarnately-understood woundedness.

7.1.2 Hospitality

The notion of hospitality incorporated into Nouwen's model of Wounded Healer describes a space of welcome in which those who enter are afforded non-judgemental regard, a place where healing and care is available to all. Nouwen further articulated this pastoral model in his volume *Reaching Out* where he primarily describes hospitality as "the creation of a free space where the stranger can enter and become a friend instead of an enemy. Hospitality is not to change people, but to offer them space where change can take place."[641] Here, the implication is that the carer does not fill the space with activity and words for to do so is oppressive.[642] Alternatively, the other is free to discern their God-given identity.

It is a means of expressing welcome to the stranger who, because of their perceived threat, can be so easily regarded with hostility.[643] In invoking Old Testament notions of hospitality to the stranger Dykstra addresses the clinical setting in a holistic manner. He speaks of the chaplain addressing the practical needs of those experiencing trauma in the hospital setting, of advocating for rights and searching for adequate theological responses to trauma which may sometimes see the chaplain sitting silently with the one who is traumatized.[644]

Yong radically develops the notion of welcome to the stranger around the Pentecostal understanding of the Spirit of God being 'poured out on all flesh' (Acts 2:17), both 'believers and unbelievers' (Romans 12:13-21).[645] Hospitality extends beyond traditional denominational and faith notions of membership to be inclusive of all at an individual and structural level. As Yong asserts, "it is in this wider eschatological framework ... that we see that the hospitality of God involves not just interpersonal relationships but also the structural relations of common humanity (Isa.35:15-20)."[646] Within this universal framework of

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[641] Nouwen, Henri. *Reaching Out*. (Glasgow: Collins Fount Paperbacks, 1980), 68-69.

[642] ibid., 70.

[643] ibid., 66-68.

[644] Dykstra, Robert. "The Intimate Stranger." In *Images of Pastoral Care: Classic Readings,* edited by Robert Dykstra, 123-36. (St. Louis: Chalice Press, 2005), 131-33.

[645] Yong, Amos. *Hospitality and the Other: Pentecost, Christian Practices and the Neighbour*. Edited by William Burrows, *Faith Meets Faith: An Orbis Series in Interreligious Dialogue*. (New York: Orbis Books, 2008), 62-63, 143.

[646] ibid., 143.

hospitality all people have the capacity to be guests and hosts to each other. In thus expressing welcome God’s true redemptive character is revealed.[647]

Again, McNamara equates such notions of hospitality to people with disability serving to reveal to us our true humanity.[648] It is through openness to the stranger that we discover our true collective identity.

The contribution of this model to the understanding of a pastoral model pertinent to this extended reflection is that it challenges the carer to understand relationship in a broad-based, non-judgmental form in which God’s redemptive character is revealed. It describes a pastoral space which the carer does not fill with his or her agenda, that is, with words and activities that suggest that the carer knows best. To do so unjustly imposes power over the one who shares that same space with the carer and who needs the freedom to fully articulate their own pastoral agenda in an accepting, interpersonal environment.

7.1.3 Liberating Presence

Whilst much has been said regarding presence in the previous chapter it is worth naming the benefits of this model of care specifically from a socio-political, liberationist perspective.

Janet Stokes describes Presence as a model of care which is a "form of servanthood ... characterized by suffering, alongside of and with the hurt of the oppressed ...”[649] In suffering with the other as they consider agonising life decisions, the pastoral carer gives expression to the brokenness of God.[650] In giving pastoral expression to such brokenness, the pastoral carer models God’s incarnate care and concern for suffering humanity, including those with intellectual disability marginalised through their institutional location.

Presence, thus described, regards care as a deliberate political act in which the carer chooses to side with the vulnerable person in opposition to those socio-political forces and institutions that oppress. For the pastoral carer it invites keen awareness of the socio-politically constituted context in which the carer exercises care. As Pattison asserts, it is a pastoral care model that takes place amidst the

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[647] ibid., 159-60.

[648] McNamara, “Ethics, Ageing and Disability”, 42.

[649] Stokes, "Ministry of Presence," 192.

[650] Newell, "Pastoral Care and Ethics,” 104.
See also,
Calder, "God Has Chosen This for You," 15.

values of justice and peace.[651] As Swinton claims, from a mental health perspective, the very act of 'being with' those who have been historically oppressed is of itself an act of liberation.[652] It is a 'being with' which, whilst certainly not dismissive of pastoral care as action, firstly places the focus on relationship rather than task.[653]

It is also an act of friendship because friends don't have to do anything to realize their friendship.[654] Solidarity and strength can be found in the one who is simply committed to the other as a friend. Such commitment contains a liberating dimension when considered in contrast to the prevailing medicalised mode of institutional relationship. It dares to value the whole person and not just the objectified medical identity.

In terms of developing a liberating model of pastoral care for people with intellectual disability this point is invaluable because it accords value in terms of who they are rather than their limited cognitive capacity. It also acknowledges the socio-political location in which the caring occurs, thus accounting for the effect of place upon the lives of those who engage in pastoral relationship. It also describes the need for the pastoral carer to divest himself or herself of all that may prevent the carer from being fully attentive to the agenda of the other.

7.1.4 Embrace

This is a pastoral model originally authored by liberation theologian Miroslav Volf in his volume, *Exclusion and Embrace: A Theological Exploration of Identity, Otherness, and Reconciliation.* Against the radical exclusionary nature of 'ethnic otherness,'[655] he develops a four-part pastoral process called 'Embrace' which is defined as "the will to give ourselves to others and 'welcome' them, to readjust our identities to make space for them, ... prior to any judgement about others, except that of identifying them in their humanity."[656] It is at the point of 'identification of humanity' that this model bears application to those 'medicalised others' who are the focus of this extended reflection.

The process of embracing is thus described:

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[651] Pattison, A Critique of Pastoral Care, 99.

[652] Swinton, Resurrecting the Person, 22.

[653] O'Connor, Thomas. "Ministry without a Future: A Pastoral Care Approach to Patients with Senile Dementia." *The Journal of Pastoral Care* 46, no. 1 (1992): 5-12, 12.

[654] Swinton, Resurrecting the Person, 190.

[655] Volf, Exclusion and Embrace, 57-92.

[656] ibid., 29.

1. Opening the arms: This is a self-emptying gesture, by which the carer reaches out to the other out of a sense of discontent with one’s self-identity alone. The opening of arms signifies an invitation to the other for relationship and creates a space into which the other may enter.[657]
2. Waiting: This stance suggests a preparedness to see whether or not the other person
   wishes to accept the invitation of an embrace. The embrace cannot be coercive in nature. It can only be because both persons freely desire to embrace.[658]
3. Closing the arms: This is the goal of embrace. Each person enters the space of the other, feeling the presence of the other, and making their own presence felt as well. Presence of each for the other is felt softly so as to preserve the identity of each, but to also allow for transformation as the alterity of the other is partly received into the ever-changing identity of the self.[659]
4. Opening the arms again: A letting go is required so that the alterity of the other is preserved, and the self takes its self back into itself so that its own enriched identity may be preserved. The differences of one identity from the other must be negotiated.[660]

In this pastoral model there is no sense of imposition of one upon the other, nothing that generates the experience of relational powerlessness. Those involved in the relationship are empowered to choose or not choose to engage in the act of embrace. This equates with systems that can serve to oppress or liberate. As Volf claims, “when structures and persons that perpetuate powerlessness are replaced by structures that allow people to stand on their own feet and have their own voice, we speak of liberation."[661]

Volf is describing social systems concerned with binding and separating, and that exclusion concerns being bound in relationships that stifle the full expression of humanity. This bears close relation to the binding nature of those institutions that are the focus of this extended reflection and to which Hallahan

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[657] ibid., 141.
[658] ibid., 142-43.
[659] ibid., 143.
[660] ibid., 144-45.
[661] ibid., 102.

refers in reference to Volf when she states, “[o]ur history of institutionalisation, and congregation into human services and special schools certainly fits here, and shows up the other side of exclusion: segregation and separation.”[662]

The relevance of ‘Embrace’ to this extended reflection is two-fold. Firstly, it serves to explain exclusion in a manner that describes the oppressively disempowering and segregating nature of institutions and the effect of institutional influence upon those for whom they bear responsibility. Alternatively, it also holds up a vision of liberating relationship for people with intellectual disability, one characterised by empowerment, freedom of choice, nurtured identity and mutual regard.

7.1.5 Journey

The concept of care as Journey invites consideration of pastoral care as an ongoing process. Engagement between carer and cared is not defined in terms of momentary encounter but as commitment and communion.

Hallahan evokes the immigrant image of the journey to the distant Australian shore to deconstruct myths and sentiments concerning the concept of community. In confronting these lies[663] she advocates for community solidarity with those who live with disabilities, a “we mentality.”[664] It is a communion that says that not all humanity has walked away from people with disability and the prejudice, separation and segregation they have experienced and do experience through institutional living. There is strength to be received by the oppressed through a moral commitment to journeying,[665] a strength that states that all life is worthy, including the lives of those who live with intellectual disability.

This is a shared journey that allows life to be lived with dignity on an ongoing basis, even in the knowledge that ideals concerning full inclusion and an end to prejudice may remain distant. As Hallahan states, “I believe a reachable ‘farther shore’ is not so much a place to attain as a journey to be made in company.”[666]

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[662] Hallahan, Embrace, 20.

[663] Hallahan, Lorna. ""Believe That a Farther Shore Is Reachable from Here": Mapping Community as Moral Loving Journeying." In *Voices in Disability and Spirituality from the Land Down Under*, edited by Christopher Newell and Andy Calder, 33-44. (New York: The Haworth Pastoral Press, 2004), 35.

[664] ibid., 39.

[665] ibid., 40-41.

[666] ibid., 41.

