A Transformatory Ethic of Inclusion

Rupturing concepts of disability and inclusion

Jayne Clapton
A Transformatory Ethic of Inclusion
STUDIES IN INCLUSIVE EDUCATION
Volume 1

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Scope
This series addresses the many different forms of exclusion that occur in schooling across a range of international contexts and considers strategies for increasing the inclusion and success of all students. In many school jurisdictions the most reliable predictors of educational failure include poverty, Aboriginality and disability. Traditionally schools have not been pressed to deal with exclusion and failure. Failing students were blamed for their lack of attainment and were either placed in segregated educational settings or encouraged to leave and enter the unskilled labour market. The crisis in the labor market and the call by parents for the inclusion of their children in their neighborhood school has made visible the failure of schools to include all children.

Drawing from a range of researchers and educators from around the world, Studies in Inclusive Education will demonstrate the ways in which schools contribute to the failure of different student identities on the basis of gender, race, language, sexuality, disability, socio-economic status and geographic isolation. This series differs from existing work in inclusive education by expanding the focus from a narrow consideration of what has been traditionally referred to as special educational needs to understand school failure and exclusion in all its forms. Moreover, the series will consider exclusion and inclusion across all sectors of education: early years, elementary and secondary schooling, and higher education.
A Transformatory Ethic of Inclusion

_Rupturing Concepts of Disability and Inclusion_

Jayne Clapton
_
Griffith University, School of Human Services and Social Work, Australia_

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DEDICATIONS

This book is dedicated to:
My mother, Ruth Clapton, and my dearly-missed father, Kevin Clapton, for their endearing love and encouragement throughout my life; and

My husband, Robert Harriman, and my children, Luke, Kate, Innes and Sarah Harriman for their unconditional love and support always.
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FOREWORD

Over the past decade social inclusion has become firmly entrenched in the language of politics and policy. Indeed it is now on the pages of newspapers, in reports, in news bulletins and in conversations. In the United Kingdom, the Blair government under New Labour launched its Social Exclusion Unit within a few months of coming to power in 1997. Its focus was to explore why social trends on poverty, unemployment, addictions and other indicators were so negative. Later in June 2006 the Social Exclusion Taskforce was set up to coordinate the Government's drive against social exclusion, ensuring that the cross-departmental approach delivers for those most in need. The EU’s Social Protection and Social Inclusion Process coordinates and encourages actions of Member States to fight social exclusion through policy exchanges and mutual learning. In Australia the social inclusion policy agenda has become one of the most dominant features of the Rudd government during 2008. Social exclusion and inclusion can now be found in the policies and plans of universities, government departments and the non-government sector.

For many people living with disability or those working alongside them, the challenge of inclusion has been a long standing challenge for decades – well prior to the current focus. Disability has been the site for long standing debates on social integration, inclusive education and community inclusion since the shift from institutions to community living began. Those involved with disability have all wrestled with questions such as: How can people with a disability be included? How can people with disability truly belong in our communities, our schools and our workplaces? This has been described in various ways. We find discussions that reflect on community presence being more achievable than community participation.

For some of us, and I would include myself in this group, this space has always been deeply troubling. How is it that despite hard work and passionate commitment to this endeavour people with intellectual disability have somehow missed out on truly belonging? Somehow being “included” has been not been achieved as a fundamental right for people with a disability.

Here in *A Transformatory Ethic of Inclusion* we have some answers or at least some pointers as to how we should proceed towards those answers. Jayne Clapton provides us with the tools for unpacking and more importantly questioning the meanings of inclusion from an ethical standpoint. She argues that until we engage with a fundamental ethical reality in Judeo-Christian theology and philosophy we will be merely limited to technical approaches to inclusion that are doomed to never realise the original objective. The fundamental way we do ethics has allowed the place of people with a disability in society to be optional. There has been a long standing and deeply rooted failure to morally protect people with a disability to belong.

In this work Jayne Clapton has engaged in rigorous and sustained scholarship to inform our thinking and guide our efforts. Investing time and intellectual energy to do the hard research for us, she has meticulously unpacked the notion of inclusion
and subjected it to painstaking critique. Using the metaphor of the patchwork quilt, Clapton directs and steers the reader through the ethical maze of inclusion. Her work concludes that the fundamentals of western philosophy have not afforded sufficient moral protection of people with disability so that inclusion becomes optional. This fundamental optional status rests on the assumptions that people with disability – especially those with an intellectual disability are not human, are not worthy of protection. If one is determined to be not human or less than human, a vegetable or creature or animal, then how can one be afforded protection of human rights?

This work is timely. While the conceptual work was originally begun some ten years ago as Jayne completed her doctoral work, a journey I had the privilege of sharing, its relevance transcends time and indeed is perhaps more crucially important today. Current bioethics would tell us that the profound injustice of a moral position that people with disability do not matter or should be ‘put down at birth’ confronts us all. Arguing that social inclusion has its roots in liberal egalitarianism, Jayne puts forward the view that this is indeed a risky position. She suggest that inclusion may well work in times of prosperity but that social inclusion can all too readily be diluted and that what is needed is a transformatory ethic that brings us to a position of integrality. With integrality there is no binary of in or out, of wanted or not wanted, of good or not good, of included or excluded. Rather we find ourselves in a moral space where all are valued and all belong.

For some of those engaged in the lives of people with disability whether as parents, friends, workers and services many of which continue to be underpinned by Christian values and their derivatives, this book will be confronting. It is not an easy read and does not contain easy ideas and concepts. How we then transform these ideas to actions that support imperatives for better lives for marginalised people, is perhaps even more confronting. But I thank Jayne for paving the path and bringing the critique to our attention. I hope we can ultimately enjoy a world where all people can truly belong as part of the richness of being human.

Lesley Chenoweth
Professor of Social Work, Griffith University
15th November 2008
I came to this task of conceiving and developing this research as a mother of four children. However, no prior knowledge of conception, gestation, labour or birth could have prepared me for the commitment I had undertaken. Although many long, lonely, and sometimes painful hours have been spent on this research, I also have had the privilege and enjoyment of much support, encouragement and affection from colleagues, friends and family. To all that have contributed, I express my heartfelt appreciation and thanks.

Specifically, though, I thank the birth attendants. Trevor Jordan, Lesley Chenoweth, David Massey, Peter Isaacs, and Colleen Geyer, as colleagues who have not only helped me learn the craft of researching ethics and disability, but have also provided me with profound guidance, care, and nurture during this (sometimes chaotic) journey. For their ability to do this without ever diminishing my passion, or expecting me to ‘conform’ to rationalist procedures and methods, is testament to the richness of the encouragement they have offered me. For their scholarship, and their willingness to share knowledge, I am deeply, and soulfully, thankful.

The publication of this research as a book has come to fruition by the encouragement and support of my colleagues at Griffith University. Naomi Sunderland is responsible for initiating the process; and Natalie Clements has spent much time preparing the manuscript for publication. I am indebted to their commitment and am profoundly thankful.

During the long, journey, friends and extended family have been a precious source of support, affection, provision and comfort. To my friends from whom I have learnt to understand more about disability, I am extremely grateful. I especially thank Julie and Graham for their permission to share some of their story to tell my story. I am particularly appreciative of my many friends I have engaged with within the disability context.

Family has also been an important source of care. For my parents, Ruth and Kevin Clapton, I am eternally thankful. For the support offered by Wayne and Kay Clapton, Maurice and Ruth Harriman, John and Sandra Harriman, and Peter and Leanne Harriman, I am very appreciative.

Finally, I thank my husband Robert Harriman, and my children Sarah, Innes, Kate and Luke Harriman. These are last not because of insignificance, rather because words simply cannot express my appreciation for their contribution to this achievement. Years of sacrifice, tolerance and understanding towards the gestation of the metaphorical sibling, have indeed been a precious gift. My hope is that all will share some joy from my labouring.

To all who I have mentioned, and to those who may have been overlooked, I offer two words: Thank you.
Vision begins to happen in such a life
as if a woman quietly walked away
from the argument and jargon in a room
and sitting down in the kitchen, began turning in her lap
bits of yarn, calico and velvet scraps,
laying them out absently on the scrubbed boards
in the lamplight, with small rainbow-colored shells....
Such a composition has nothing to do with eternity,
the striving for greatness, brilliance –
only with the musing of the mind
one with her body, experienced fingers quietly pushing
dark against bright, silk against roughness,
pulling the tenets of life together
with no mere will to mastery,
only care....

- Adrienne Rich.
THE QUILTER’S JOURNAL

She cries.
Her blue eyes squint.
Her skin is pink.
The warmth of her touch expresses life.
The miracle of birth has occurred;
And she is perfect.

Our baby did not cry.
The blue of her eyes matched her skin.
Her little cold hand was warmed by tears
When she touched our memories forever.
So perfect; yet so lifeless.

Only God knows
Why we lost Karen as a daughter and sister.
But now we have the gift of Sarah;
Whose love and joy
Illuminates thirty-three years of memories.
Thanks be to God.

When I was about seven years old, I went with my parents to the cemetery to visit the grave of my paternal grandmother who had recently died. On the way out, my parents took the time to go to another grave – a small grave. It was the grave of my sister. At that time, and in that place, I learnt that my mother had given birth to a baby girl between my brother and me. She was a big baby – over 5 kg; and the birth had been quite traumatic. My mother had needed to recover; so, little did she know of the cloud of despair that had descended into the delivery room. Karen was stillborn; and my mother never saw her or held her. However, my father had briefly sighted his daughter; and he remembers her beauty; a memory acutely rekindled when, some 33 years later, he saw his second granddaughter shortly after her birth.

My parents were told that, had my sister lived, she would have had significant brain damage, and been quite affected intellectually. Quite probably, she would have had cerebral palsy.

What happened in the cemetery that day was more than my parents passively telling me some family history. This was my first memorable touch with what is now described as ‘disability’; and that experience was to lead to an enduring, active and embodied response to people perceived as disabled. From my childhood, this familial event formed my gaze of such others. I did not see people as tragedies,
burdens, or, in fact, as potential death. My gaze on such otherness became centred, not around the notion of the distressed and suffering stranger, but of the potential sibling; and therefore, of imagined relationships.

I recall my mother’s willingness to ‘mind’ people with disability for parents to go out. I remember the respect shown to the Spastic Centre building located a few streets away, and the way the work inside was held in the highest regard. This was work never visited but always reified. And I recollect the disallowing of certain language; for example, to call someone a ‘spastic’, a ‘retard’, an ‘idiot’, or a ‘simpleton’ received similar rebukes to that reserved for blasphemy. I have since often wondered why these actions, though subtle, were so dominant. Obviously, the stillbirth had had a large impact. But this had not been the totality of my parents’ experiences. I am sure, though, that the influence of different experiences initiated particular moral responses.

My father, a war veteran, was a labourer, employed as a council worker, then a gardener. My mother, though employed for a short time, mainly shared her skills in a volunteer context. So their different experiences were ones lived by the embracing of hardship always in tension with determination to seek betterment, ‘rightness’ and success, often at personal cost. This has been their gift to their children; and to any community in which they have lived. But these actions, performed on the margins, are invisible to popular media portrayal or public award. These actions are primarily acknowledged in the private lives of those in accepting relationships. Therefore, I have gained an embodied inheritance – my body has been inscribed with compassion, sensitivity, respect and empathy; captioning a text about difference formed in my imagination from the seeds of my parents’ experience. So it was somewhat inevitable that some of these texts were to become expressed in another medium, namely a vocational choice.

After completing secondary school in the mid-1970s, I chose to undertake training to become a registered general nurse at a large metropolitan hospital some 700 km from home. This was, in my eyes, an inferior choice. I had always yearned to study medicine, but this proved to be an unachievable goal. Undertaking nurse training, though seemingly gender-appropriate and romantically endorsed as a ‘helping’ profession, proved to be an achievable nightmare! During the three and a half years of being at that hospital (3 years of training plus 1/2 year employed as a registered nurse), I could never feel comfortable with the militaristic style of the profession. Compliance to ‘authority’ through the surrendering of any sense of self was not only commanded, but any form of non-compliance brought reprimand and humiliation. Status was hierarchically determined from senior medical staff down, and this was played out in every arena. This included the staff dining room where one could only sit within the bounds of pre-determined areas, according to status. The ethos of the hospital was configured on the premises of power, expert knowledge and authority, all of which covertly depended on a dialectical relationship with vulnerability, naivety and submission. The latter descriptors represented, then, the experience of subservient groups such as nurses and patients; groups which overtly depended on the dominating forces.
The hospital setting and workplace culture made no allowances for challenge. Use of personal initiative was interpreted as a threat to overarching control; surveillance extended beyond the public work space to private bedrooms in nursing quarters; and any personal hardship or illness suffered by nurses was treated as inadequacy of commitment or dishonesty to the required loyalty. Humour, suspicion, frustration and bitterness became co-inhabiters of my vocational survival kit which I made, very early in my training, from a fabric of contempt. Living the paradox of an environment, supposedly designed as an institution of care, but hypocritically flaunting and sustaining oppression, became, for me, untenable. From my background, this seemed nothing short of moral antithesis. Therefore, becoming involved with the Christian church during this time served, somewhat, as an antidote.

After having resigned from the hospital in the late 1970s, I successfully applied for a position as a supervisor in a sheltered workshop. This workshop was run by Special Caring Services Division, a section of the newly-formed Uniting Church in Australia, of which I was a member. It was a workshop for people with intellectual disability, and was founded on notions of Christian service easily identifiable with the Methodist tradition brought to church union. Like other people there, I became proficient in rubber doormat making, the main activity of the workshop. As well, I learnt to spoke bicycle wheels very sloppily.

This was an interesting era in disability work, for the ideas of normalisation principles, espoused by such people as Nirje in Europe and Wolfensberger in North America, had begun to infiltrate practice in Australia. A predominant outcome was a shift to deinstitutionalisation. In Queensland, the director of Special Caring Services, the Reverend Wal Gregory, was approached by the Queensland Government to work collaboratively to move people with intellectual disability from state-controlled institutions to community/church-based agencies to provide community care and employment. Thus, these adults working in the sheltered workshop came from diverse backgrounds - some who had lived with their families since birth, and others who had only recently entered ‘community’ life, having been incarcerated, in most situations, since their birth. This latter group were now being housed in hostels in suburban settings. Diversity included differences of educational and recreational opportunities; but most obviously, differences in familial experiences. Such were the differences in histories that the easiest options for work culture seemed to be to treat everyone in the present tense.

By not attending to people’s histories, and by ignoring the invisibilities as such, a yearning was created within me to become more actively involved in the deinstitutionalisation process. I was struggling to understand how groups of people could have been locked away from society, when my background had constantly informed me that such people could not only live in communities, but be liked and accepted. As this struggle was agitating and desire was stirring, Wal Gregory approached me to ask if my husband, Bob, and I had ever given consideration to becoming house parents in one of the church family group homes established in a joint project with government. These homes housed 4 to 6 young people with intellectual disability, and both partners were employed full time, 24 hours a day. After much deliberation, we decided to undertake this move. Interestingly, our friends and families not involved in the church applauded our intentions and read
them as sacrificial philanthropy; whilst friends and relatives involved with the church told us we were fools!

The decision was made. So with a one-year old marriage, we prepared to move to a suburban, white, Spanish-style house situated approximately one hour west of the metropolitan city. After 4 months of working in the workshop, and a trail of doormats and damaged bicycle hubs behind me, my husband and I moved in with 4 young people who had lived in this house for a year - their inaugural houseparents had recently left, but were living in the same town. So began an incredible experience for the next four years.

Who were these people? Firstly, there was Angela, aged 17 years, the eldest and the “leader”. Having Down Syndrome, she had been institutionalised since birth, living in a hospital children’s unit until she was 12, then at another institution until she was 16. She had never known her family. Then there was Simon, 11 years old, institutionalised since a toddler because his autism-like characteristics could not be understood within his family and had resulted in instances of abuse. Desmond was 9 years old, and had been removed from his mother as a baby, because the state had deemed her incapable of caring for him. His bilateral hearing loss had not been discovered until he had been sent to school at 8 years old to prepare him for transfer from the institution. The youngest and the smallest (size 6 for clothes) was Wally, aged 8. Having Down Syndrome had been the reason for his ‘hospitalisation’ since birth, because, it was said, his wealthy parents could not come to terms with the social embarrassment of having such a child. The boys, being under 12, had come from the children’s unit where Angela had lived.

It is not unusual that, when writing about such people, their defining deficits are noted. Their incapacities and inadequacies in relation to their intellectual incompetencies, traditionally dominate descriptions of their personhood. However, these were not the deficits by which we learnt to focus. Their life had been determined by the lack of personal histories - stories and photos; the lack of familial relationships; the lack of life’s everyday experiences; the lack of educational opportunities; and the lack of choices: these were the deficits inflicted by a stigmatising society which took little responsibility for such actions. Therefore, the malignancy of these occult deficits flourished in nutritious social media constituted by institutional excesses of routine and depersonalisation; chemical restraint; and physical and emotional abuse - all ‘practised’ as medicalised care.

Our initial observations supported these conclusions. More than one of the children were still on tranquilising medication - one of our first activities was to ask a medical practitioner to justify this action. No justification could be found other than that it was a remnant of institutional care where it had been used for the purpose of behaviour control to enable better compliance to routines. On this basis, we set about to cease the medication.

Another startling feature of this new household was the way everyone fought to do basic household tasks, such as washing the dishes, vacuuming etc. Again, another remnant from where there had been no access to such activities. There were other indications of well-ordered lives, beds always well made and personal belongings placed protectively in personal spaces such as bookshelves.
Relational aspects were to take time. There was overt agitation and irritation to flexibility (or our ‘induced chaos’). Mistrust and uncertainty constituted the environment as much as the welcoming of a new adventure. Also, we had to understand that they had known each other not just in the constructed context of the previous 12 months, but for many years in the other venues. These had, to a large degree, been the only example of constancy and stability, whilst other relationships such as those with staff, had not only been at the mercy of rosters and rotations, but also resignations and retirements. We were, indeed, the strangers; and it was important for us to know this dynamic. While some found it easy to touch, others were not just shy, but fearful of any forms of such – we were to learn later of their earlier experiences of abuse.

But there was to be another significant episode during the early weeks, which would add complexity for the next four years. After we had been in the house for a week, Wal Gregory informed us that we were to receive another ‘child’. Trudy was 16 years old, and in the same institution that Angela had left; they had been close friends for many years. As well as having Down Syndrome, Trudy was an insulin-dependent diabetic. She had a different background to the others in that she had lived with her parents in rural Queensland until she was 6 years old. Because of the instability of her diabetes, she needed to be closer to medical assistance. This had resulted in her parents undertaking the heart-wrenching decision to have her admitted to institutional care.

I found the announcement of Trudy coming to live with us to be quite challenging. Life with the others had its particularities; but quite clearly, we were able to separate living and any medical concerns. They were not symbiotic. However, Trudy, with life-threatening unstable diabetes commanding control, would call on my experience of medical astuteness and proficiencies not tested since ceasing to nurse. Whether we had the skills and the confidence to meet these challenges was about to be tested. Wal pointedly asked if I didn’t have the skills, who would?

Our visit to the institution in which she was living left a lasting imprint on my sensory memories. Our sight and hearing noted how the environment and activities represented and screamed the characteristics of custodial care. However, my olfactory senses have not been able to erase the particular stench of an atmospheric cocktail of urine, faeces and other body odours mixed with the splashings of bulk-stored disinfectants from state-stores. (I’ve only smelt that stench once since, and it was some 14 years later when I visited a young sole-parent living with her child in squalor.)

Trudy came to live with us soon after, bringing her cherished possessions regularly supplied by caring parents. Although she was 16 years old, she was only about 120 centimetres tall. Her skin was dry, her abdomen distended, and her hair dull and coarse. She was unhappy, disengaged, and irritable. She would sit in a corner with her back to everyone else, and incessantly make an ‘urring’ noise as she turned each page of a magazine, or did some colouring-in. If we hadn’t known otherwise, we could easily have assumed that she had come from a refugee camp in middle Africa. She presented with characteristics of malnutrition, but her diabetic diet was large enough to sustain a working, mature male. However, we seemed to be dealing with more than just difficulties of ‘settling-in’. 
One thing that did come to our attention very quickly was that Trudy had incredibly foul-smelling diarrhoea, for which we sought medical attention. The local doctor thought that it may have been due to intestinal parasites, and prescribed medications, for her and the rest of the household. When these were ineffective, we sought to find out some of her medical history from the institution. We were informed that they were aware of the diarrhoea, and likewise had tested her for parasites. However, as nothing had shown up, they could not make any other conclusions other than that she was somebody with Down Syndrome, and people such as this weren’t very hygienic, so episodes of diarrhoea could be quite predictable. Basically, this was something we all had to live with.

From our medical backgrounds coupled with our suspicions of some of the inherent shortfalls of some practices, Bob and I weren’t convinced. Although she was interacting more easily, and occasionally would smile, her diabetes was still considerably unstable; subjecting her to other medical opinions. Unfortunately, these were often unpleasant and negative. A memorable example is when she was unconscious from a hypoglycaemic episode at 2am while we were away at a camp. Needing an injection of dextrose, we had to seek medical attention from a local doctor in the small town. Whilst reversing her unconscious state, he felt obliged to tell Bob that personally he felt that all children such as these (with Down Syndrome) should be put down at birth, and not cause a burden to society.

This was not to be the only time we were confronted with this sort of opinion. Such notions of dispensability could emerge in very different contexts. A new road-safety policy of the time had declared that all children traveling in cars needed to wear seat-belts. However, the taxis which transported children to special schools were often allowed to carry over seven children - obviously unable to wear seat-belts. However, when the government department responsible for enforcing the new laws was questioned about this disparity, their response was that children such as these were exempt from the law, and therefore the ambition for safety offered by the law did not apply to such children.

There were other instances where well-being ‘didn’t matter’. Because of his particular facial features, Desmond had an incredibly small palate. However, orthodontic dental treatment was denied for some years because junior dental officers declared that having a small and ineffective bite didn’t matter for someone like Desmond. On another occasion, Simon had dental treatment which required a local anaesthetic. We weren’t informed that this had been given, therefore neither were we informed that he should not have eaten anything that would have required biting for a few hours. Afterwards, he had lunch, and consequently bit into his numbed lip, leaving a large laceration. We took him to a doctor for treatment only to be told that, because he had an intellectual disability, he would not be caring how he would look in the future; therefore, because it wouldn’t matter, it would not be worth suturing his lip. Once again, we were forced to use the response which we had now had to retort to many times. It ‘did matter’ to this person because of his/her humanity and no reason otherwise would be acceptable. At times it was even necessary to situate this claim by suggesting that if this child was the
offspring of one of the opinion-makers, would this opinion still be given? Always, the answer was in the negative.

Our persistent efforts in relation to Trudy’s diarrhoea were to endure another 18 months. In that time, she was much more engaged socially, and despite what appeared to be obvious discomfort, we could see that she had an incredible sense of humour waiting to ambush any unsuspecting ‘helper’. We taught her how to manage her diet more independently, and then set about teaching her to prepare and inject her own insulin. Progress was noteworthy, but not completely satisfactory. We had suspicions that she may have had a malabsorption problem in her intestine; but all doctors had been reluctant to undertake any invasive diagnostic procedures. By chance at a large hospital one day, Bob met a doctor with whom he had worked at another hospital previous to becoming a house-parent. They exchanged general conversation about what each other was doing. The doctor explained that he was now working as a gastroenterology registrar, and Bob explained the difficulties we had been having with Trudy. Within a month, the doctor arranged for Trudy to have a small-bowel biopsy.