Campbell asserts that a fundamental quality of the communal journey is that of companionship in which bread is shared. Such interpersonal engagement asserts the need to share resources in order to survive as human beings, and to restore lagging faith[667] We share what we have with the other not out of relational superiority but because, in seeking to address the need of the other, we acknowledge such need in ourselves. As Campbell states, "[i]f we manage to speak to their fear it is because we know it ourselves and make ourselves no better than they in pointing it out. If we manage to comfort their sense of loss, it is only because the loss strikes to our heart and starts tears in our eyes."[668] To this, Newell, from an embodied disability perspective, concurs, in his assertion that genuine human journeying involves an acceptance of personal imperfection and frailty.[669] Such sentiment describes a journeying born of needful humanity and genuine mutuality.

The hermeneutical circle as described in the methodology chapter indicates the importance of developing a pastoral model whereby the pastoral carer shows commitment to people with intellectual disability on an ongoing, journeyed basis. This is a pastoral model of incomplete conclusions. The ongoing institutional narratives will keep changing, requiring an ever-evolving pastoral understanding and modelling. So the major issue concerns the pastoral carer staying committed to caring for those for whom he or she bears responsibility. The point of this is two-fold. Firstly, it shows that people with intellectual disability deserve the most liberating form of pastoral relationship available at any given moment in time. Also, through pastoral commitment, it shows that these people are not alone, that they are worthy of being 'journeyed with,' in communion, in heartfelt, human mutuality, to that reachable 'farther shore.'

And so a liberating model of pastoral care is sought that not only takes cognisance of the strong narrative threads detailed in the previous chapter but also seeks to comprehensively build upon the liberating qualities detailed in these pastoral models.

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[667] Campbell, Rediscovering Pastoral Care, 91.
[668] ibid.
[669] Newell, Promises, Promises, 36.

7.2 Towards a Liberating Conceptualisation of Mutuality

In the previous chapter the concept of a mutuality of care was identified as a strong thread evident in the pastoral narratives. This pastoral concept was described in shared, reciprocal terms whereby both the person with intellectual disability and the chaplain bring to the relationship an identity, qualities and resources that the other needs. At the same time I regard the other person and I as whole, relational, human beings created in the image of God. It is this identity that is nurtured and sustained in the context of the pastoral relationship that develops between the other person and I. A relationship of healthy, loving dependence emerges. Whether it is explicitly or implicitly understood we need each other to more fully be the people we were created to be.

With the detailing of an appropriate pastoral model being the principal aim of this chapter, such a model, no matter its eventual shape, requires a sound foundation upon which it can be based. The foundation concerns a suitably-formulated conceptualisation of a mutuality of care as outlined above. However, for the concept to be appropriately understood more detail is required than has thus far been tendered, either through the strong narrative threads or through the detailing of relevant pastoral models. It is particularly necessary to detail a conceptualisation that is undergirded by a relevant and thorough understanding of liberation from a pastoral theological perspective. This is necessary because it is those people with intellectual disability who live in institutions who require a pastoral model that offers a theologically-derived sense of liberation from their oppressive circumstances.

7.2.1 Mutuality Expressed as Immanent Thou-ness: “I and Thou”

In 1923, writing from a Jewish, mystical perspective, Austrian-born philosopher and religious existentialist Martin Buber wrote *I and Thou*, a seminal essay on the nature of human existence. It is an essay which is most instructive for this extended reflection in terms of developing a pastoral model with an authentic, liberatory foundation described in terms of mutuality.

In this work, Buber, from a human orientation, details a two-fold perspective of the world, namely ‘I-Thou’ and ‘I-It.’ The former term is expressive of one’s whole being, the world of relation in its pure, universal form, whilst the latter speaks in bounded, objectified terms.[670] The realm of Thou-ness is where causality is no more, where objectively-regarded material acquisitions are cast to one side as one approaches the Eternal, unencumbered and free.[671] As Buber asserts, it is in the hallowing of life that one encounters the living God.[672]

In contrast, the realm of It-ness develops out of a lack of true relation. In place of accepting what is in the present moment, that which is of this world is quantified, classified and managed. This is the realm of suppression[673] or, in terms of the language of this extended reflection, oppression. Indeed, Buber exemplifies this notion by reference to institutions.

> Institutions are ... where all sorts of aims are pursued, where a man (sic) works, negotiates, bears influence, undertakes, concurs, organises, conducts business, officiates, preaches. They are the tolerably well-ordered and to some extent harmonious structure, in which, with the manifold help of men’s brains and hands, the process of affairs is fulfilled.[674]

This is the realm which represents the antithesis of the unfettered expression of feelings which of themselves give expression to a mutuality of relationship. Instead, feelings are contained in the interests of a more mechanised world view.[675]

Such a culture of suppression even extends to one’s regard for God who, through the pursuit of possession and objectification, assumes the form of It-ness.

> Man desires to possess God; he desires a continuity in space and time of possession of God. He is not content with the inexpressible confirmation of meaning, but wants to see this confirmation stretched out as something that can be continually taken up and handled, a continuum unbroken in space and time that insures his life at every point and every moment.
> ... Thus God becomes an object of faith.[676]

Such consideration of It-ness does not mean to suggest that this scientific, objectified realm counts for nought. The sense in Buber’s volume is that It-ness requires the ongoing infusion and nurturing input of Thou-ness so that one can

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[670] Buber, Martin. *I and Thou*. (Mansfield Centre: Martino Publishing, 2010), 3-6.
[671] ibid., 51-53.
[672] ibid., 79.
[673] ibid., 39-40.
[674] ibid., 43.
[675] ibid., 45.
[676] ibid., 113.

fulfil roles and relationships in the realm of It-ness "with free heart in the universal bounds of fate."[677]

However, in contrast to It-ness alone, in the realm of Thou-ness, Thou is allowed to be Thou[678] for this is the unfettered realm of relation. This is the realm in which "I" is absorbed up into Thou-ness, into one thinking essence with the Eternal.[679]

This is the realm in which the Eternal is experienced in the Thou-ness of the other. Indeed, Buber variously refers to God in terms of Face.[680] This is the realm in which encounter with the Thou confirms meaning.

This is the realm of the Spirit, where the I encounters the Thou, like the air we breathe,[681] uncontained, ever-present and energising, maintaining the essence of the encounter.

Within this realm the I encounters the Thou through grace. This is not an act of seeking by the I. Indeed it is the Thou who meets the I amidst the act of the I's being.[682] Through being met, the I encounters grace.

This is the realm of revelation, of elemental human transformation, where "ever new provinces of the world and spirit are raised to form, summoned to divine form. Ever new spheres become regions of a theophany".[683] This is a moment beyond experience; it is heightened reality; this is "the cradle of Real Life."[684] And it is within this realm of revelation that the transcendent moment is realized, as Buber describes in almost biblical imagery when he speaks of "... the great shudder, the holding of the breath in the dark, and the preparing silence."[685] For this is a moment not to be contained by words. Only silence can describe the moment.

Furthermore, and of particular import to this extended reflection, this revelatory, transcendent realization of the I-Thou relationship is to be regarded in terms of mutuality. There is a shared recognition of the Thou in the Face of the other: "Between you and it there is mutual giving: you say Thou to it and give

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[677] ibid., 55.
[678] ibid., 112.
[679] ibid., 89.
[680] ibid., 53, 83, 118.
[681] ibid., 39.
[682] ibid., 11.
[683] ibid., 117.
[684] ibid., 9.
[685] ibid., 119.

yourself to it, it says Thou to you and gives itself to you."[686] In the language of this extended reflection, in the face of the other, each person sees the image of God.

It is a mutuality that expresses itself in terms of immanent sharing, one with the other: "[h]ere alone, then, as reality that cannot be lost, are gazing and being gazed upon, knowing and being known, loving and being loved ... true address receives true response."[687] This is the language of intimate, mutual relationship, of lovers for whom there is only now, who dare not seek to quantify the moment at risk of the moment being lost. This transcendent image is Buber's intention.

Whilst this moment cannot last, and the realm of It-ness renews focus, there is that which can be taken from the realm of Thou-ness into the realm of It-ness, and that is a confirmation of meaning. Encounter with Thou-ness is not an end in itself. Such revelation is of the nature of the commissioning of disciples. As Buber describes, "meeting with God does not come to man in order that he may concern himself with God, but in order that he may confirm that there is meaning in the world. All revelation is summons and sending."[688]

As the realization of Thou-ness diminishes and the boundedness of It-ness re-emerges God assumes a more objectified form, that is, It-God. Whilst God can no longer be realized in terms of revelation it becomes incumbent upon the It, with the acquired meaning, to speak about God, thus assuming a missional mantle.[689]

Thus, as with the ongoing and ever-developing nature of pastoral analysis and ever new pastoral modelling inherent in the hermeneutic process of this extended reflection, salvific-type work assumes a spiralling form. The I returns to a world of oppression, and the Thou serves as an ever more vivid bearer of revelatory meaning. As Buber asserts hopefully,

> In each new aeon fate becomes more oppressive, reversal more shattering. And the theophany becomes ever nearer to the sphere that lies between beings, to the Kingdom that is hidden in our midst, there between us. History is a mysterious approach. Every spiral of its way leads us both into profounder perversion and

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[686] ibid., 33.
[687] ibid., 103.
[688] ibid., 115.
[689] ibid., 115-16.

> more fundamental reversal. But the event that from the side of the world is called reversal is called from God's side salvation.[690]

7.2.2 Mutuality: Thou-ness and Coming Down the Mountain

It is my assertion that Buber's conceptualisation of Thou-ness, in terms of this extended reflection and my conceptualisation of a liberating foundation of mutuality, affords considerable merit for which I'm indebted, but also warrants thoughtful critique.