So after 18 months, with Trudy now being nearly 18 years old, we got the diagnosis we had so determinedly been seeking. And, it confirmed our long-term suspicions of what may have been the problem. Trudy was diagnosed with Coeliac Disease, a condition manifested by an intolerance to gluten in wheat. The disease affects humans by damaging the lining of the small intestine, thus creating serious malabsorption. It can be present from infancy when wheat products are introduced in a baby’s diet. Indeed, we were able to track that Trudy had been showing symptoms of this condition since she was 6 months old - some 17 1/2 years, 10 of which had been spent within medicalised institutional care.

Obviously, damage was considerable. However, there were some quick responses. Within a week, her diabetic diet was able to be reduced to be congruent with her size rather than that of a working male. Her hair started to shine; her irritability decreased markedly; and her ‘funniness’ certainly dominated her life. It would be some time before she had a solid bowel motion; but it was certainly a time of celebration when it happened!

However, during this time, life didn’t stay still for the rest of the household. Angela moved out of the house after the first 12 months, as her schooling had finished, so she was moved in to a women’s hostel to be closer to work options. Simon, Desmond and Wally, along with Trudy, got involved with ordinary activities such as learning to ride a pushbike, establishing and maintaining a vegetable garden, building a cubby house, playing cricket and soccer as well as outings with our friends and families who fulfilled extended familial roles. Holidays and camping activities were regularly undertaken.

We were expected to attend the local Uniting Church, a very traditional ‘newly ex-Methodist’ church; and that presented some interesting experiences. The first time he attended, Simon apparently stood up on the seat at the end and called out in his not-very-easily-discernible-language, “Shut-up, you big fat bastard!” Trudy got through church by ‘urr’ing’ and counting her way through the hymn book; Wally threw imaginary hand grenades at the senior choir; and I think, week by week, Desmond rendered his hearing aids ineffective. But there was one experience...
which caused us tremendous concern and that was the church’s insistence that these 4 to 5 people could not be included with their peers in Sunday School. They had to be in a ‘special class’ with a ‘special teacher’; and this special class just happened to be made up only with these particular 4 to 5 people. This caused us a lot of heartache and prolonged discussion. However, it was one battle we would not win; so the only acceptable outcome for us was to go to another Uniting Church where we were not subjected to such restrictions.

Another memorable event was the birth of our first-born son after being with the children 18 months. I distinctly remember the stares of people when I would go out shopping etc. Their looks spoke the words, “The poor thing. Four like that, and she’s trying again!” Pregnancy, birth and breastfeeding weren’t just new experiences for me as a mother. It was the first time for everyone. Our son, Luke, was born with bright red hair, a considerable talking point amongst all who saw him. But no comments were as poignant as the questions Desmond asked. Peering in through the nursery window, he turned and asked, “How is his hair going to grow? Do we have to water it every day?” What seemed to be ludicrous questions, perhaps encapsulated the particularity of his life. Brought up in a ‘hospital ward for handicapped children’, there had been no exposure to ordinary family activities such as being with babies; nor had there been any one person who could tell him stories from his own babyhood. There were no anecdotes; there were no photographs; and there was no knowledge of how a baby’s hair grows!

Everyone loved Luke. Wally was absolutely enthralled with a baby in the house. Luke became a great playmate. Trudy loved feeding him, cooing in her dulcet tones of “Are you hungry, Baby? Here. You have it!” It was during the pregnancy and afterwards, that we could note some distinct differences between Trudy and the others. Having lived with her family for the first 6 years of her life, she appeared to be much more aware of others; and showed a degree of compassion and care simply not there with the boys.

As Luke turned 2 years old, there were some other events which brought their own idiosyncrasies. Roslyn, aged 10, came to live with us from the children’s unit. This commenced another ‘it doesn’t matter’ experience as Roslyn had a persistently runny nose. We were battle-hard by this stage, so within 6 months she had ear, nose and throat surgery to correct the problem.

Friends and relatives were starting to subtly suggest that it was not in the best interests of Luke’s developmental well-being for him to be in a house with 5 others with intellectual disability – views that we would readily dispute if anyone said them openly. However, by this time, I was pregnant with our second child, and it looked like the purely heavy emotional and physical demands could not be sustained with 2 small children; so we made the very difficult decision that we would have to resign with Kate’s birth. And this is indeed what happened.

However, the time leading up to the point of separation was made harder with Trudy’s health taking more uncertain turns. Her diabetes had been fairly stable since the diagnosis of Coeliac Disease, with very few hypoglycaemic attacks. However, out of this stability came about four months of life-threatening difficulties. Numerous times, we were wakened during the night to hear her thrashing around
the bed in a fit, which rendered her unconscious and incontinent. Our local doctor (we at last had a supportive one) had supplied us with an injection that I could administer that would help her regain consciousness by releasing stored sugar in her liver. This would be enough to get her conscious to be able to have sugar orally. Whilst unconscious, most times she bit her tongue, and therefore had a bloodied mouth. What I was to learn most from those episodes, which usually occurred in the early hours of the morning, was the importance of touch. Although I was 6 months plus pregnant, I would sit down on the kitchen floor with her supported between my legs. As I held her firmly and securely, she would become conscious quicker than if I didn’t hold her. But more noticeably, she would be less frightened knowing that someone was with her in the darkness between unconsciousness and consciousness.

Kate was born, and we not only left the children and the house, but also the community, to move to another town some 300 kilometres away. In that time of separation, I wondered what we had all achieved over that 4-year period. Physically, and emotionally, everyone seemed to be better off. I must be careful not to romanticise this period. In simple terms, it was very hard work. Twenty-four hours a day for 4 years (equivalent to 17 years of a regular work pattern), we attended to all needs from domestic tasks to attending to bed-wetting to enduring severe illness such as Hepatitis B. We worked with the other family group homes; and we had the privilege of ‘assessing’ other children for discharge from institutions into the community.

But what about this so-called ‘community’? And what is community? From my experiences and observations, I am left with the following to make sense of. As well as positive encounters, community is the place where one set of neighbours can refuse any conversations between their children and ours – the same neighbours who had vehemently claimed to the local council that a house such as ours would devalue their property; community is a place that can view people with disabilities with gazes of specialness and braveness, but tell them that their needs ‘don’t matter’; community is a place where options are decided by others who think they have that right, such as teachers who write home to say that Wally needs a hair cut; community is a place that appoints professionals to decide if certain people can have access to it; and community is a place where different agents are allowed to flaunt their acts of duty and charity without ever having to enter into a relationship with the stranger among them. The paradoxes of community have, indeed, been enduring mysteries.

Although some contact was maintained with established relationships, another intimate contact with disability issues was not appropriated until some 10 years later. In the intervening years, the disability field was said to have changed significantly. New Commonwealth legislation had been implemented in 1986, and there had been a significant shift of practice from older frameworks of care and dependency to support for independence. Integration, inclusion and community participation either synonymously or particularly were ideals being strived for. However, even with this universal legislation in place, along with new policy and program directions, families that I worked with were still experiencing significant
hardships in terms of access and opportunity; but most importantly, understanding of their particular experiences and needs.

Misinterpretation and ignorance manifested itself in many forms. From my position as a Supplementary Services Worker in child care services, I saw parents and families continually be subjected to ‘professionals’ who thrived on discretionary opinions. I found myself somewhat of a liminal position - on the threshold because of the knowledge gained as a pseudo-parent, and of now being employed as a professional worker with newly-acquired university knowledge. But I found the same sort of misused power active in the context of professionalism that had underpinned my nursing experience some 15 years earlier. I saw people making decisions about worth, desires and opportunities from the security and distant isolation of nice workplaces, rarely daring to visit families in their own environment. These decisions were made with the power that could determine someone’s access to services, to education, and to financial entitlements. I also saw first hand the despair of invisibility felt by families as they struggled to be understood and heard.

But most alarmingly, I was exposed to the crippling effects of guilt constantly imposed on parents by a society who determined that these conditions were self-imposed. I heard stories of how parents were told that their child’s condition had been the result of parental sin; for living in particular relationships; and for not choosing certain moral paths. And I found it disturbing that these assessments were propagated by different Christian churches. A paradox was evident - publicly, churches were involved in service activities; whilst privately, certain members felt they had a right to police what they perceived as expressions of the immorality of society. Somehow, legislation and professionalism couldn't address these realities.

A couple of years later, we again lived in the large metropolitan city. One evening, we received a telephone call from a friend to tell us that Trudy had been admitted to a hospital. She was very unwell, and cancer of the liver was suspected – the diagnosis confirmed, in fact, a couple of days later. When we visited her that night, we effectively turned the clock back to the late 1970s. She was sitting up in bed when we arrived around 8pm. Her meal tray, which had been distributed around 5.30pm, was still on her bedtable. With an intravenous drip in her arm, and crying with each small mouthful because of pain, she was endeavouring to eat her dinner, committed to her lifelong discipline of needing to eat everything provided to meet her dietary requirements. We immediately engaged in conversations of the past, and again to hold her had a small, yet still significant, effect.

When a nurse did come to attend to her, I asked if Trudy could have something for the obvious discomfort she was in. His reply was that she had been offered an injection a couple of hours earlier, but had grizzled when they tried to give it to her. He then declared how they assumed she mustn’t like needles; and how they can’t waste these drugs, “you know”, so it was decided to abandon the attempt. Pulling out my nursing survival tool kit which I surprisingly discovered I still carried, I made an icy response. It seemed quite unimaginable to me, and now hopefully to him, how this young woman with insulin-dependent diabetes requiring two injections a day since she was 6 years old, could be scared of needles. I then
stated how I would be very happy to sit with her while she had the injection that he was now going to go and prepare!

A couple of days later after a liver biopsy resulting with the diagnosis of liver cancer, Trudy was moved to a palliative care ward where she was nursed in an individual room. Open access was available to family and friends. During the next 10 days that she lived, Bob and I were privileged to sit with her and share that time with her mother, and a couple who had cared for her, as a member of their own family, during the previous few years. We exchanged stories; we laughed together and we cried together. We all made room for each other’s need for private space; and we facilitated the opportunities for friends such as Angela to come and say good-bye. And we celebrated that even as she was dying, Trudy still managed to ambush some unsuspecting nurses and other professionals. We talked to Trudy about death, preparing her in a way that we hoped would be adequate.

The previous few years that Trudy had spent with Julie and Graham had been as fun-filled, yet as ordinary, as that which anyone could have hoped for. For instance, Trudy went with them for a weekly counter-tea at the local hotel where Graham played pool. She was there as one of the crowd, accepted and always interacting with fun and friendship to the authentic friend. She had regular telephone conversations with her mother who still lived in a rural area; and she dearly missed her father who had died.

This, then, seemed to be what deinstitutionalisation, integration, inclusion, and all the other technical terms were about. This was about goodness and about life, that no piece of legislation or policy or program could adequately script. It was something that could only be experienced through intimate, yet intentional, relationships; and people willing to engage in them in a profound sense of mutuality. And these were people who were willing to confront evil, to stand up for what they believed was right, and to challenge what they perceived to be unjust.

These, then, are issues of morality which have remained unspoken in conversations of deafening silence.

This is a story which begins and ends with death. It is also a story which articulates community exclusion; its plot centering around the defiance and rejection of processes of social death imposed, and continually played out, by different communities towards some members of the human race. It is, and will continue to be, therefore, a counter-story which strives for living. It is out of these diverse notions of death, that a theory about inclusion – what it takes for inclusive living – is born.

For it was you who formed my inward parts;
you knit me together in my mother’s womb.
I praise you, for I am fearfully and wonderfully made.
Wonderful are your works; that I know very well.
My frame was not hidden from you,
when I was being made in secret,  
intricately woven in the depths of the earth.  
Your eyes beheld my unformed substance.  
In your book were written  
all the days that were formed for me,  
when none of them as yet existed.  
How weighty to me are your thoughts, O God!  
How vast is the sum of them!  
I try to count them - they are more than the sand;  
I come to the end - I am still with you.  

CHAPTER 1

INTRODUCTION

1.1 INCLUSION AS A CONCEPT

In human service circles, the word ‘inclusion’ has become a buzz word. It is commonly used in relation to people whom our Western Judeo-Christian society describes as disabled and, in the context of this present discussion, particularly for people perceived as having an intellectual disability. ‘Inclusion’ has been used as a noun to name a process and as an adjective to describe many and varied activities and projects such as inclusion networks, inclusion workshops, inclusion policies, inclusion conferences, inclusion kits, and inclusion workers. In contemporary frameworks shaping services and education for people with intellectual disability, it is used synonymously with words such as integration, mainstreaming, community care, institutional reform and deinstitutionalisation. Therefore, inclusion has come to represent a topical notion with wide ranging conceptual and practical implications.4

Inclusion has been defined as the action of including, or the condition of being included.5 Human service practices reflect this understanding. How people can be included, that is, contained, embraced or placed in an aggregate, is planned intentionally, politically and strategically. This is most often done with undertones of the notions of integration or insertion.6 Utilising processes of assimilation, these notions are enacted on foundational aspects such as ‘access to’, ‘accommodation in’, ‘facilitation of’, and ‘appropriateness to’. Therefore, emphasis is placed on technical and legislative processes to achieve these required ends - the common commitment being to include people with intellectual disability into social institutions, an assumed perception of community, and the built environment.

As will be indicated in Chapter Two of this book, a comprehensive review of the literature about inclusion in the disability context reveals that inclusion is predominantly conceived within a linear continuum of translocation from ‘special’ or ‘separate’ to ‘regular’ or ‘normal’ environments or settings. These changing social arrangements are often underpinned by policies, in conjunction with human service personnel and technologies, which, in turn, assume an available network of ‘community care’ and ‘community concern’. I argue that the notion of inclusion promoted in such significations is somewhat simplistic in understanding and application, failing to recognise the necessity to address the conceptual complexities of the term.
‘Inclusion’ is a metaconcept. Different facets of inclusion can be metaphorically conceptualised as a position, a belief, an aspiration, a policy, a practice, an action, a sense of being, and an ideal. However, it is essential to recognise that inclusion is conceptually embedded in a dualistic and dichotomous relationship with exclusion. Whilst exclusion can be beneficial and positive in some contexts by protecting notions of choice, solidarity and particular social practices or actions, it is ‘negative exclusion’ which is most prevalent in the lives of people with intellectual disability. Such negative exclusion is seemingly founded upon lack of choice, assumptions of inferiority, and burden. An inclusion/exclusion relationship is, therefore, structurally similar to other dichotomies whereby power, hierarchy and containment are implicit. These are dichotomies such as abled and disabled, normal and abnormal, male and female, white and black, mind and body.

Inclusion and exclusion are also second-order concepts. They are terms which cannot exist in their own right such as the objects of first order concepts; but which are conjoined to other concepts such as order, humanity, society, community, school, group, church and so on. Inclusion is subjected to the values therein of such concepts, and membership is defined on the basis of pre-defined legitimacy to be similar to the dominant members.

It can be claimed, then, that while understandings of integration for people with disability, particularly intellectual disability, have sought to highlight and address characteristics of segregation: proponents of the notion of inclusion, though implicitly recognising marginality, have inadequately addressed the structural dynamics of societal and community exclusion, that is, morally speaking, inclusion is so bound up with its opposite – exclusion – that it must be rendered with care. I contend that addressing structural exclusion is not merely about attending to ‘absence’ or the state of ‘being left out’. It involves the intentional deconstruction of processes of active exclusion configured with existing relationships of power, orthodoxy, and hegemony.

In this research, I promote this extended view. I assert that ‘inclusion’ is not only a dualistic term in a dichotomous relationship with ‘exclusion’, but also is a multifaceted, complex concept which commands a socio-ethical critique. I explore such an assertion by arguing that historical and contemporary conceptualisations of exclusion for people with disability have been constructed from various philosophical and theological matrices imbued with particular values. These matrices, I contend, are immersed, impregnated, controlled, and bounded by contexts of patriarchy (rule of the father linked to the male-female gender dualism underpinning the Western Logic of Identity) and kyriarchy (rule of the master and Lord linked to the power of social arrangements and structures) – contexts to be explored in depth later. In doing so, I identify two dominating ethics underpinning various practice frameworks of services for people with intellectual disability. These practices which embrace policies and human services in a Judeo-Christian context represent various types of inclusion, and are, therefore, mapped with a contextual applied ethics framework to highlight various assumptions about power, position, personhood and principles within them.
INTRODUCTION

Considering ‘inclusion’ and ‘exclusion’ suggests the notion of space, and, in particular, spatial differentiation. I contend that whilst inclusion and exclusion in the context of intellectual disability, have been explored in socio-historical and socio-political spaces, there has been little attention applied to socio-ethical spaces that have constructed the concepts. However, caution is called for in the use of the metaphorical expression ‘space’, a common metaphor for such explorations. In suggesting the existence of ‘spaces’, I do not want to imply that these areas are self-sustaining, separate domains. Rather, they are interconnected, interconstructed, and interdependent. For this reason, a more appropriate metaphor is necessary. Therefore, in this research, I will use the metaphor of a textile ‘weave’ to represent a spatial configuration to describe the intersection of conceptual dimensions.

I propose, then, that certain socio-historical, socio-political and socio-ethical aspects are integrated within the weaves of Western Judeo-Christian social fabrics which enfold notions of inclusion and exclusion for people with intellectual disability. Although these are usually calendered fabrics, I intend to wipe away the calendering to identify the structure of the fabrics. I assert that these are fabrics constructed by visible interfacing threads which I see as the warps of disability theories and the wefts of social practices of disability. As in the art of sculpture, the holes, that is, the spaces between the threads are as important as the visible material in creating form. It is in these holes in the weave that ubiquitous assumptions and values are created and that particular ethical constructions though present, are most often concealed. However, these are bounded fabrics.

Significantly, whether one is ‘in’ or ‘out’ implies boundaries. According to Martha Minow, boundaries and categories within society are inevitable, for she describes how categories, being “humanly made and mutable,” identify and emphasise difference as “expressions of ourselves and our values.” Boundaries can be points of connection and solidarity as in seams; but they also provide the unspoken and powerful media of negative categorisation, definition and containment as in selvedges of fabric. Boundaries demarcate, and thus define, what is denied and “who is rendered invisible and unacceptable.” These are most often the boundaries which impact on the lives of people with intellectual disability. Minow states, “Legal rules in Western societies have historically drawn a boundary between normal and abnormal, or competent or incompetent people.” In doing so, she concludes: “Law has treated as marginal, inferior, and different any person who does not fit the normal model of autonomous, competent individual.”

Therefore, I contend that the ethical significance of inclusion and exclusion in the context of intellectual disability, lies not in the concepts themselves, but is defined and perpetuated by expressions of a particular socio-symbolic order. Feminist theologian, Rebecca Chopp uses a similar phrase ‘social-symbolic order’, which she states:

... calls attention, in linguistic fashion, to how a dominant ordering operates in subjectivity, language and politics. …the phrase “the social-symbolic order” underscores the structural as well as the symbolic perspectives of language. This ordering is an economy, a patterning of certain values and principles establishing often anonymous rules that run through discourses about different arenas and different discourses about one arena of social life.
The qualifier social-symbolic indicates that this ordering, though dominant in a particular historical period or era, is nonetheless a historical construct, and thus open to change and transformation. Around the social-symbolic order are margins and fissures that allow language and thus the social-symbolic order to be corrected, changed, subverted, interrupted, and transformed.

Such an order which silently, yet definitively, excludes certain people to the margins and beyond, is contained by constructed boundaries which legitimate the hegemonic centre of society. This is a socio-symbolic order co-configured by patriarchy and kyriarchy, for it privileges and protects the subjectivity of rational, white, propertied males by inferiorising ‘Others’. As Chopp eloquently states, the voices of the subjects “who suffer history and the subjects who control history are interwoven, forming the warp of our lives, the weft of our history.”

A socio-symbolic order, derived from patriarchal monotheism in the Western Judeo-Christian tradition, uses God the Father as a ruling sovereign to separate, divide and exclude. As well as the sovereignty of masculinity, the traditional socio-symbolic order of Western Judeo-Christian society is also dominated by the sovereignty of reason and rationality. Mark Johnson highlights this claim from both theological and non-theological viewpoints. He states theologically:

> Among the animals, we alone have duties to obey God’s will, because we alone are able to discern rationally what is required of us, both in our relations with others, who, like ourselves, are made in God’s image, and also in our dealings with non-rational creation...

Drawing from the work of Immanuel Kant, he states a non-theological view, describing that:

> Kant’s project was to provide a rational foundation for the non-theological part of the Judeo-Christian tradition, … the part that sees moral laws as coming out of a universal human reason, independent of divine reason.

Therefore, male humanity, self-ascribed with the superiority of reason and rationality, assumes authority to represent the omnipotent God as head of the social order in Western Judeo-Christian society. According to Bryan Turner, the masculine character of God and Christ in New Testament Christianity created a social system of hierarchical and patriarchal power in which women and others with embodied difference to the patriarchal priesthood were assigned to and inscribed in inferior positions. However, these positions have not been differentiated by gender alone, for as Elisabeth Schüssler Fiorenza highlights, axes of power structures and domination are linked with notions of race, class, culture and religion - to which I add ability.

Boundaries are formed to intentionally and oppressively exclude those who are deemed different or anomalous. The weave of these boundaries, being dense and occluding, provide a definitive edge. For the purposes of this research, I will call these ‘Selvedges of Definition’ for their function to recognise or reject, accept or ignore, proclaim or prohibit, authenticate or illegitimate.

Chopp issues a challenge:
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It is no longer enough to assert, under the rules of modernity’s monotheism, the inclusion of the marginal: they are, at best, included only if they obey monotheistic practices as representatives of autonomy, identify, self-referentiality. Rather, the policies of inclusion and exclusion, the rules of formation and expulsion, the figurations of public and private as forms of the dominant ordering must be uncovered. 22

To conceptualise inclusion in relation to people with intellectual disability, these disclosures become imperative.

The processes of exclusion of people with intellectual disability activated in the public arena stand in stark contrast to the natural and implicit inclusion present and easily observed in the privacy of accepting relationships (including families) involving a person with a disability. The contrasting scenario is embraced usually in what appears to be a relational, domestic context. By applying feminist scholarship, particularly feminist theology and feminist ethics, the orthodoxy of the patriarchal matrices is challenged. Just as women claim a position from which to challenge and transform the socio-symbolic order from the domestic sphere, so can people with intellectual disability claim a similar conceptual conjunction. It is through the “pursuit” of what has been described as ‘Other’, seen as “both taboo and a precondition”, that the patriarchal monotheistic ordering which legitimates and defines processes of inclusion and exclusion is exposed and scrutinised. 23 New visions about how we, as a society, respond to embodied difference become apparent. In this research, ‘A Transformatory Ethic of Inclusion’, a particular ethical framework of inclusion, is offered as an instrument of rupture of the Selvedges of Definition to facilitate the challenge of realising these new visions as different practices.

1.2 AN EXPLORATION

‘Exclusion’ as a term has, in contemporary times, been used to express certain social phenomena. In the 1990s, there are two outstanding examples. First, ‘social exclusion’ has become a major consideration in the formation of economic policy within the European Community Programme; 24 and second, in a local context but with global importance, processes of exclusion formed the basis of a national inquiry into the separation of Aboriginal and Torres Strait Islander children from their families. At this point, it is useful to explore this latter example for the insights that emerge for this research.