I am indebted to the regard he invests in the other with whom relationship is sought, a regard he sanctifies in terms of Thou-ness. For Buber, relationship with the other is not simply relationship with another human being, but an invitation to be drawn up into an encounter beyond objectifying constraints, the Face of the Eternal. The invitation to realize such relationship with one's whole undivided being represents a sacred calling "... out of the false security into the venture of the infinite – out of the community, that is now overarched only by the temple dome and not also by the firmament, into the final solitude."[691] In terms of this extended reflection it is thus a calling to infuse the sacred into the temporal relationship with people with intellectual disability, who live in the institutional context. Far beyond the level of medicalised, objectified regard relationship is sought that invites one to see "life face to face with God ..."[692]

The term 'Thou-ness' also affirms the one with whom relationship is sought as one who is beyond objectified definition. They are not one who is to be medically defined or classified, or controlled in a manner that entrenches and oppresses them within the world of It-ness. Buber speaks scathingly of this institutional effect upon the other,

> But the separated It of institutions is an animated clod without soul, and the separated I of feelings an uneasily fluttering soul-bird ... institutions know only the specimen, feelings only the "object"; neither knows the person, or mutual life.[693]

Thou-ness restores the other to one who is beyond classification and management. It regards the other beyond the limitation and confinement of words

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[690] ibid., 119-20.

[691] ibid., 118.

[692] ibid.

[693] ibid., 44.

and allows them, from a pastoral theological perspective, to simply be, to be the one they were created to be.

For the pastoral carer to thus regard the institutionalised person with intellectual disability is to restore them to the God-given dignity and estimation with which they and all people were invested through the act of creation, signified by the biblical utterance, “[s]o God created humankind in his (sic) image ... (Genesis 1:27).” [694]

Through this identification and regard the other is restored to true creational status. Life, from an interpersonal, relational perspective, is restored. From Buber’s perspective, the investing of such sanctified regard in the one with whom relationship is sought is nothing less than the reality and evidence of salvation.[695]

Having thus extolled Buber for his honoured conceptualisation of human life and relationship a clear point of reinterpretation of Thou-ness needs to be tendered.

For Buber, Thou-ness, in biblical terms, is the momentary transcendent revelation that occurs atop the mountain. As with Moses atop Mount Sinai to receive the 10 commandments (Exodus chs 19-32)[696] and Jesus encountering God in a cloud before his journey to Jerusalem (Luke 9:28-36),[697] it is a place of spiritual and philosophical orientation. Of necessity it is far removed from the joys and sorrows of everyday life, the place where life is lived the vast majority of the time. It is a place far removed from the objectifying influence of It-ness, sufficiently removed to enable a relationship with the Thou of pure relation.[698] This is a place where past and future are lost in the present moment, where the Eternal is encountered as unquantifiable Being.

This encounter with the Eternal is, by its very nature, momentary. It is human nature to move out of the realm of Thou-ness and back to It-ness. As Buber states, “[a]nd yet in accordance with our nature we are continually making

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[694] National Council of the Churches of Christ in the United States of America, Holy Bible, Old Testament, 1.

[695] Buber, I and Thou, 120.

[696] National Council of the Churches of Christ in the United States of America, Holy Bible, Old Testament, 65-79.

[697] ibid., 69-70.

[698] Buber, I and Thou, 109-115.

the eternal Thou into It, into some thing – making God into a thing."[699] Elsewhere, he similarly speaks of the inevitable disintegration of 'the Word,' God's truth.[700] This should not be considered to mean that relationship with God is no more, on account of the passing of the transcendent moment. Relationship is more than the impermanence of encounter.[701]

However, under the understanding of Thou-ness thus described, true regard for the one with whom relationship is sought can only be momentary. The inevitable call to come down the mountain requires the passing of the moment and for our relationship with the Thou to be reconceived in terms of It-ness. We will return to the top of the mountain time and again, but the returns remain momentary. The God encountered atop Mount Sinai remains detached from the minutiae of everyday life and relationships where so much of life must be lived.

In terms of developing the type of pastoral relationship that shows ongoing commitment to people with intellectual disability amidst, and not far removed, from the reality of their day-to-day lives, it is at this point that Buber's Thou-ness proves unsustainable. For Buber, true, unadulterated mutuality of relationship is realized atop the mountain. For the purposes of this extended reflection a form of mutuality is required that can be grounded and remain effective amidst the living of everyday life, amidst the medicalised routine of institutional living. The pastoral call for people with intellectual disability to live their whole lives with dignity requires nothing less.

People living with intellectual disability in the institutional context require a mutual model of care that is not momentary but remains sustainable and liberating (i.e. from the oppressive tendencies of It-ness) in all circumstances. What is required is a pastoral conceptualisation of mutuality that is not 'either/or', atop the mountain or not at all, but is comfortable with ambiguity, with transcendence and immanence, and that honours Thou-ness in all places.

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[699] ibid., 112.

[700] ibid., 119.

[701] In a wider discussion of Buber this point is made in,
Pembroke, Neil. *The Art of Listening: Dialogue, Shame, and Pastoral Care*. London & New York: T & T Clark/Handsell Press, 2002, 39. Here the author asserts that Buber has regard for a sense of permanency through the primary concept of relation. There has to be an ongoing relation or relationship of some form before any encounter can occur.

7.2.3 Immanent Thou-ness: Mutuality Made Possible Through Confession

In turning to the Christian theological concept of Immanence we are concerned with a term that is descriptive of an essential component of God's nature. It describes the active presence of God in human affairs.[702] In definition, it is the polar opposite of the notion of transcendence which is concerned with that realm of being, with that realm of the nature of God that lies beyond human comprehension.[703] These terms, although logically opposite in definition, are to be regarded as complementary and collectively essential to the fully-realized character and activity of God. In Buber's terms we are concerned with an understanding of God that fully inhabits the realm of Thou and It. Both require each other for a full conceptualisation of God to be realized.

But this being so the issue becomes as to how we construct a notion of mutuality that holds both understandings in tension without disregarding one for the other, or elevating one over the other. The task is to search for an understanding of God that, while still honouring the transcendent conceptualisation, maintains such regard whilst coming near amidst the ordinariness of everyday life. This is necessary otherwise God only becomes truly known in brief transcendent moments. It concerns realizing God as the Thou who draws near to us not apart from but amidst the routine of institutional life. I wish to assert that we discern the answer in the Christian concept of confession, confession that leads to repentance.

7.2.3.1 Understanding the Confession that Makes Mutuality Possible

Those of an orthodox Christian persuasion who engage in the act of worship are familiar with the regular intoning of the Prayer of Confession and Words of Assurance.[704] Here, sin is confessed and forgiveness affirmed through

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[702] Blackman, E. "Incarnation." In *The Interpreter's Dictionary of the Bible: An Illustrated Encyclopaedia - Volume 2,* edited by George Butterick, Thomas Kepler, John Knox, Herbert May, Samuel Terrien and Emory Bucke, 691-97. (Nashville: Abingdon, 1980), 691-97.

[703] Richardson, Alan. "Transcendence." In *A Dictionary of Christian Theology,* edited by Alan Richardson, 343a-b. (London: SCM Press Ltd, 1982), 343.

[704] In terms of printed liturgy see, for example,
The Church of England The Book of Common Prayer. (London, Cambridge University Press, date unknown), and,
Assembly Commission on Liturgy. *Uniting in Worship: Leaders Book*. (Melbourne: The Joint Board of Christian Education, 1988).

the grace of God, expressed through the redeeming work of Christ. Such prayer signifies the need for repentance within the formalised, communal context. However, most importantly, there is the need for a heartfelt, nuanced confession and a call to repentance that is expressive of an ongoing desire to relate to God and others as honourably as possible. This desire is free from the notions of hubris that claims disempowering control over others. Such hubris does not seek to honour the other in terms of Thou-ness but seeks to diminish the other through institutionally-influenced patterns of It-ness from which the pastoral carer is not immune. Thus, it is the prayer of confession that necessarily becomes the constant companion of the pastoral carer in his or her daily journey through the institutional setting, through their regular visitation to living area, bedside, or wherever the person may be.

Whilst this prayer of confession serves as a valuable resource for all in their ongoing relationship with God it is vital for the pastoral carer who seeks to relate with people with intellectual disability in the institutional context. It is the prayer and attitude that enables a mutuality of relationship between the pastoral carer and the person with intellectual disability which of itself can lead to liberation from institutionally-objectifying modes of relationship.

The linking of repentance to liberation is the approach of feminist theologian Sharon Welch as she cites the calls for liberation or transformation from the oppression of Afro-American enslavement in North America. It is in this context that she cites Karen Baker-Fletcher’s analysis of Morrison’s Beloved in *Sisters of Dust, Sisters of Spirit*.

> What is most important, it seems, is that we be ready to repent our tragic flaws and forgive them in others ... It is important to consider disconnection from the earth and one another in a way that does not condemn or judge but that simply lifts up the reality of how tragic we can be ...[705]

Here we have the linking of confession to love of self. Thus, we are not concerned with repenting of flaws for the purpose of judging oneself harshly. Rather, we are concerned with honestly seeking heartfelt repentance of the reality that relating with others under the influence of the institutional context will inevitably reveal flaws in the self. These flaws serve to create barriers between

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[705] cited in,
Welch, Sharon. *A Feminist Ethic of Risk*. (Minneapolis: Fortress Press, 2000), 33.

oneself and the other with whom liberating and mutually-enriching pastoral relationship is sought. It is the lack of confession that maintains a distance between the pastoral carer and the person with intellectual disability in which the pastoral carer sees only an objectified identity and not a human being fully invested with God-given regard, that is, with Thou-ness.

Furthermore, the tense of Baker-Fletcher's exhortation is crucial, that is, that confession begins with us. It is vital that amidst our forgiveness of others we look to our own self and acknowledge our capacity to oppress. However, this level of self-acceptance does not come easily when we invest so much of ourselves in the task of projecting the image of being free of human weakness, of being the one who is sufficient, able and powerful amidst the weakness of others. As Gill-Austern asserts in relation to the practice of exclusion,

> Only through honest self-examination can we move to confess where and how we have practiced exclusion in our lives. Only then can we begin to withdraw projections, confess to our moral self-righteousness, and take the first step to seeing others in their distinctiveness and not simply as our projection. The bottom line is the need to stop seeing evil as 'out there'... [706]

Such honest self-examination involves seeing ourselves for who we are, that is, as flawed human beings functioning within a particular context. This is the implication of Welch's conceptualisation of the recognition of the nature of sin.