In April, 1997, the Australian Human Rights and Equal Opportunity Commission released ‘Bringing them Home, Report of the national inquiry into the separation of Aboriginal and Torres Strait Islander children from their families’. 25 The Report records narratives of grief and loss, tenacity and survival, courage and suffering, as the ‘laws, practices and policies which resulted in the separation of Indigenous children from their families by compulsion, duress or undue influence’ since colonisation are described, and ultimately condemned, for their contribution to the continuing devastation of the lives of Indigenous Australians. 26

The Report describes social practices where people with different skin colours have been systematically, and most often forcibly, removed from their kin, their
communities and their culture because of a dominating white-skinned colonial ideology of Eurocentric superiority: an ideology promoted and enacted by both church and state. As a nation, Australians are now asked to feel the pains of the wounds inflicted on Indigenous people; to collectively be committed to tending the wounds towards repair; and to be honest enough to live with the presence of the ongoing and ever-present scarring. This process of recognition has not been straight-forward, however, for the nation has been asked to respond to an articulated immorality of actions of the past, and contemporary responses vary as to what responsibilities should be taken for apologies.

Theological, philosophical and social discourses, over time, separately and intersectionally, have served to create conditions for the exclusion of many different types of people from their birth origins and their communities. This exclusion has consistently and complexly been underpinned by moralities of goodness, rightness and the provision of ‘care’. Therefore, different practices such as the removal of children for institutional care and or assimilation within white families, were founded on principles of utility, duty and virtue, which were enacted for a pre-determined notion of ‘good’ for the inferior individuals, their families of origin, and the wider society. Practices such as these were hegemonically legitimated to affect marginalised people with pre-defined and prescriptive notions of well-being - excluding and including actions being the very tenets of such intentionality. The Selvedges of Definition metaphorically controlled the process of recognition and entitlement to the ‘good’ implicit in these practices.

In Western society, founded on the values and structures of such beliefs as Christianity, most often these exclusions have affected embodied persons who differ from white, well-educated, able-bodied males. In contemporary times, there are intentional processes in place to promote access and inclusion for such groups of excluded people into the public arenas at the centre of societies. However, the ethics, underpinned by goodness, rightness and/or virtuous acts, which historically founded, practised, and promoted exclusion have received little public scrutiny.

James Rachels describes a common understanding of ethics, when he states, “Ethics is the subject that attempts to provide directions for conduct.” Paul Komesaroff critically expands this understanding when he states:

The task of ethics is no longer to define the nature of the good, or duty, or “the ends of man (sic)”, much less to derive irrefragable principles of correct action. Rather it is to uncover the nature of ethical values and the process of value creation; it is to examine existing concepts and to expose their hidden assumptions; and it is to challenge the hegemony of existing value systems and so to expand the possibilities for ethical action.

Roslyn Diprose adds a spatial element when she declares:

Even if we grant that ethics is about moral principles and moral judgement, it is also about location, position and place. It is about being positioned by, and taking a position in relation to, others. Being positioned and locating others requires embodiment and some assumption about the nature of the place from which one moves towards others. It should not be surprising then that ‘ethics’ is derived from the Greek word ethos, meaning character and dwelling, or
INTRODUCTION

habitat. Dwelling is both a noun (the place to which one returns) and a verb (the practice of dwelling); my dwelling is both my habitat and my habitual way of life.\(^{29}\)

I contend that the investigation and Report of the ‘stolen generation’ of Indigenous people, when considered by a template of ethical understanding, reveals critical analyses of two dominating ethics promoted, applied and enacted by governments and churches. I identify and name these as an ‘Ethic of Normalcy’ and an ‘Ethic of Anomaly’. In crude terms, these are the ‘Ethics of In or Out’. An Ethic of Normalcy is underpinned by the morality of, and sustained by an ideology of, sameness and superiority. Legitimated processes such as authority, control, compulsion, coercion, duress and justification are utilised to perpetuate hegemonic and normative power ascribed with an Ethic of Normalcy to support the belief that normality can be defined and defended; and as well, be recognised and practised as a social good. These processes result in overt practices of domination of the powerful to use the Selvedges of Definition to exempt, reject, expel, and/or eliminate those deemed as not-normal or ‘anomalous’. Consequently perceived as inferior, affected people are excluded from certain arenas of society to the margins. These people then, because of embodied difference, are inferiorised and constrained by an Ethic of Anomaly, and forced into an aporetic and definitive relationship with the regnant, and therefore dominating, subjects controlling and operating an Ethic of Normalcy.\(^{30}\) This is an excluding and essentialist relationship of anomalous Otherness. These hegemonically applied ethics channel conduct without exposing the hidden assumptions of negative valuing of personhood, and the resulting positions of marginalisation.

For Indigenous Australians, these arenas of exclusion were so profound as to even affect their families of origin. Whether to be biologically absorbed, or socio-culturally assimilated, Indigenous people were forcibly removed to other social sites such as white families or institutions which promoted white ideals for the ‘good’ of the inferior individuals, and the ‘normal’ society as a whole – the conditions by which Indigenous people could pass through the Selvedges.

However, the removal of Indigenous children from their families is but one example of the dynamics of these ethics consistently applied in a negative sense to certain groups of people. In Western predominantly Judeo-Christian societies such as Australia, people with disabilities, usually under the guidance and authority of medical personnel, also were taken from families. An Ethic of Normalcy and an Ethic of Anomaly have operated definitively and prescriptively to legitimate different practices for such people.\(^{31}\) This research will explore how the construction and powerful influence of these applied ethics and the controlling Selvedges of Definition in relation to the notions of exclusion and inclusion, impact on the lives of people with intellectual disability.

Although the construction of normalcy is minimally explored in a literature review of disability, a commitment is made to undertake an in-depth look at the conjunction between disability and normalcy later in this research.\(^{32}\) The notion of disability, as a negative experience from an assumed state of normality and normative practices, represents how embodied difference is assigned inferior and undesirable connotations. The defining gaze of able-bodiedness interprets and evaluates various
anomalies of accepted norms which include somatic anomaly, spiritual anomaly, scientific anomaly and social anomaly. The authority and orthodoxy of this gaze contributing to the ‘disability dynamic’ is challenged for authenticity.33

Peter Clough and Len Barton reflect the power of such a gaze when they discuss who people with disability are:

They are the recipients of powerful professional categories. These envelope their identities. They are the ‘lunatics’, the ‘idiots’, the ‘mentally handicapped’, the ‘subnormal’ the ‘spastics’, the ‘cripples’ and ‘level-one child’. The point is: We know who They are. They are conspicuous, because their world is set about with a particularly forceful categorical thinking. (Authors’ emphases) 34

Australian writers, Jan Branson and Don Miller also elaborate:

The ‘disabled’, a marginalized group whose failures to satisfy the culturally-specific, historically-specific standards of physical or behavioural ‘normality’, display ‘handicaps’, inabilities to deal ‘effectively’ as individuals, with life in Western capitalist society, their ‘handicaps’ demanding, in the eyes of those for whom they are an ‘other’, a policy, an objective, clearly-formulated, bureaucratically-realizable, logical, coherent approach to dealing with/coping with, their ‘handicaps’.35

Exclusion, as a negative practice or a negative process of action, in the context of intellectual disability, takes many forms and wears many disguises. Responses to the common ethical questions of ‘What ought I/we to do?’ or ‘What should I/we do?’ have evoked normative processes of exclusion throughout history such as exemption, extermination, expulsion and incarceration. In contemporary Australian society, there is little recognition of the similarity of these actions to those enacted upon Indigenous Australians. This research seeks to explore the ethical significance of inclusion, though, from wider, more critical perspectives, which will account for ‘ethics’ being expressed in a somewhat negative context for people with intellectual disability. Implicit immorality in a disability context, remains to a large extent, concealed. Therefore, expressions of shame and disgust appear to be rarely articulated in relation to the historical and contemporary dislocated experiences of people with intellectual disability.

One reason for such omissions may be a failure to understand the particularity of such a context. Although it is seemingly critical to note the similarities of the situations, it is also imperative to note significant differences. It could be that an Ethic of Normalcy and an Ethic of Anomaly have been enacted differently in certain contexts and that the Selvedges of Definition have different powers of discernment. These differences can be illuminated by narratives about the lives of people with intellectual disability, as has been articulated in the account of Angela, Trudy, Simon, Desmond, Wally and Roslyn.

It appears that Indigenous children were removed from their families and communities to facilitate ‘social life’ by assimilating them to the values and lifestyles of white European society, and therefore facilitating ‘cultural death’. Indigenous children, with genealogical characteristics, were actively removed from
their site of origin of their families and culture to be taught the ways of a supposed superior culture. However, it could also be suggested that people with disability were removed to facilitate ‘social death’. People with disability, perceived as non-genealogical entities, were passively, yet decisively, released from that ‘superior’ culture because of the perceived burden they placed upon it and, in the process, were forced to live in an artificial and segregated culture of ‘the disabled’. This was the experience of Angela, Simon, Desmond, Wally, Trudy and Roslyn.

The category of the disabled was not only created by, but became dependent upon the ethics, works and services of the ‘able-bodied’. According to British sociologist Vic Finkelstein, the able-bodied have often offered two intervention choices, either cure of care to be administered by human service practitioners to ameliorate the effects of ‘social death’ caused by the impairment.

To elaborate, Indigenous people were subjected to certain practices to ‘make them normal’ in a particular community; whilst people with intellectual disability were removed from the same communities because of perceptions of those people’s ‘inability to be normal’. Branson and Miller in describing how they are defined and condemned out of society itself, state:

They are desexed, degendered and thus dehumanized. Their oppression does not involve ‘boundary maintenance’ within social life as is the case with sexism or racism, nor does it involve ongoing strategies for exclusion to ensure the ongoing dominance of the oppressors. The ‘disabled’ offer no immediate, tangible gratification, nothing that the ‘able-bodied’ want – no pleasure, no labour. The ‘disabled’ threaten with their presence. They are an ideological necessity in a humanist world based in ‘normality’. Their existence is of central importance for their asocial presence – they are ‘there’ reinforcing the social, cultural ‘normality’ of others – maintains the illusion of the reality of nature viewed mechanistically as ordered, bounded, tangible, humanity integrated through the physically-based clinical gaze. They define the limits of humanity. (Authors’ emphases)

Exclusion, then, is a phenomenon in relation to membership defined and legitimated in the Selvedges of Definition. For some, it is about membership to communities and society; for others, it is about membership to the human race. But the applied ethics determining such actions are the same; and practised in a certain moral context which is restricted to consideration of the morality and ethics of the agents offering their works, rather than the socio-ethical structuration of exclusion and inclusion.

The construction of normalcy and the evaluation of anomaly, are culturally embedded, and hegemonically defined. Susan Reynolds Whyte and Benedicte Ingstad state that:

Cultural assumptions about the body and personhood need to be seen in the context of ordinary social interaction [whereby] impairment raises moral and metaphysical problems about personhood, responsibility, and the meaning of differences.
CHAPTER 1

How our society responds to such metaphysical challenges becomes critical, and therefore forms the basis of this research.

1.3 THE RESEARCH FOCUS, OBJECTIVES, AND QUESTION

The focus of this research is an exploration of the ethical significance of ‘inclusion’ in the context of intellectual disability. This research argues that inclusion and exclusion, as concepts influentially shaping human service practices, are complex socio-ethical constructs informed by, and embedded not only in socio-historical and socio-political contexts, but also in the moral structuration of a dominant socio-symbolic ordering of the fabrics of Western Judeo-Christian societies. Therefore, critical to any understanding of inclusion and exclusion in relation to people with intellectual disability is the exploration of the prevailing normative ethics which underpin notions of right and wrong, good and bad, just and unjust, beneficent and malevolent. The construction, configuration and action of dense boundaries, which I name as Selvedges of Definition, command attention. A belief in a state of normality which remains uncritically implicit, becomes contestable. I contend that an Ethic of Normalcy and an Ethic of Anomaly are applied ethics (though negative in character), which underpin different social practices for people with intellectual disability. Dualistically and hegemonically structured and sustained by the Selvedges of Definition, these ethics are similarly embedded in notions of inclusion and exclusion, abled and disabled, black and white, male and female, mind and body. They are formed, and informed, from matrices of patriarchal and kyriarchal philosophical, theological and social discourses. The challenge emerges as to whether these dualisms can continue to validly exist in our contemporary society of diversity; and if not, then the vapidity of such dualisms needs to be exposed.