> Such turning away requires seeing the sin, knowing what constitutes it, and knowing what creates its power. Without understanding the mechanisms of sin and its hold on themselves, conversion, the turn away from exploitative habits of action and thought, is impossible.[707]

Understanding such mechanisms only occurs through due commitment to and cognisance of the processes and practices of the institution in which the carer exercises pastoral responsibility. It is incumbent upon the particularised character of pastoral theology and practice to be fully cognisant of the specific context. This includes a clear understanding of the socio-politically constituted structures

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[706] Gill-Austern, Brita. "Engaging Diversity and Difference: From Practice of Exclusion to Practices of Practical Solidarity." In *Injustice and the Care of Souls: Taking Oppression Seriously in Pastoral Care*, edited by Sheryl Kujawa-Holbrook and Karen Montago, 29-44. (Minneapolis: Fortress Press, 2009), 38.
[707] Welch, A Feminist Ethic of Risk, 55.

of the particular institution and its capacity to oppress those who are cared for amidst those structures. It is only through such awareness that true confession may emerge.[708] As Vamik Volkan states, from the perspective of ethnic conflict, in *The Need to Have Enemies: From Clinical Practice to International Relationships*, without such awareness "others become scapegoats, concocted from our own shadows as repositories for our sins and weaknesses, so we can relish the illusion of our sinlessness and strength."[709]

What is being advocated for here is not the prayer prayed from the perspective of the grand vista atop the mountain where Buber locates Thou-ness. Indeed, this is more than some generic understanding of the institutional capacity to generate It-ness. It is the specific confession that is grounded in the specific institutional setting where there is due cognisance of that institution's capacity to regard the other as the It.

For the pastoral carer of this extended reflection the issue is the fundamental need to look to oneself and see the institutionally-derived flaws that serve to generate the I-It relationship between the self and the person with intellectual disability. It concerns the awareness by the pastoral carer of his or her capacity to absorb those It-ness influences into their own pastoral identity and practice, either knowingly or subconsciously. Such specific understanding of the grounds for It-ness and its personal effect forms the content of genuine confession and repentance.

7.2.3.2 Describing the Mutuality Made Possible Through Confession

It is at the point of repentance that the other adopts an immanent identity, and can be seen and regarded as the Thou. The identity of God, the face of Christ, is revealed in the other as the other comes near.

In the language of theologian Molly Haslam, the moment is impregnated with God as a yearning presence, beyond intellect, in the midst of the mutual

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[708] Pattison, Stephen, and James Woodward. "A Vision of Pastoral Theology: In Search of Words That Resurrect the Dead." In *Spiritual Dimensions of Pastoral Care: Practical Theology in a Multidisciplinary Context*, edited by David Willows and John Swinton, 36-50. (London & New York: Jessica Kingsley Publishers Ltd, 1994). Regarding the issue of confession, see 40.

[709] cited in,
Volf, Exclusion and Embrace, 78.

relationship of I and the other, in which “God is portrayed as both yearning itself and the object of that yearning.”[710]

The moment is also impregnated with grace. By grace, the Thou, or the God, in the person with intellectual disability, approaches me whilst I wait in a state of being. Whilst the one who waits is liberated from an objectifying agenda this posture does not assume a completely passive guise, for the one who waits remains wholly attentive to the coming of the Thou. As Simone Weil states,

> We do not obtain the most precious gifts by going in search of them but by waiting for them ... This way of looking is, in the first place, attentive. The soul empties itself of all its own contents in order to receive the human being it is looking at, just as he (sic) is, in all his truth.[711]

The Thou has graciously approached me out of regard for me as a flawed yet forgiven and loved person created in the image of God. Likewise, I see that they have only come close to me because they too are similarly created in God’s likeness. As the Thou comes near to me I can but choose to engage in relationship with them with the whole of my being.[712] This giving of my whole self to and reception of the Thou is assisted through waiting with a focus on the present moment, casting aside past or future considerations.

It is in the realization of being flawed yet forgiven and loved that the revelation of our shared God-given mutual identity is affirmed. It is an identity that is truly egalitarian in nature. It is an identity that makes real the presence of shared, God-given love. As feminist theologian Beverly Harrison asserts, “[w]henever one party is invulnerable, and therefore unwilling or unable to be affected by another, there is and can be no love present.”[713] However, through a confessing spirit that leads to repentance, the objectifying effect of institutionally-realized It-ness is cast aside in the interests of unconditional love.

Fundamentally I realize that I do not see myself through the prism of professional status or assumed competency. Nor do I see myself through any other objectifying effect that serves to disempower the one before me who is truly my sister or brother in Christ.

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[710] Haslam, Molly. *A Constructive Theology of Intellectual Disability: Human Being as Mutuality and Response*. (New York: Fordham University Press, 2012), 108.

[711] Weil, Simone. *Waiting on God*. (London: Fontana, 1959), 169.

[712] Buber, I and Thou, 11.

[713] Harrison, Beverly. *Justice in the Making: Feminist Social Ethics*. (Louisville & London: Westminster John Knox Press, 2004), 59.

It is a mutuality of relationship that affirms our communal identity. As Welch cites from an emancipatory perspective in Townes' 'In a Blaze of Glory,' it is through confession -- or 'communal lament' as Welch describes it -- that "we move away from 'those people' and 'they' language and behaviour to 'we' and 'us' and 'our' ways of living and believing."[714]

Through the language of themism people with disabilities are objectified according to socially and arbitrarily-constructed norms. [715] Here we refer to the themism that regards the person with an intellectual disability as an object of charity, as an adult yet a child, as a *Minda*, *Retard*, or some other demeaning attribution based on the threat to personal perfection posed by those deemed weak. [716] However, through the act of confession, the barriers generated by themism are dismantled. In confession we discover that we are designed to live and to be sustained in mutually-enriching community. We discover our wholeness through realizing the Thou in the one who has become immanent, or close, to us through confession and repentance.

7.2.3.3 Immanence and Transcendence

In terms of this extended reflection what is being described is an understanding of Thou-ness that is located within the everyday routine of institutional life. It is found amidst the flawed yet forgiven and loved mutual relationship that exists between I and Thou, that is, between the pastoral carer and the person with an intellectual disability. This raises the issue of where Buber's transcendent moment is to be discerned, if anywhere, if Thou-ness can now be co-located in the midst of, and not apart from, the It-ness, or flawed nature, of human identity.

Amongst the 12 narratives detailed in the previous chapter I proffer one incident (there may be others) as at least somewhat approximating "the great shudder, the holding of the breath in the dark, and the preparing silence"[717] that Buber describes. This is in 'Blessing' where there is the story of ailing Jim, close to death, touching me and saying as I prepare to leave, "Thanks mate."

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[714] cited in,
Welch, A Feminist Ethic of Risk, 36.

[715] Blair, Daniel. "Christian Theology and Human Disability: A Literature Review." In *Graduate Theological Education and the Human Experience of Disability*, edited by Robert Anderson, 69-79. (New York: The Haworth Pastoral Press, 2003).

[716] Moltmann, "Liberate Yourselves", 113.

[717] Buber, I and Thou, 119.

This incident appears to contain elements of Buber's transcendental encounter. It has a momentary feel to it in which there is that which seems to approximate Buber's description of a heightened sense of reality, that moment which he describes as "... the heaven of Thou ... spread out over me ..."[718]

It is an incident that generates a moment when that which occurs evokes a wordless reaction [719] which, although partly born of a sense of utter surprise, also seems to contain an element of awe at the occurrence of something beyond easy, rational understanding. Indeed, it could be described as an awe-filled moment in which there is a fleeting sense of life focused purely in the present, when past or future considerations seem non-existent.[720] It is in such a moment that Jim, in a most evocative sense, assumes a sense of the Thou. It is as if, in a moment of being, I am seeing Buber's 'Face' in a most extraordinary manner. God is revealed to me through Jim in a form that suggests that I need ailing Jim at least as much as he needs me. Thus, mutuality of relationship is realized.

There is also the presence of grace expressed through the loving offering of a blessing no matter the extent to which such a gesture was merited.

Finally, the incident certainly contains a time very soon afterwards in which the realm of It-ness begins to resume effect in terms of quickly seeking to rationalise what has just happened. This is a time in which that which may have approximated a momentary realization of the Thou begins to disintegrate.[721]

However, it is in such extraordinary moments that, rather than experiencing the sense of immanently waiting, as expressed earlier in this chapter, there is more a sense of being grasped or confronted with a reality no matter one's state of preparedness.

Having said this I cannot categorically claim such an incident to fully equate with Buber's understanding of the I-Thou realm. However, it is asserted that such a brief incident does contain something of the transcendental character to which he refers, and there is a sense in which God is revealed as the Thou in a most extraordinary manner.

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[718] ibid., 9.
[719] ibid., 39, 104.
[720] ibid., 13.
[721] ibid., 119.

I would also claim that pastoral ministry ought to be accepting of the Thou, on occasions, being realized within the realm of the extraordinary, as realized in those stories I discern as approximating Jim’s blessing.

Nonetheless, I do claim, as a point of departure from Buber that, through the pastoral model of Immanent Thou-ness, that while Thou-ness can be understood as residing within the realm of the transcendent, as in the incident with Jim, it is also realized through the ordinary and mundane. It can be located at the foot of the mountain where we live the vast majority of our lives. It is not a realization that can be described in such shuddering terms as those of which Buber speaks, but nonetheless describes a Thou-ness born of a confessing spirit. It waits for the Thou to immanently approach the one who, by grace and a pastoral posture of mutuality, knows that although they and the other are flawed, yet they are loved immeasurably.

7.2.3.4 Conscious Political Action

One of the crucial advantages of pastoral care expressed as Immanent Thou-ness is that it is expressive of a pastoral commitment that favours the marginalised. In the confessional act of drawing near, waiting and seeing the other in terms of a mutuality of relationship, we are implicitly making a strong statement concerning those persons to whom we ultimately bear allegiance. It is stating that we are prepared to cast to one side the objectifying, institutional influences that serve to oppress in favour of engaging in committed, authentic relationship with the people with intellectual disability who live in the institutional context. We are asserting the primacy of the Immanent Thou-ness model of pastoral relationship. This model seeks liberation through mutual relation over and above medical models of institutional relationship that exercise a professionalised form of care and service over those for whom they bear responsibility.

If the pastoral carer does not deliberately choose to move near to the person with an intellectual disability, if they do not choose the path of the confessing spirit, then they are in danger of becoming comfortable with the distance between themselves and those for whom they care. They may come to be regarded largely as indistinguishable in professional identity from those health care professionals with whom they share care responsibilities. Pattison claims, from the perspective of liberation theology, that it is easy for chaplains working in the secular institutional context to be ignorant of the socio-political structures around them and the capacity of those structures to generate injustice. In this context he claims that, "... at best, pastoral care is myopic. At worst, it colludes with forces of sin, sorrow, and injustice which prevent people realizing their human potential."[722]

Pattison may well claim that the concept of Immanent Thou-ness fails to attend to structural injustice because this model of care, with its close proximity to the individual, prevents one seeing injustice at the corporate level and taking specific action in response to perceived structural injustice.[723] Indeed, Campbell asserts that, "[t]he intensity of the one-to-one encounters of professional practice appears to create a blind spot with respect to the socio-political context of care."[724] Whilst I would concur that uncritical pastoral practice can make that blind spot a reality, from the perspective of Immanent Thou-ness I would argue to the contrary.

Certainly Immanent Thou-ness does involve developing a pastoral nearness to the individual with whom pastoral relationship is sought. However, the decision to draw close through a confessing spirit occurs as a deliberate response to the socio-politically constituted structures in which pastoral care is exercised. Under this model the pastoral carer has to begin by seeing and understanding the oppressive and unjust effects that that institution's structures have on those for whom the institution bears responsibility.

Pastoral theologian Carolyn Thompson, in speaking in general social terms, describes the role of the Christian carer in relation to culturally-based power structures and people with a disability when she states,

> Part of dealing with cultural imperialism is becoming aware that it exists and realizing how people with disabilities, like everyone else, have internalized its precepts. We may still have to function in that world of the dominant culture, but we can be conscious of what it is we are doing and find ways to be less entrapped. As Christians, we are called to be in the world but not of the world; we have a different way of belonging that runs counter to much of what the dominant culture prescribes.[725]

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[722] Pattison, Pastoral Care and Liberation Theology, 5.
[723] ibid., 5-7.
[724] Campbell, Professionalism and Pastoral Care, 52.
[725] Thompson, "Ableism," 221.

Thompson’s call for the Christian to develop a consciously-considered understanding of the place of people with disabilities in the world bears close relation to the institutional context described in this extended reflection, and the place of people with intellectual disabilities and the pastoral carer in that setting. Due cognisance of institutional power structures and their effect needs to determine the pastoral carer’s relationship to those power structures and the people with intellectual disabilities who are duly oppressed.

Therefore, for the pastoral carer who shows due awareness of structural relationships and influences, who seeks a position of immanence and mutuality with those with whom they exercise care, pastoral care is observed to not be a simple engagement in some form of benign, uncritical, good deed. To the contrary, by moving close to the individual, the pastoral carer is consciously making a political protest against established modes of relationship that generally exist between professional carers and administrators and those for whom they bear responsibility.

Furthermore, the deliberate decision to move close to the individual comes as a response to not just seeing and understanding the oppressive effect of institutional structures and practices upon individuals. It comes through understanding the effect of those structures and practices upon the whole community of people for whom the institution bears responsibility. In coming close to the individual through Immanent Thou-ness one is being expressive of a personal commitment to and care for an oppressed community. It is at this point that we can speak of the necessity of regarding the care of the individual and the community as indivisible. Holistic care involves caring for each and every part of the body.[726]

It is also at the point of drawing near through confession that our gaze moves from a self-absorbed sense of self to focusing on the person with the disability for who they are, both as a human being and as one living in the institutional context. With this clarity of vision, we see the other as both a flawed yet loved and forgiven human being, which is also what we see in ourselves. We see the other from the perspective of their whole human identity. We are able to see the person specifically within the context of the institution in which they live

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[726] Forrester, Truthful Action, 79.

and the structural influences that bear upon them. We see them in tragedy and triumph, and amidst the ordinariness of everyday routine. As with ‘invisible Alice,’ we see them amidst their institutionalised acquiescence to the extent that the pastoral carer may be filled with sorrow or rage. And as with those Good Friday worshippers reaching out to the wooden cross before them we see them in moments of sacramental resistance displaying spontaneous, momentary triumph over institutional strictures, which may see the pastoral carer cry a loudly affirming ‘Amen!’ But it is a clarity of vision made possible through a pastoral relationship described as Immanent Thou-ness that makes such distinct evocations possible.

7.3 Immanent Thou-ness and the Threads of Liberation: Affirmation and Critique

At this point it is pertinent to consider the extent to which the three strong threads identified in the previous chapter concerning narrative analysis are affirmed and critiqued through the Immanent Thou-ness model of pastoral care. Furthermore, the question needs to be asked as to the extent to which this pastoral approach serves to offer liberation to those oppressed by their institutional circumstances, as is the goal for those who regard the institutional context through the lens of liberation theology.

7.3.1 Immanent Thou-ness and Pastoral Presence

The concept of pastoral presence as identified in the previous chapter concerned a pastoral mode of relationship that stands in contradistinction to the dominant institutional medicalised mode of relationship. The narrative analysis indicated the need for institutionalised people with intellectual disability to be understood and related to as more than a medically-regarded identity. Pastoral presence was presented as creating the possibility of engaging with the person with intellectual disability beyond the level of medical regard. It offered the possibility of the person in question sharing their story whatever that story may be. It offered the possibility of being non-judgementally welcomed in a pastorally-hospitable space. In other words, relationship is sought beyond the level of medical objectification, at a level that has regard for the other as a whole human being created in the image of God. Thou-ness as expressed through the concept of Immanent Thou-ness is concerned with that realm of realization that lies beyond the objectifying effect of the realm of It-ness. Through that confession that leads to repentance the other person moves from being principally regarded as medicalised identity to one who bears the image of God. It is the act of confession that casts aside the medicalised idea of the one whose approach to the person with intellectual disability controls the nature of the discourse. This is so even though there may be times when the pastoral carer may need to take initiative in the pastoral relationship. This may occur when it can be in the best interests of the person with intellectual disability to do so. The issue in such situations concerns whether or not the exercising of such pastoral power serves to liberate.

Pastoral presence also describes presence being realized through a focus on the present moment in order to be fully attentive to the one with whom pastoral relationship is sought. This understanding is located in the concept of Immanent Thou-ness. This is because attentive waiting for the Thou implies a focus on the present so as to be fully open to the realization of the Thou. This understanding points to the importance of giving to the other one's undivided focus, of casting aside past or future considerations. However, it does not assume the level of importance that it does with Buber's conceptualisation of Thou-ness where the realization of the Face of God depends on being in the present. This point of departure serves as an endorsement of the Immanent Thou-ness model of pastoral relationship in which the realization of the Thou, or the image of God, in the other is not dependent on whether or not the pastoral carer wavers from the present moment. We are loved immeasurably amidst our flawed nature, not simply in the brevity of the transcendent.

As with pastoral presence Buber's Thou-ness speaks of the presence of grace in terms of the significance of God's unmerited love in the realization of the I and Thou, or the pastoral carer and the person with intellectual disability. As Buber states, "[t]he Thou meets me through grace – it is not found by seeking ... *the* act of my being."[727] Similarly, Immanent Thou-ness regards grace as at the heart of the confession that enables the pastoral carer to know they are loved just as they are. It is not something that can be attained through seeking but is that

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[727] Buber, I and Thou, 11.
Italics are those of the author.

which is affirmed through that confession that affirms the realization that one is loved and forgiven amidst one's flawed nature.

Pastoral presence was also described in terms of a whole-hearted giving of oneself to the other. It speaks of a sacrificial level of giving that enables the revealing of a broken God to the other person. Thus, a point of identity is realized with the brokenness of the other person. While Immanent Thou-ness describes a sense of presence that seeks for the realization of God-given identity this notion of presence is impregnated with a greater measure of active seeking than can be attributed to Immanent Thou-ness. With this proposed model the focus is upon waiting attentively for the Thou to become immanent. In her critique of Volf's concept of waiting that emerges from his 'Embrace' pastoral model Hallahan advocates for a more active sense of waiting with the concept of 'expecting'.[728] So it remains possible that the somewhat less active sense of waiting as presented in the concept of Immanent Thou-ness may, at some point, need to be reflected upon in the light of future literature review and narrative analysis concerning pastoral presence. It remains to be seen as to whether or not a more active conceptualisation of presence can or should be incorporated into a future remodelling of Immanent Thou-ness, or that some other altogether alternative pastoral model may eventually emerge from such considerations.

7.3.2 Immanent Thou-ness and Mutuality of Care

As with Immanent Thou-ness, the pastoral concept of mutuality of care, as expressed earlier in the narrative analysis, is presented as that in which both the pastoral carer and the person with intellectual disability, either consciously or subconsciously, but inevitably, bring qualities and resources to the relationship. It is claimed that the giving of such qualities and resources can serve to enrich the other. Such sharing serves as a reminder that we are all made whole through such mutuality of relationship. Such relationship stands in contra-distinction to the dominant institutional mode of medical relationship.