It is within these considerations that an ultimate research question emerges:

How ethically defensible is the notion of inclusion in relation to people with intellectual disability?

This research seeks to address critically the inherent orthodoxy and dualistic structurations implicit within the ethical context of the multifaceted inclusion/exclusion relationship. By seeking to rupture the Selvedges of Definition, I contend that the ethical configuration of the metaconcepts of inclusion and exclusion can be reconceived to a transformatory context of integrality. According to The Shorter Oxford English Dictionary, ‘integrality’ means ‘the condition of being integral - of wholeness, entirety, or completeness.’ I argue that if people with intellectual disability are seen to be valid or authentic ontological subjects of a socio-ethical context of Western Judeo-Christian society which celebrates difference within entirety, concepts of exclusion and inclusion become redundant by a superseding concept of integrality. ‘A Transformatory Ethic of Inclusion’, then, is proposed as a conceptual instrument of rupture to promote such change.

It is with these intentions in mind, that the research objectives can be stated:
INTRODUCTION

– To consider and conceptualise, from an enriched and embedded understanding, the ethical significance of the notion of ‘inclusion’ in relation to people with intellectual disability in Western Judeo-Christian society (Chapter Two).
– To develop an applied ethics methodology framed upon a quilting metaphor, which more adequately explores the structural complexities of the notion of the inclusion/exclusion relationship, and which can transform ethical understanding to embrace the diversity of humanity. (Chapter Two).
– To identify and critique, for ethical exploration, various theoretical and discursive perspectives of disability, as well as historical and contemporary social practices for people with intellectual disability in Western Judeo-Christian society. (Chapters Three and Four).
– To consider the constructions and influences of the Selvedges of Definition, an Ethic of Normalcy, and an Ethic of Anomaly which influence and prefigure the ethical significance of inclusion. (Chapter Five).
– To critique existing ethics discourses in relation to intellectual disability, identify aporia, and evoke an appropriate, contextual, applied ethics framework by which to adequately account for an ethical exploration of exclusion and inclusion. (Chapter Six).
– To apply a contextual applied ethics framework to outline identified notions of exclusion and inclusion, and to note, and critically consider, emerging ambivalence. (Chapter Seven).
– To construct ‘A Transformatory Ethic of Inclusion’ as an instrument of rupture to conceive and conceptualise a new socio-ethical Fabric of Integrality as a response as to whether inclusion is ethically defensible. (Chapter Eight).

1.4 SUMMARY

In this chapter, I have described how ‘inclusion’, in the contemporary context of intellectual disability within Western Judeo-Christian society, is a topical notion with wide ranging conceptual and practical implications. ‘Inclusion’ is predominantly conceived within a linear continuum of translocation from ‘special’ or ‘separate’ to ‘regular’ or ‘normal’ environments or settings such as education, communities, churches and so on. With undertones of the notions of integration or insertion, ‘how’ people can be included, is planned intentionally, politically and strategically. Changing social arrangements are often underpinned by policies, in conjunction with human service personnel and technologies, which, in turn, assume an available network of ‘community care’ and ‘community concern’. However, I argue that the notion of inclusion promoted in such significations is not only somewhat simplistic in understanding and application, but fails to recognise the necessity to address the conceptual complexities of the term. In contesting that ‘inclusion’ is a metacopcept, I assert that such a notion is a dualistic term in a dichotomous relationship with ‘exclusion’, and also is a multifaceted, complex concept which commands a socio-ethical critique.

I explore such an assertion by arguing that historical and contemporary conceptualisations of exclusion for people with disability have been constructed from various philosophical and theological matrices imbued with particular values.
Furthermore, I contend that the ethical significance of inclusion and exclusion in the context of intellectual disability, lies not in the concepts themselves, but is defined and perpetuated by expressions of a particular socio-symbolic order underpinned by patriarchy and kyriarchy, and subjected to two controlling ethics – an Ethic of Normalcy and an Ethic of Anomaly.

Inclusion and exclusion, then, are phenomena conceived in relation to membership defined, legitimated or repelled in occluding boundaries. Using the metaphor of a textile ‘weave’ to explore the socio-ethical fabric, I name the containing boundaries as Selvedges of Definition, for people with intellectual disability are subjected to, and defined by, evaluations against ablist constructions of normalcy. Therefore, to explore the ethical significance of inclusion will necessarily challenge the implicit orthodoxy within traditional socio-ethical fabrics.
CHAPTER 2

CONCEIVING A QUILT: CREATING A METHOD

2.1 INTRODUCTION

Inclusion, as is being explored in this research, is deeply embedded within cultural and intellectual understandings of intellectual disability. The nature of inclusion, within a Judeo-Christian context, for example, has been directly related to the values of biblical references, philosophical interpretations, and medical and service practices. Different interpretations and trends in the disability context directly influence notions of exclusion and inclusion. In the past twenty years, the subject of disability has undergone major shifts. Normalisation theories espoused by Bengt Nirje and Wolf Wolfensberger in the 1960s and 70s, and the International Year of Disabled People in 1981 provided catalysts for the increased momentum of the disability rights movement. Situated contemporaneously with other social movements such as the civil rights movement and the current women’s movement, these influences have resulted in ideological and legislative changes in the Western world about people with disability. Ideologically, and enacted through legislation and social policies, the most prominent practical outcomes have been processes of deinstitutionalisation and expectations of community inclusion. These have had significant impacts on the translocation of care, accommodation, housing, educational, employment and recreational options for people with disability and their families.

So called ‘care’ for disabled people in a post-Enlightenment and post-industrial Western Judeo-Christian society has predominantly been provided in segregated contexts, often resulting in a physical placement in institutions. The insidious relationship between social worth and productivity has been fostered on foundations such as capitalism and the Protestant Work Ethic, and scientific disciplines (such as medicine and statistical analyses) in the construction of normalcy. As a consequence, people with intellectual disability were systematically categorised as unproductive and excluded from the concept of ‘mainstream’ community. Under the disguises of ‘care’, the segregative and institutional process (performed then in the public realm) often perpetuated notions of hegemonic dependency and social control, social devaluation, and deprivation of autonomy and power.

Traditionally, there has been an emphasis on effective ways of managing such a phenomenon by bureaucratic, administrative and professional procedures without closer analysis of how this social segregation legitimates continual denial of societal membership.

This research contends that the dominant socio-symbolic ordering of Western Judeo-Christian society has been prefigured with, and by, the assumptions of orthodoxy, characteristic of patriarchal theology and patriarchal philosophy. Such an ordering is contemporarily configured by an Ethic of Normalcy and an Ethic of
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Anomaly. Therefore, it seems that it would be futile to continue to shape inclusion policies and practices without giving due attention to redefining the structures of signification, that is, the frameworks of meaning and valuation where the momentum of hidden ontological and epistemological assumptions keeps people with intellectual disability in particular socio-ethical positions within Judeo-Christian subcultures.

2.2 THE RELEVANCE OF A JUDEO-CHRISTIAN CONTEXT

A Judeo-Christian society is a purposefully chosen context, because it serves not only as an ethnographic focus for analysis, but also as a locus for social change. There are two specific reasons for this. The first reason is that descriptions of, and responses to, ‘impairment’ as described in the theological narratives recorded in the Hebrew Scriptures and Christian Scriptures have shaped practices of how “people of God perceived, treated, and lived with people with disabilities.”44

A second reason for choosing a Judeo-Christian context is that Christian churches, in the past and in the present, represent a large body of responders of care and service-providers, and therefore, provide not only a site for historical reflections of ‘traditional’ practices, but also could be a site for creative refiguration of disability practices using contemporary scholarship.45

2.2.1 Biblical Understandings of Disability

Over the centuries, Christian responses of sin or sanctity, curse or compassion, ridicule, rejection or romanticisation, appear to have had significant historical links with the established and perpetuated dominant socio-symbolic order created from the orthodoxy of patriarchal theology. A religious cosmo-biological understanding of forms of disability mysteriously pondered the question if people were born either as punishment because of sin caused by moral impropriety particularly of the mother; or as special representatives of the Divine as agents of God’s grace.46 This is exemplified biblically:

As he walked along, he [Jesus] saw a man blind from birth. His disciples asked him, “Rabbi, who sinned, this man or his parents, that he was born blind?” Jesus answered, “Neither this man nor his parents sinned; he was born blind so that God’s works might be revealed in him.” (John 9: 1-3)47

How disability practices are embedded within a Judeo-Christian context can be understood by exploring biblical representations, interpretations and appropriations. This is critical to an ethical understanding. Deborah Selway and Adrian Ashman have previously claimed that literature on the impact of religious beliefs and practices on people with disability is sparsely distributed across the fields of studies in religion, health, aging and disability. Therefore, they claim that the “study of religious textual reference to disability is in its infancy.”48 In conclusion, they suggest, “studies focusing on the role of religion in the lives of people with a disability themselves have yet to be conducted.”49 However, whilst I agree that these are contemporary, and indeed, only recent areas of inquiry, I contend that
Selway and Ashman have failed to adequately acknowledge existing literature in this area. To suggest that no research has been done appears somewhat limited. A more accurate assessment is provided by Nancy Eiesland, who states:

The experience of disability has been an enduring area of religious involvement and spiritual exploration. ... Though the notion of disability has never been religiously neutral, its meanings within diverse religious, cultural, and historical contexts have only recently been explored as a significant thematic in religious studies.

Eiesland describes how the exploration of disability in religion has proceeded in three directions:

- religious autobiography and biography of people with disabilities and/or their caregivers, ... [which] offer experiences and exemplars as important sources for the spiritual identity of people with disability:
- pastoral care, religious ethics, and theology, ... [which provide] examination and elaboration of religious ideas by pastoral and/or academic specialists ... [to embrace] theology, religious ethics, and pastoral care and liturgical or ritual guidance, and
- disability in religious studies ... [which] utilizes social scientific and humanistic theories and methods in understanding disability within a multicultural religious context.

An exploration of social practices of disability services falls within the second and third categories above.

References to notions of ‘disability’ are located throughout the Bible (See Table 1).

Table 1: Examples of biblical references to notions of disability.

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>NUMBER OF REFERENCES</th>
<th>EXAMPLES OF VERSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Without) Blemish</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(a) animals</td>
<td>52</td>
<td>(a) He shall provide a lamb, a yearling, without blemish, for a burnt offering to the LORD daily: morning by morning he shall provide it. (Ezekiel 46: 13)</td>
</tr>
<tr>
<td>(b) people/God</td>
<td>12</td>
<td>(b) ... so that you may be blameless and innocent, children of God without blemish in the midst of a crooked and perverse generation, in which you shine like stars in the world. (Philippians 2: 15)</td>
</tr>
<tr>
<td>Blindness</td>
<td>64</td>
<td>Listen, you that are deaf; and you that are blind, look up and see! (Isaiah 42: 18) Some people brought a blind man to him and begged him to touch him. (Mark 8: 22)</td>
</tr>
<tr>
<td>Deafness</td>
<td>12</td>
<td>You shall not revile the deaf or put a stumbling block before the blind; you shall fear your God: I am the LORD. (Leviticus 19: 14)</td>
</tr>
<tr>
<td>Demonic possession</td>
<td>4</td>
<td>They brought to him a demoniac who was blind and mute; and he cured him, so that the one who had been mute could speak and see. (Matthew 12: 22)</td>
</tr>
</tbody>
</table>
Illness and Disability as Undesirable Conditions – In medically naive societies, particularly ones based on agricultural production, those unable to fully participate in the common tasks of survival are seen to exist in a more precarious, and less desirable state. Where medical care is uncertain, the ill or
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disabled person presents a potent reminder to others that woundedness and
death is very close, and that, in fact, they are experiencing a non-enviable
death-in-life experience. Even with limited injunctions of specialness, the
overall view of the disabled is that, as less than whole, they are more at risk.
When the disabled are made the special objects of divine care, the remarkable
compassion of the one doing the good deed is emphasised rather than deserving
nature or dignity of the recipient.59