Correspondingly, Immanent Thou-ness also sees mutuality as foundational to a liberating pastoral relationship because it too seeks for shared relationship that is expressive of the shared need for each other. This is liberating because it is expressive of the worth of the other realized through our need of the

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[728] Hallahan, Embrace, 22.

other so as to be whole. Medical relationship is not expressive of such shared regard.

However, although I would argue that it is only a question of degree, it is reasonable to say that Immanent Thou-ness is more expressive of mutuality that emerges from a clear sense of being. Although the mutuality of the narrative analysis does speak of the God who is encountered before ‘loving gestures and insights,’ Immanent Thou-ness particularly focuses on being through the act of confession where God’s fundamental regard for us is specifically defined in terms of who we are in relation to God, and not in terms of what we may seek to do for God.

The concept of Immanent Thou-ness does not discount mutuality at the level of the sharing of qualities and resources. Such sharing affirms, at a practical level, our need for each other in order to be regarded as whole human beings. However, the focus is pre-eminently on liberation through shared identity at the foundational level of being.

Future narrative analysis and literature review may find the need to reconsider this issue. I concede that there is a body of literature that describes mutuality more in terms of practical imperatives than is expressed in Immanent-Thou-ness. This can include; from a feminist, pastoral perspective, the shared construction of knowledge;[729] from a pastoral perspective, the sacrificial giving of time as a practical sign of friendship one for the other;[730] from a liberationist perspective, mutuality as a foundation to practical justice-making in the world;[731] and also from a liberationist perspective, mutuality and solidarity that serve as a counter to global, socio-politically constructed tendencies to disable.[732]

Liberation theology is most expressive of liberation in terms of practical outcome rather than that which may be regarded by some as more prosaic. However, it is through the radicalness of choosing a mode of relationship that affirms the worth of an oppressed person that a compatibility with the liberationist endeavour is observed.

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[729] Gill-Austern, Pedagogy, 150.

[730] Glass, Eileen. "The Particular Needs of Older People with Intellectual Disabilities and Their Carers: A Perspective from the Experience of L'Arche." In *Ageing, Disability and Spirituality: Addressing the Challenge of Disability in Later Life*, edited by Elizabeth MacKinlay, 57-71. (London & Philadelphia: Jessica Kingsley Publishers, 2008), 60.

[731] Harrison, Justice in the Making, 65.

[732] Moltmann, “Liberate Yourselves”, 121-22.

7.3.3 Immanent Thou-ness and Uncontained Lives

The narrative analysis of this extended reflection also strongly pointed to those personal qualities and behaviours of people with intellectual disability that were expressive of those who are not fully contained by negatively-constructed institutional philosophy and regimen. Such qualities and behaviours show signs of resilience and resistance that give evidence of life-giving contact with that which lies beyond the containing and oppressive institutional influence. In a broad-based spiritual sense this can be conceived of in sacramental terms in that, through the lives of those with intellectual disability, there are qualities and gestures displayed that, like a light shining through a stained glass window, point to a form of spiritual reality that describes life with attendant meaning and value that cannot be accounted for by institutional measure.

I would argue that the sense of pastoral nearness afforded by Immanent Thou-ness enables a clarity of discernment and insight that affirms the possibility that, within a lived context that exercises control and policies of containment, there can still be evidence of life uncontainable by rationalist, deductive processes. This pastoral model, with its focus on seeing and affirming the Thou, or the image of God, in the other, is open to the notion of the spiritual breaking into the lives of those living in the institutional context. Immanent-Thou-ness affirms the inbreaking of the spiritual in the lives of people with intellectual disability as expressed through wooden cross, paper and pencil, or imaginary baton. It is for the pastoral carer to affirm such uncontained signs of a more transcendent reality. In doing so he or she either consciously or subconsciously affirms in the person with intellectual disability the presence of life that cannot be contained by institutional strictures.

7.3.4 Immanent Thou-ness and Evidence for Liberation

It has been the goal of this extended reflection to give expression to a model of pastoral care that, according to the tenets of liberation theology, is expressive of liberation from the oppression afforded by institutionalised modes of relationship imposed on people with intellectual disability. Liberation, understood from the pastoral dimensions that undergird this extended reflection, is that which affords status for the other over and above the oppressed value afforded by the institution. As such, it seeks for the other to be regarded as a whole human being created in the image of God. In doing so it seeks for the person with intellectual disability to assume a shared God-given status and identity commensurate with all human beings. This is a status that enables the person with intellectual disability to link arms with their sister and brother located beyond the confines of institutional walls. It is this understanding that gives to the institutionalised person with intellectual disability the worth and dignity that institutional living alone takes away.

It is the conviction of this pastoral carer, and the author of this extended reflection, that Immanent Thou-ness, as pointed to through the strong threads of narrative analysis, and through the ensuing pastoral, theological exposition, is a valid, bold and necessary pastoral model that gives faithful expression to such liberating aspirations.

7.4 Conclusion: Immanent Thou-ness and Commitment to the Ongoing Story

Immanent Thou-ness affords a clarity of vision that invites the pastoral carer to write new stories. Whether they are stories of those whose stories have been told often or not at all, or those described by the pastoral carer, they are stories to be told. Here is a pastoral immanence and posture that invites the carer to see the one near to them with ever-newly discerned nuance and detail, and with ever-developing understanding of the nuances that are sacramental or institutionalised, ordinary or unique, in detail. This story writing and telling can never acquire a normative status. There is always more detail. There is always more to understand. The task of pastoral remodelling must continue.

As has been described earlier in this extended reflection, the history of people with intellectual disability who have lived their lives in asylums or institutions is of those whose story has not been told, whose voice has been and is silenced, whose identity remains to be authentically detailed. As long as that remains so it is incumbent upon the carer who exercises committed pastoral ministry in institutions to keep writing and telling the stories that come from drawing near to the flawed yet forgiven and loved person before them regarded quite rightly as the Thou.

The task of liberation, whilst realized through the pastoral nearness described in this chapter, also remains as aspiration and as call to the pastoral task, as long as there are stories to be told.

Molly’s story, as detailed in the Prologue to this extended reflection, along with the questioning that framed its conclusion, must constantly be described, with new questions asked, and new understanding sought, as long as Molly lives.

come carers come
come and write the stories

come carers come
come and speak the truth

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Intellectual Disability and Holy Communion: The Peace that Passes Understanding

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This article details and analyzes a service of Holy Communion in which most participants have some form of intellectual disability. The context in which the worship is experienced is examined. Critical reflection on the service, and those participating in it, is used to address the issue of what the celebrating of this sacrament has to say about the relationship these people have with God, and how they seek to live their lives. Discussion also centers on what this experience of worship has to say to the wider Christian community. In exploring these issues it is contended that these people derive meaning from this worship experience with the use of faculties beyond the cerebral, and experience a God beyond intellectual understanding who accepts them as they are. Through the freely given act of grace ritually expressed in the Communion service the recipients of the host are seen as people who, though restrained by the medicalized environment in which they live, experience freedom from restraint within the sacramental context. Ecumenical and non-cerebral issues are raised in regard to the wider Christian community, as is the embracing nature of God's love for humankind.

KEYWORDS Disability, community, meaning, peace, communion, freedom

Within the Uniting Church of Australia, South Australia, I work as a Disabilities Ministry Chaplain. I have ministered in this position for approximately 7 years. Prior to my present ministry, I worked as a Minister of the Word in congregational placements for fourteen years.

My present position involves fulfilling a variety of roles. These include the roles of community advocacy, church 'resourcing' and Christian

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Education. But the bedrock ministry, amongst all others, is that of institutional chaplaincy. I am the Chaplain at two of Adelaide's main institutions for people living with various forms of disability.

One of these institutions, which accommodates and offers services to approximately 130 residents in a mass accommodation facility, affords me the regular opportunity to celebrate Holy Communion with the thirty to forty residents who choose to attend this service at the institution's chapel.

The chapel has a creatively reflective aspect to it. It has large windows around three sides of the space. The windows look out on spacious lawns, trees and plants. The changing of the seasons can be observed from inside. The chapel itself is an open space large enough to accommodate about 80 people in wheelchairs. Chairs can be located in the space whenever and wherever required. From the windows behind the sanctuary hang beautiful mock stain glass wall hangings visually describing various biblical scenes and highlighted by the sunlight shining through the windows. The wall hangings are changed according to the religious seasons of the year. Banners hang adjacent to and within the sanctuary space. A quite large, creative piece of craft work depicting flourishing and colorful flowers done with a form of acrylic compound adorns one of the windows towards the back of the space.

Most of the residents who attend services in the chapel have some form of intellectual impairment. Almost all who attend are wheelchair-bound and the majority require assistance to get to and from the chapel. There are some able-bodied people from the community who attend the service as well. They are comprised of volunteers from the local church who assist the residents to and from the chapel and help in any way required during the worship, along with family members and carers of residents who also sit and worship with the residents.

QUALIFYING COMMENTS

Method

I reflect on the Communion narrative both in terms of the wider institutional context, through my role as institutional chaplain, as well as the immediate sacramental context, through my role as worship leader. The service is analyzed from a qualitative perspective. The empirical nature of quantitative analysis simply cannot describe the meaning being sought from this sacramental and institutional context. However, at the same time, the qualitative perspective is inherently subjective because it is based on the observational skills of the observer, and on non-quantifiable observer qualities such as intuition and creativity (Ruler, 2000). Furthermore, the narrative is what Riessman (1993) refers to as "plurivocal" (p. 14) in nature. That is, it can be 'heard' and interpreted from a variety of perspectives, depending on issues such as the biases of the observer, and the extent to which the narrative's context is carefully observed. As Denzin and Lincoln (1994) assert, "There are no objective observations, only observations socially situated in the worlds of the observer and the observed. . . ." (p. 12).

So, while there can be no completely objective observation and analysis of the Communion narrative represented in this paper, subjectivity will be minimized through thorough consideration of both the sacramental and institutional context, as well as through the seeking of meaning, and patterns of meaning, from the observation of numerous participants in the Communion service.

THE WORSHIP CONTEXT

In what follows I am not describing an ideal worship scenario. Because it is their wish to stay where they are people who worship in this institution's chapel may not be transferred to appropriate community accommodation where they may find an inclusive experience of worship in their local community. I would still love to see them worshipping in contexts that afford them the opportunity to worship in ways that are integrated into the life of accessible nearby faith communities.

As Eiesland (1994) states, from a sacramental perspective, it is through the full inclusion of people with disability that the church sees God as disabled and is thus called "to become a communion of struggle" (p. 115). Full inclusion involves honest engagement, and that engagement can only happen, as Reid (1994) asserts "when every member of the body, with his or her brokenness, is included and participates fully" (p. 50). So though full integration into the life of a local faith community is the desired goal, both for people living with disabilities and the whole Body of Christ, this is not how it is this day, so we worship as we are.

A "Typical" Service of Holy Communion

I would like to describe what amounts to a fairly typical worship scenario on a Holy Communion Sunday. The word *typical*, however, is a word to be used advisably given that some who attend the worship are prone to fairly spontaneous physical and verbal gestures. Furthermore, there are those who attend who are simply not concerned with or cognizant of what your average worshipper may consider normal worship protocols.

So here this morning, for example, is Barry who likes to laugh at the most seemingly inopportune moments, such as during the sharing of a concern over a resident who is dying. There is Angela who offers me a geranium she has pulled up from a large pot placed just outside the entrance to the chapel. She takes pleasure seeing it placed on the Communion table. There is Eileen who keeps singing loudly long after the song has finished provoking Nicole to utter quite loudly, "Oh, shut up." But the singing continues.

There is Mario who may have an anxiety attack at a moment's notice. There is Janet who needs to be woken up in order to receive the communion elements. No reflection on me as worship leader, I hope. There is Rodney, hearing and intellectually impaired, and one of the most committed up-front worshippers in this place. And there is quiet, undemonstrative Howard, who sits erect in his wheelchair seemingly oblivious or unconcerned at whatever else may be going on around him. All such folk, and numerous others, are present for this service of Holy Communion.

The service follows a familiar liturgical form—bright, well-remembered hymns and songs; opportunities to share good news and concerns for those who can verbalize; and descriptive and familiar biblical stories, such as parables. Added to this there is some laughter and spontaneous feedback. And so we proceed to Holy Communion.

A short, less verbal liturgy is intoned. The bread and cup are raised; the traditional Lord's Prayer is spoken with some residents who can speak joining in with this familiar prayer. The bread is raised again and broken as the words are uttered,

> *Jesus is the Lamb of God,*
> *who takes away the sin of the world.*
> *Happy are those who are called to his supper.*
> —The Uniting Church in Australia Assembly Commission on Liturgy, (1980, p. 34)

An invitation to all to receive the elements where they are seated is offered. Whilst I take hold of a small plate of wafers, I offer the chalice of grape juice to my assistant. We proceed to the congregation.

The method of distribution is by *intinction*. In intinction a soluble wafer is dipped in juice and placed on the tongues of those who wish to receive. Especially for those who cannot hold the elements or chew a piece of bread, this is the most accessible form of distribution. The residents wait their turn as familiar hymns and songs are played on the piano. The dipped wafer is placed on the tongue and left to dissolve as the Words of Distribution are uttered: "The body and blood of Christ keep you in eternal life."

Smiles are shared. A gentle hand on the shoulder offered where welcomed. Those who can speak mouth an occasional "thank you". A few, for reasons of denominational sensitivity, prefer not to receive the elements. Words of inclusion are still offered, "God bless you and keep you always."

With the distribution complete I return to the Communion table and, with arms outstretched, offer the Words of Peace.

> The Peace of the Lord be always with you.
> . . . And also with you.

I invite those who are physically able to move to those less able and share with them words of peace. With the noise of this sharing subsiding, a final familiar hymn is sung.

A Benediction is offered with arms stretched wide. Those present are invited to say with me if able at the top of their collective voice an almighty "*Amen!!*" The service is complete. As church and institutional volunteers gradually return residents to their dining rooms the pianist continues to play.

Making Sense of This Service

And I reflect, as I sometimes do, on the significance of what has just occurred. I reflect on the individuals of this community of faith who generally receive the communion elements. Despite most having levels of intellectual impairment that presumably inhibit them from attaching much significance to the more cerebral elements of the liturgy, they receive with much intent and, on occasion, passion.

And I think to myself: What of those who are literally deaf to the liturgical words I speak? What of those who may hear my words as nothing more than an incoherent jumble? What of those for whom the finely honed theological sentiment of the communion liturgy is indistinguishable from the script of their favorite daytime 'soapie'? What of those who, amidst the communion call to eat and drink "... in remembrance of me," struggle to remember because their remembrances of people, places, events, and key elements of their faith formation, including the actions of Christ in their life, now escape them?

How can I make sense of their keen desire to participate in this sacrament when, for many here, the service seemingly communicates so little at a cerebral level? What is going on in their being that, despite a lack of intellectual comprehension, seems to still make participation in the communion service a deeply significant component in their faith formation?

I speculate as to what may be going on. Perhaps it has something to do with the presentation of the visual symbols—the overt display of bread and juice denoting the presence of the crucified Christ. Perhaps there is some unconscious connection that those present make between the broken Christ depicted through the breaking of bread, and their own sense of brokenness—a sense of being loved and accepted amidst brokenness, just as they are. Perhaps it's the physical movement that takes place during the distribution of the Communion elements, the bread and juice being brought to each member and placed on their tongues, as if the broken Christ is coming to them and being absorbed into their being. Perhaps it has something to do with receiving these elements in an environment in which, through various visual depictions—the cross, the banners, the murals—people have Christ's sacrificial nature reinforced for them in a visual form that can be appreciated. Perhaps it has something to do with sharing in this sacrament with all those around them, thus offering them a sense of strength and solidarity through community, and with it, a sense of belonging to something worthwhile. Perhaps the regular celebration of Communion speaks to those present of a constancy of love and acceptance amidst a world where their bodies and minds have failed them, and where others treat them more as problems than as acceptable and loved human beings. Perhaps the sacrament speaks to them of a God-given value invested in them that is not dependent upon successes or failures of their minds and bodies.

It may be all these things, or possibly something else altogether simpler, or more profound. I simply do not know, and I never will. And perhaps if the likes of Barry, Angela, Eileen, Nicole, Mario, Janet, and Howard could articulate clearly they may not be able to tell me because their experience is beyond words, or too personal.

What Does this Sacrament Say About the Relationship These People Have With God?

It would appear that for many who have acquired an intellectual impairment and who have subsequently come to live at this institution the important issue is the celebration of communion and not so much allegiance to a denominational brand. For those who choose to receive the Communion elements at this Sunday worship, which is nearly all, the experience is observed by me to be very ecumenical in nature. There are those present who share my Uniting/Reformed persuasion (i.e., formerly Methodist, Presbyterian, and Congregational) along with those who share a variety of other denominations, including Anglican, Catholic, Lutheran, and Baptist. While I am aware of various communion participants forming particular denominational allegiances in their younger years, nonetheless there seems to be a majority here claiming allegiance to the Christian faith for whom observance of the sacrament of Communion without denominational bias is the clearly overriding concern.

This is not to discount those who live in this institution for whom continuity with the denominational sacramental practices of their past remains important for their faith to maintain coherence in the present. It affords a secure connection between past and present, firmly held, faith practices. That is completely understandable.

However, for a number who have received Communion this day, it would seem that the acquisition of an intellectual impairment diminishes the need to maintain strict loyalty to the brand of sacramental rites of former times. It would appear to be more important to maintain and nurture a sacramental faith connection according to the more universally held tenets of the Communion liturgy, tenets such as that of the grace of God expressed through the sacrifice of the broken Christ.

Perhaps there is a connection between the precarious nature of human life following the acquisition of a major intellectual impairment and the need to strip bare the Communion rite to its most critical and needful components. Amidst the frailty and brokenness of human life, the critical issue becomes the need to be affirmed sacramentally in the realization that one is loved, indeed embraced, by God. Then, perhaps debates about exactly how the Communion elements denote the body and blood of Christ and who is or isn't worthy to receive (God help us) lose meaning.

My reflections this day also reaffirm for me the significance for all people, but certainly these people, of a God who embraces them so much beyond the level of their intellectual capacity, and who appears to connect with them at the point of what Ryan et al. (2005) refer to as "enduring abilities" (p. 42). This act of Communion describes a God who affirms human worth, and who affirms the faith of people, not principally on the basis of intellectually held tenets, but on the basis that nothing can separate humankind from the love of God (Romans 8:39) which is freely offered to all.

Over time the primacy of reason in the formation of human identity has been endorsed. It was the ancient Greek philosopher Plato who asserted that intellect was seen to be the quality that defined human beings as superior to the rest of creation (Plumwood, 1993). It was 17th-century French philosopher and mathematician, Rene Descartes, who famously said, "I think, therefore I am," thus defining human identity and worth in terms of capacity for reason (Gibson, 1967, p. 82).

Often through history those determined to have diminished intellectual capacity have been variously described as idiots, feeble-minded, or morons, or some such disparaging term. This has led to social alienation, abuse and dehumanizing institutionalization.

The God who reaches out to and expresses love to these people through the sacrament of Communion defines worth in terms of unconditional acceptance, not intellectual achievement. This sacrament defines their worth not in terms of human aspiration or merit, but in terms of a God who acts to affirm their created value solely and wholly in terms of being made "in the image of God" (Genesis 1:26).

I also see this sacrament, and the nature of its reception, describing a God who is not received in terms of proposition or dogma, but who is accepted as mystery, beyond understanding. The people with intellectual impairment who have received this sacrament this day are not concerned with the truths of the sacramental theology espoused through the Communion liturgy. They are there to embrace the import of the sacramental moment and to absorb the moment with the human faculties at their disposal. Therefore, with their impaired intellectual understanding, the God who is present in this sacramental moment becomes that which is imagined, experienced and sensed more so than understood.