2 Distinctive Problems of Disabled or Ill Women – Because the Bible views
women as a group who is fulfilled, legitimated, given full membership into their
community, and cared for in old-age by their children (especially their sons),
anything which threatens a woman’s ability to be a fertile, able sexual partner
is considered disastrous. Therefore, any disability or illness which threatens a
woman’s ability to fulfill her patriarchal purpose indelibly strikes her self-
esteeem, structured as it is by patriarchal expectations, and in doing so, denies
her ‘rightful’ place within the fabric of society. When the polluting, almost
magical quality of women’s functional blood is added to this mixture of
sociocultural and theological attitudes, the situation of the disabled or ill
woman becomes quite dire. Not only has she been denied the self-validating act
of procreation, and hence full entrance into participation in her society, but she
is rendered ritually impure, and therefore, a perpetual outsider to her
community and an object of pity and scorn.60

3 Special Origin of Disabilities – It is clear that in the Bible, the nature of
‘disabilities’ has something to do with the deity or malicious sub-deities.
Although this is not a new concept invented by Israel or the New Testament
because it is present in some of the earliest myths from Mesopotamia, it is
‘Yahweh’ who is seen to create the disabled, and who can reverse the
disabilities. 61 Therefore, the motive for such actions is seen as punishment for
sins and, in later times, malicious spirits and sub-deities are explicitly named as
responsible for brokenness. This ‘other-worldly’ origin, then, sets its bearer
apart, marked as specially cursed, protected, or objectified for the sake of
divine healing action.62

4 Disability and Illness as Forms of Impurity – There are concepts of purity at
work in society’s view of the disabled who are seen to represent how fragile and
precarious bodily purity really is. This is exemplified in the (commonly stated)
Levitical passages about access to the sacred precincts:

And the LORD said to Moses, “Say to Aaron, None of your descendants
throughout their generations who has a blemish may approach to offer the
bread of his God. For no one who has a blemish shall draw near, a man
blind or lame, or one who has a mutilated face or a limb too long, or a man
who has an injured foot or an injured hand, or a hunchback, or a dwarf, or a
man with a defect in his sight or an itching disease or scabs or crushed
testicles; no man of the descendants of Aaron the priest who has a blemish,
he shall not come near to offer the bread of his God. (RSV; Lev. 21: 16-22)
Whilst this passage refers to disabled men, women, as ‘non-men’, are disabled by nature in this kind of thinking. Disabilities in men cannot totally eradicate their rights as males, but they are severely curtailed at least in matters of holiness. In the paradigm of male honor and shame, being less than fully male is certain cause for self-loathing.\(^{65}\)

5 The Disabled as Objects of Divine Action – The dignity of the disabled and their status as potentially valued members of their societies is directly challenged by the Bible’s continuous portrayal of them as objects of divine action. They are presented as ‘plot-devices’ that show off the power of God or the Anointed One; however, if the healing fails to materialise, they are viewed negatively and seen as agents of sin. For those whose physical conditions are not likely to improve, the questions of faith and personal meaning raised by the Bible’s continued stress on the disabled/ill person as one in the state of awaiting divine healing can demoralise and disempower rather than provide a means of continued growth.\(^{64}\)

In her theological examination, Avi Rose also finds similar attitudes towards those with disabilities. Rose categorises them “under four general headings, which together can be seen to form the basis of many beliefs within organised Western religion.”\(^{65}\) According to Rose, these are:

1. disability as a sign of punishment or evil incarnation;
2. disability as challenge to divine perfection;
3. disability as object of pity and charity; and
4. disability as incompetence and exemption from religious practice.\(^{66}\)

Henri-Jacques Stiker, who surveys the Bible for notions of ‘infirmity’ as well, draws similar conclusions to Fontaine and Rose.\(^{67}\) He highlights the notions of legal, cultural and sacral impurity that linked people with disability in the Biblical texts to identities of difference and profanity, and to positions of segregation and exclusion.\(^{68}\) Stiker also makes some illuminating comments about an implicit denunciation of violence towards the ‘unfortunate and disfigured’. He contends that it seems to be the case that the Hebrew biblical texts of the Old Testament reveal deep-seated violence towards disability and physical or mental misfortune in as much as the person struck down by misfortune is expected to play the role of the scapegoat in carrying the burden of sin and the burden of evil.\(^{69}\) However, this is not what develops. Instead, there is the imperative for social responsibility. Stiker outlines how the Hebrew Scriptures do not promote violence of a sacred and religious nature, but rather promote ethics of a social nature so as not to ‘contaminate’ the divine with sacrifices of ‘abnormal’ beings. The existence of abnormal deviants as representations of evil are seen to result from the sinfulness of the human domain, thus requiring moral considerations.\(^{70}\) New Testament texts present a different picture due to the actions of Jesus of Nazareth, who, without denying the overarching link between evil/misfortune and sin, breaks the link between disability and individual guilt by redefining evil not as external blemishes, but rather as the way one behaves towards others. Therefore, ethics is no longer just the consequence of the sacred order of things, but comes to be its foundation.\(^{71}\)

These different beliefs would evoke different practices. This research will show that Christian churches have emphatically influenced historical understandings and
practices of exclusion through such practices as extermination, expulsion, incarceration or exemption, thus supporting Rose’s claims that ancient belief systems of Judeo-Christian theology which view disability in a “highly negative manner”, have helped to create the social construction of disability as a political state of oppression.72

2.2.2 The Christian Church As A Service Respondent

Christian churches, in the past and in the present, represent a large body of service-providers as respondents to care for people with disability. As was the situation of being involved with the ‘care’ of Indigenous people, there appears to be a strong relationship between historical Christian values of benevolence and the ethical roots of service practices in the wider society. In a contemporary context, church organisations in Australia represent a significant proportion of non-government service providers of disability services within the community, and are therefore expected to facilitate inclusion post-institutionalisation. This fact is exemplified in the profile of the 2004/05 Commonwealth State and Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) collection. It shows that in Queensland, there were 1513 service points – 477 being government, and 1036 being non-government. Of the 16,432 people using disability services on that day, 6720 were categorised as having intellectual disability as the primary disability type. In Queensland, there was a total of 16432 consumers – 5868 within government services and 13 064 within non-government services.73 Therefore, value frameworks which inform how churches respond to people with disability, have wide-ranging influences in practice and policy contexts.

This research contests, however, that expectations to facilitate inclusion fail to recognise the ethical imbroglio in which inclusion is caught. Stanley Hauerwas and Bonita Raine comment that, whilst churches have observed biblical ethical imperatives such as altruism (embracing notions such as compassion, care, welfare and charity), they have failed to offer cohesive or explicit moral notions for the ‘inclusion’ of people with disability in communities.74 They contend that an ethical focus which only addresses the question of “How ought we to treat the retarded? (sic)” is misguided in as much as it fails to recognise that the intrinsic ethical question must be centered around “the very way we are taught to perceive and relate to them.”75 They state:

It is not simply a matter of coming out with ethical principles that can justify better and more extensive treatment of the retarded (sic); it is not simply a matter of trying to suggest those values that are inherent in all life that underwrites claims of the dignity of the retarded. Rather, the true moral question is what kind of community ought we to be so that we can welcome and care for the other in our midst without that “otherness” being used to justify discrimination?76

Although it is not the aim of this research to develop a particular theological model for people with disability, theological models and the root metaphors which appear
to underpin various human service responses will be discussed.\textsuperscript{77} Somewhat dialectically then, having people in excluded states has enabled the outpouring of charity and mercy-giving by committed members of the Church. Paradoxically, these actions by the mercy-givers have been often undertaken to ‘firm-up’ their belief of inclusion into the ‘Kingdom of God’. Implicit in these responses is an assumed acceptance of the marginalised positioning of people with disability within the dominant socio-symbolic order.

### 2.3 INTERSECTIONS BETWEEN JUDEO-CHRISTIAN AND WESTERN PHILOSOPHICAL INFLUENCES

How Judeo-Christian beliefs and practices have intersected with philosophical notions of the superiority of the mind, the orthodoxy of reason, the primacy of rationality, and the control of the body is of significant importance. For example, Ancient Greek culture, of which philosophers Plato and Aristotle were part, linked certain high ideals of physical beauty and healthy bodies with soundness of the mind.\textsuperscript{78} Likewise the philosophical view of the body in ancient Greco-Roman culture connected mind (soul), body, matter, and pneuma (spirit).\textsuperscript{79} According to Brett Webb-Mitchell, “a disabling of any part of the body would therefore affect other parts of the self, and the causes of such impairments would be seen to be from a variety of sources of physical, environmental and/or spiritual origins.”\textsuperscript{80}

The Enlightenment philosophers of seventeenth century Europe challenged this particular cosmo-biological expression. The scientific method, proposed by the likes of Francis Bacon, promoted a view that the phenomenal world could be understood best by empirical investigation, replacing the authority of existing philosophical constructs and theological dogma.\textsuperscript{81} Rene Descartes refigured the ancient Greco-Roman philosophers’ understandings of the relationship between mind and body when he granted superiority to the mind (“I think, therefore I am”), and granted the body the statues of the mechanical model of automata, that is, of moving machines which could be studied and repaired.\textsuperscript{82} Therefore, Descartes’ dictum articulates how his perceived “radical distinction between soul and body, thought and extension implies the substantial unity of matter, whatever its form; and thought, whatever its function.”\textsuperscript{83} As Georges Canguilhem highlights, Descartes made another significant distinction, that between humans and animals. For Descartes claimed that as “judgement is the soul’s only function, there is no reason to believe in the existence of an “animal soul”, since animals bereft of language and invention show no sign of being capable of judgement.”\textsuperscript{84} Canguilhem continues:

The denial that animals possess souls (or the faculty of reason) does not imply they are devoid of life (defined as warmth in the heart) or sensibility (insofar as the sensory faculties depend on the dispositions of the organs). ... Descartes does for animals what Aristotle did for slaves: he devalues them in order to justify using them as instruments. ... This attitude is typical of Western man (sic). The theoretical mechanization of life is inseparable from the technological utilization of the animal. Man (sic) can claim possession
and mastery over nature only by denying that nature has any purpose in itself, and then only by regarding all of nature other than himself (sic) – even that which appears to be animate – as a means to an end. Such as an attitude justified the construction of a mechanical model of the living body, including the human body – for Descartes, the human body, if not man (sic) himself, was a machine.85

It can be assumed that Descartes’ distinctions had significant impact on the understanding of personhood of humans also seemingly bereft of the capacity to reason. According to Branson and Miller, the mind/body dualism as the legacy of Cartesianism, elevates “the products of the human mind to the status of eternal disembodied knowledge, and stresses the materiality of the body to be understood like any other physical object.”86 They describe how the ‘mechanical model’ of science became oriented towards technological supremacy as a means to the control of nature and humanity. Branson and Miller elaborate:

But science soon penetrated everyday life as the scientific experts became the ‘theologians’ serving the interests of those in positions of economic and political power. Glorification of God was displaced by a glorification of the scientific method – rational, and ordered, the product of human mind – a logical procedure free of individual vagaries. Faith in God gives way to faith in science, a faith in the reproduction of rational knowledge and advancement towards the rational society. Prejudices are then legitimized by scientific rather than religious experts …The medical model, through the birth of the clinic and the asylum, established the contours of humanity, of normality, which the economy and the polity required. These new contours of humanity created the ‘disabled’. (Authors’ emphases)87

However, I will explore in the forthcoming chapters Davis’ notion that “the ‘disabled body’ is not a discrete object to be controlled; but rather represents a set of social relations.”88 I contend that these social relations are controlled by ablist and hegemonic sensory frameworks which perceive and interpret an actual or imaginary encounter. These frameworks, whilst perhaps dominated by the visual gaze, also include notions of hearing, touch and smell, and are then cognitively contained by interpretations of acceptance or rejection, solidarity or resistance, and ultimately exclusion or inclusion. Such judgements are ethically embedded, and the prospects of change, therefore, require the focus of attention on the construction of these frameworks and the construction of more liberating alternatives.