With this in mind Francis (1994) speaks of absorbing the meaning of the sacraments through a sense of symbolic “knowing” (p. 85). Fowler (1981) also contends that, at a more foundational level than our conceptual sense, most of our knowing is shaped by images, symbols and rituals, and that this sense of knowing has a determining effect on our faith formation. It is this sense of knowing that engages the person of faith at a greater level of mystery and ambiguity than can be discerned in more rational sacramental forms. And so God, perhaps more readily than in the wider church community, is accepted as beyond understanding, a mystery, by these people with whom I have shared the Communion host this day.

What Does this Sacrament Say About How These People Seek to Live Their Lives?

Having pastorally and sacramentally ministered with these people for the past 7 years, it is clear that they find themselves having a restrained lifestyle imposed upon them, from within and without of their minds and bodies. Their own embodied state of mind and/or body may evince constantly frustrating and life-sapping struggles. There may be struggles with pain along with regular assaults on dignity. There may be accompanying incapacities to perform those physical and mental functions, such as walking, talking and reasoning, which many of us take for granted until our own functioning is similarly threatened.

These people live in an institution where they receive a reasonable level of healthcare. There is a battery of health care professionals, including doctors, nurses, dieticians, speech pathologists, social workers, occupational therapists, psychologists, physiotherapists, and recreational health workers who are here to do all they can to preserve the health of these residents. This institution is built around an administrative structure that is designed to offer residents an appropriate quality of accommodation and financial support. Such institutional services are offered professionally and with skill. Staff members generally display a commitment and pride in their area of professional expertise.

Yet all this professional care is predicated on the understanding that relationships are to be established with the residents because they have some form of intellectual and/or physical impairment. They are needful people, and therefore, as McKnight (1995) argues, perceived by the institutionalized health care system as deficient human beings requiring constant professional care. And so the primary relationship these people experience on a daily basis is that of client to professional carers, that is, deficient, dependent person, to persons with the requisite professional expertise.

Every day these people are reminded of what they have either never been able to do, or, through the acquiring of an impairment at some point in their lives, can no longer do for themselves. Because they cannot walk, most move, or are assisted, around the institution in wheelchairs. Because they cannot talk, a few are required to communicate through some form of speech board.

A number need professional assistance with eating and drinking because they cannot eat and drink on their own. Many need professional assistance with their showering and ablutions because such personal capacities are beyond them. Most have to watch as professionals tidy their room. Most have to approach a finance department for significant personal expenditures. All live with major denied life ambitions.

These people live every day in need of professional services in order to maintain their health, their domestic and personal routines, and a very modest social lifestyle. They are restrained by the limitations of their minds and/or bodies, and by the relationship of dependence they have with those who offer them professional care. Thus they do not even come close to living a lifestyle that most of us would claim for ourselves as normal or appropriate. And yet, through the act of coming regularly to a Communion service in this institution's chapel, these people appear to experience a certain freedom from such restraints.

The body and blood of Christ is freely offered, with no judgment made concerning disabilities. Rather than experience restraint and vulnerability, through Communion, people living with an intellectual disability, and all others, can experience, as Wadell (1994) states, a vulnerable God who is "exposed and handed over . . . . delivered into hands that can caress or crush" (p. 67). Bread and juice are offered not as part of a professional/client relationship, but as a freely offered gift that demonstrates beyond words and intellectual understanding that they are as welcomed and included in the embrace of the Body of Christ as anyone else in God's creation.

I have observed elsewhere people who demonstrate the relentless, contorting physical restraints imposed on them by dint of living with cerebral palsy. And yet when they are eased into the gentle waters of a heated pool they experience moments of freedom:

> Freedom from wheelchairs supporting their twisted bodies;
> Freedom from mechanical lifting devices;
> Freedom from medical interventions;
> Freedom from tedious daily routines;
> Freedom from administrative edicts;
> Freedom from patronizing attitudes;
> The beautiful freedom of soothing, supportive, warm waters.

Perhaps for some at least who receive Communion in this chapel, they too experience a certain, brief freedom from the restraints imposed by impaired mind, body and imposed routine—the freely offered and received body and blood of Christ gently supporting and sustaining the faith of those present.

In the midst of all their restraints these people seem to be demonstrating a capacity to describe themselves beyond definitions imposed by those for whom they are primarily 'clients'. British social worker, Finkelstein (1993), once graphically described people with disabilities and all the restraints imposed upon them through institutional living, as "socially dead" (p.21), that is, dead to being accepted as valid and fully contributing members of society. However, through the embracing of the life and faith affirmed through the receiving of Communion, I am seeing a quiet resilience, defiance in the face of dependence, a determination to live and not simply acquiesce to imposed restraints.

What Does this Sacrament and the Way These People Receive it Say to the Wider Christian Community?

Having just led this Communion liturgy, and witnessed the whole-hearted reception of the host by a diverse people from various denominational backgrounds, I can't help but believe more than ever that this sacrament is a gift. It is a gift for the whole church designed to embrace all people of faith under the banner of a broken yet life-giving God. Just as this sacrament sends a message to these people with intellectual disability that they too are included unconditionally in the embrace of the universal Body of Christ, they send a message to those of us who consider ourselves able-minded people of faith. A broken Christ offering life to the world is the fundamental truth contained in this sacrament. That is a message designed to unite people, and override the denominational labels that divide.

From an arguable historical perspective people with disability have widely been viewed as amongst the most socially marginalized of peoples. This includes those with an intellectual impairment who are viewed often as "the other of the other "(Clapton & Fitzgerald, 1997, p. 1). If these people can lay claim to the gift of the Communion host, then what of other peoples who may, depending on their socio-political, socio-economic or ecclesial context, find themselves marginalized from participation in this sacrament. What of others regarded as "not normal" or "sinners", or what Vanier (2001) refers to as "the excluded" (p. 84)? What of those who may not assent to all the membership requirements of a particular denomination, but who, like these people to whom I serve Communion, nonetheless have a faith searching for sacramental affirmation? It is so worth considering widening the welcome and embrace that can be found through the sacrament of Communion.

This community of people with intellectual impairments can accept into their being a God who is fundamentally beyond understanding. I believe the wider Christian community has a way to go in valuing and placing faith in the God who remains a mystery who is to be discerned by non-rational faculties such as feeling, experience, intuition, sight and hearing.

I ask myself the question anew as to what it means to embrace the realm of God as a child. Not that these people are to be thought of as children at all. However, they do invite us who are often considered able-minded to consider that point in our faith formation when we are required to let go of understanding and exercise our creative imaginings—as a child can do so freely and joyously—in the presence of the one whom we are compelled to acknowledge as "the Holy Other" (Webster, 2000, p. 26).

With this in mind I am taken back to my days as a minister in congregational placements when some parents told me that they did not wish for their children to participate in Communion services because they were too young to understand the meaning of the sacrament. I found myself then, and even more so now, reflecting on the importance we place on intellectually understanding the sacraments in which we participate. Dismissing intellectualism is an invitation to make ignorance acceptable as well as to spurn a God-given gift that is offered to enrich life and faith. However, I remind myself that the issue of a lack of intellectual comprehension by my own two children, when young, of the relative merit of various foods ranging from sweets to sweet potato was not a high priority for my wife or myself. Our focus was the need for them to eat regular, healthy meals so as to grow and thrive. Many in the church regard ongoing participation in the Communion meal as requisite for healthy faith development.

Many of the people of this institution to whom I serve Communion have very limited intellectual comprehension of the sacrament in which they participate. Yet, they embrace it with much intent. Through faculties at their disposal beyond the intellectual, Communion bears much meaning and significance. This begs the question as to whether or not the meaning and significance of the Christian faith, as is expressed through sacramental rituals, might be denied to various members of the wider Christian community because of a perceived lack of intellectual comprehension. Ought we of the wider Christian community be more open to acknowledging the importance of the engagement of other human faculties with participation in the act of Communion, along with the other Church rituals that express key components of God's love for humankind?

CONCLUSION—PASSING THE PEACE

As indicated earlier the formalities of our Communion service in this chapel are concluded with an invitation to share God's peace with one another. Those who are ambulant are invited to go and share with those who are not. This mostly leads to church volunteers and other visitors to the service moving to those in wheelchairs, taking gentle hold of their hands and sharing with them a sign of God's peace. This gesture of peace is usually received warmly.

There is Nicole, fresh from telling Eileen to shut up, who holds my hand firmly, looks me in the eye and says "Thank you very much". There is Eileen the singer who offers a gentle smile. There is laughing Barry who may respond with, "No worries mate."

There is Graham, who in striving to communicate without the use of his alphabet board, is heard determinedly uttering, "And also with you." There is Mavis who may take the opportunity to pass on a prayer request for an ill friend. There is Joe who may point you to an image of Jesus on one of the murals behind the communion table. And there is quiet Howard who simply smiles through it all.

It is not for me to know exactly what the sacrament of Communion means to this community of faith. I can only surmise and offer my most considered reflections. But this I do know: through this sacrament this diverse group of people living with their intellectual disabilities, each living with their own attendant joys and struggles, are embraced by a loving God. They are embraced by a God who through this sacrament speaks to their inner beings and reminds them that they are valuable, precious, and worthy just as they are.

Once again this day they have taken into their beings a tangible affirmation of the broken Christ's sacrifice, life and love. They have done so as members of the church universal, amidst all those rich and poor, black and white, women and men, healthy and sick, hopeful and despairing, able-minded and intellectually impaired who have received this sacramental blessing somewhere this day.

And they go from this place having been affirmed in the Peace of God which, in the words of that benediction I often use, is not dependent on intellectual comprehension or any measure of rational achievement but is that which "passes all understanding" (The Uniting Church in Australia Assembly Commission on Liturgy, 1980, p. 35).

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