In a moral context, it is not hard to see, then, how people with intellectual disability are denied sentience, have been relegated to little more than animal status, are perceived as instruments for certain ends, are merely controlled, and have their pain or suffering ignored.89 Evelyn Pluhar outlines contemporary ethical homocentric debates embracing such tenets. She describes how moral agency aspects of full personhood, speciesism, marginal humanity, non-humanity and animalism are debated around issues such as theodicy, sentience, human intelligence, creativity, communication and autonomy.90
CHAPTER 2

Pluhar also outlines the “full-personhood view”, a view that all and only “full persons”, inasmuch as they can be fully aware, autonomous, rational beings, are “maximally morally significant.

This is classically articulated by Immanuel Kant, whose concept of ‘rational being’ includes the capacity for moral agency:

Beings whose existence depends not on our will but on nature have, nevertheless, if they are not rational beings, only a relative value as means and are therefore called things. On the other hand, rational beings are called persons inasmuch as their nature already marks them out as ends in themselves, i.e., as something which is not to be used merely as means and hence there is imposed thereby a limit on all arbitrary use of such beings, which are thus objects of respect.

The full-personhood view, though human-centred, is seen to be incompatible with homoceentrism. Humans who fail to be full, autonomous persons are excluded from full moral consideration and significance, unprotected by any theodic considerations, and can be at risk of vulnerability and disposability. In a full-personhood view, notions of entirety are denied and integralty is non-conceived. In such a view, marginal humans are then afforded similar moral status to animals, and this sets up a “biconditional challenge”. Pluhar describes this as the claim made by such philosophers as Peter Singer, Bernard Rollin and Tom Regan, who advocate that either marginal humans, like animals, have no moral status, or that higher-level animals are granted similar or, in some cases, superior moral status than very marginal humans such as people with intellectual disabilities, the senile, the comatose, foetuses, the insane, and brain-damaged infants. These ethical debates of personhood and human status, which must necessarily inform discussions of inclusion and exclusion, have been, to a large extent, ignored in literature about inclusion.

2.4 DIFFERENT ASPECTS OF INCLUSION

A scan of the literature suggests that in recent times, two approaches have dominated practices and scholarship about inclusion. First, the technical approach seeks to translocate within the public arena, historical deficit-focused ideologies of disability constructed from notions about individual impaired and burdensome bodies. These translocations, exemplified with the movement from special institutional to community care or regular settings, are facilitated by technical processes such as the provision of professional assessment processes, ‘inclusion’ workers, personal planning and skill training programs, and attention to the physical environment. Second, the legislative approach seeks to address the socio-political context of processes of disablement by legislation committed to the protection of human and civil rights, and anti-discrimination processes.

This research proposes another approach – an ethical approach – which challenges exclusion as well as the inadequacy of technical and legislative processes; and identifies hidden assumptions which cause flaws and problems for people with intellectual disability in particular. Descriptive processes of exclusion of marginal groups, such as people with intellectual disability, can be found in socio-historical
However, I assert that there is an implicit requirement to also understand notions of profound exclusion — exclusion practised ontologically as well as socially. To examine the notion of inclusion within an ethical framework allows for expanding such analyses by exploring two underpinning ethics, previously identified as an Ethic of Normalcy and an Ethic of Anomaly. How these ethics have been applied to address issues of what is good or bad, right or wrong, just or unjust, beneficent or maleficent commands consideration. It is also imperative to explore how these ethics are sustained by Selvedges of Definition which define membership and non-membership.

An ethical engagement is evident within the rights-based discourse contemporarily driving the disability agenda. However, inclusion, as a concept, implies a process of transition and transformation — a process of spatial movement and change. The ethical approach applied in this research will allow for a much deeper inquiry to accommodate a fuller understanding by exploring further previously stated ethical concerns. It will highlight and explore the following:

- the historical socio-political context of theories and practices in which the discussion is embedded, and the complexity of factors such as definition, language, hegemonic power, the economy and productivity, the construction of disability and normalcy;
- the dualistic structure of modern Western society which legitimates and sustains hierarchical oppositions of such notions as ability and disability, normal and anomalous; and
- the self-other relationships in terms of individual identity and collective community in the context of intellectual disability.

It is asserted that these contextual considerations are as necessary in the ethical inquiry of inclusion as are nominations of abstract ethical principles traditionally called upon. It is also contested that these considerations are absent from contemporary acontextual rights-based discourses.

### 2.5 SETTING A METHODOLOGY

#### 2.5.1 Exploring A Methodological Process

This research will undertake a conceptual theoretical analysis of the ethical significance of the notion of inclusion for people with disability as conceptualised in Western Judeo-Christian society. Conceptual theoretical research, a stipulative term coined by Peter Isaacs, umbrellas a number of different research techniques. These techniques share the common feature of critically appraising existing conceptual frameworks which traditionally underpin research, and which render and sustain invisibility of certain notions which command consideration. Therefore, conceptual theoretical research seeks to identify implicit assumptions and prior understandings of existing research frames; and to explore the possible inadequacy and incoherence of these frames. Conceptual theoretical researchers raise questions formed by suspicions that existing frameworks and assumptions are problematic in that they, as accepted and not challenged categories of thought, not only shape the questions and answers of the research, but often the research outcome.
Therefore, critical theoretical researchers seek to uncover political and structural dimensions of research; and to articulate different frameworks of social relationships in terms of their ethical implications.98

A conceptual theoretical analysis, in the context of this research, also accounts for experience. This research is embedded in passion gained from personal experience. As a woman, as a person of a lower class background, as a person who has been employed in various human services; and as a person who was a co-house-parent for four years to five young people with intellectual disability in suburban community, I share the experiences and the challenges of marginalisation. Yet I also know the richness for having had these and many other experiences. I know the joy of being in relationship with people who are different, though similarly human. I know that through accepting relationships of mutuality and solidarity, referential acts of inclusion become irrelevant; and integrality in community is an achievable goal. Therefore, with these experiences, I can situate myself as co-subject, and acknowledge the influence of my experiential knowledge. I insert my womanly voice and view into the commentary. With a hermeneutics of suspicion towards hegemonic constructions, I undertake a feminist position in questioning.99 This experience, juxtaposed with formal scholarship of nursing training, social science and textual studies provides a rich multidisciplinary medium by which to contextually explore the ethical significance of inclusion.

Having stated these contentions, this research is also qualitative and multidimensional. As a framework of qualitative research, I call on the recent work of Yvonne Lincoln and Norman Denzin.100 From a collection of thirty-five works, Lincoln and Denzin, in the concluding chapter, highlight a tension that now defines qualitative research. They contend that there is an illusive centre to what can be described as a “contradictory, tension-riddled enterprise”.101 This is a centre which is presently moving further and further away from grand narratives, and single overarching ontological, epistemological and methodological paradigms. They claim that the “centre lies in the humanistic commitment of the researcher to study the world always from the perspective of the interactive individual.”102

Lincoln and Denzin, therefore, nominate six fundamental issues embedded in these tensions. They describe these in their text as:

- Researchers continually wrestling with their research’s topic in relationship to previous positivist and post-positivist formulations;
- Crisis of representation, speaking to the ‘other’ and its representation in our texts; and
- Crisis of legitimation, whereby, in speaking to the ‘other’, the authority we claim for our texts is challenged;
- The continued emergence of a cacophony of voices speaking with various agendas from specific gender, race, class, ethnic and Third World perspectives (ability can be included in this list);
- Throughout its history, qualitative research has been defined in terms of shifting scientific, moral, sacred and religious discourses. Although since the Enlightenment, science and religion have been separated if only at the ideological level, (for, in practice religion has constantly informed science and the scientific practice), there is now a more overt blurring of the boundaries as science moves away from its
empiricist foundations and closer to a critical, interpretive project that stresses morals and moral standards of evaluation;

– The sixth issue is that of the influence of technology, as it continues to mediate, define and shape qualitative research practices.\textsuperscript{103}

Therefore, in the 1990s, it was claimed:

Qualitative research is an interdisciplinary, trans-disciplinary, and sometimes, counterdisciplinary field. It cross-cuts the humanities, the social sciences, and the physical sciences. Qualitative research is many things at the same time. It is multiparadigmatic in focus. Its practitioners are sensitive to the value of the multi-method approach. They are committed to the naturalistic perspective and to the interpretive understanding of human experience. At the same time, the field is inherently political and shaped by multiple ethical and political positions. Qualitative research embraces two tensions at the same time. On the one hand, it is drawn to a broad, interpretive, postmodern, feminist, and critical sensibility. On the other hand, it can also be drawn to more narrowly defined positivist, post-positivist, humanistic, and naturalistic conceptions of human experience and its analysis.\textsuperscript{104}

This also is a technique commonly used by feminist researchers – a position from which I choose to write, and which challenges the notion of the canonical subject. Mark Johnson states:

In our Western moral tradition the concept person is the basis for our most fundamental moral principles. ... the concept person is a radical category of certain prototypical instances (e.g. sane adult white heterosexual males) surrounded by nonprototypical instances (e.g. females, nonwhites, children, senile elderly, mentally handicapped) and fading off into borderline cases (e.g. higher primates). \textsuperscript{105}

Philosophically, then, women have been excluded from the rationalistic public arena; a position in common with people with disability, particularly those with intellectual and/or psychological disability, women with disability, people of colour, people with different sexual orientations and so on. This research draws from feminist discourses to explore traditional concepts of person and the exclusion/inclusion phenomenon.

For analytical reasons, the linking of feminist thought and disability presents an interesting and necessary, though minimally-noticed conjunction.\textsuperscript{106} It would be naive, though, not to acknowledge that it can be problematic.\textsuperscript{107} However, Rosie Braidotti is one writer who has sought to explore such a connection, both thematically and methodologically. Using the bold configuration of “mothers, monsters and machines”, Braidotti defines the relationship as “not only cerebral, but related to experience”, which implies a strengthened connection between thought and life.\textsuperscript{108} Critical to consider, is that the conjunction between disability and feminist thought highlights the connection between an experience of exclusion from a dominant patriarchal socio-symbolic order historically intolerant to difference, and differing identities – identities which authenticate, and do not seek
to deny or inferiorise the experiences of different bodies - experiences which may include pain and limitation. Therefore, by exploring the conjunction between differing and excluded bodies such as those represented by women, people of colour, and people with disability, a space could be opened for the articulation of a common voice to redress structural exclusion.

According to Shulamit Reinharz, feminists choose multiple methods not only for technical reasons, but to also reflect intellectual, emotional, and political commitments pertaining to feminist concerns. This means, that feminist researchers, combine many methods so as to “cast their net as widely as possible in the search for understanding of critical issues.” Therefore, Reinharz states:

Feminist descriptions of multimethod research express the commitment to thoroughness, the desire to be open-ended, and to take risks. Multiple methods enable feminist researchers to link past and present, “data” gathering and action, and individual behavior with social frameworks. By combining methods, feminist researchers are particularly able to illuminate previously unexamined or misunderstood experiences.

Jeanne Braham describes how feminist writer, Jane Flax, also uses multiple intersecting frames of reference to address questions of self, gender, knowledge and power, that is to “stitch together fragments” of theories in such a way that they interact and “converse” with each other. It is worthy of note that fragments are also most often the products of deconstruction. Colin MacCabe provides an insightful opinion of Gayatri Spivak’s work when he states:

Deconstruction, for Spivak, is neither a conservative aesthetic nor a radical politics but an intellectual ethic which enjoins a constant attention to the multiplicity of determination.

As previously stated, the notion of inclusion as a multifaceted concept, is oppositionally located with multifaceted concepts of exclusion. However, these facets, representing many fragments of knowledge and many texts of understanding, are not free-floating. They are embedded in particular spaces.

Therefore, to conceptualise inclusion commands the recognition that the concept itself is spatially situated, and defined and determined by constructed boundaries. This research asserts that this conceptual space is not only historical and socio-political as has been commonly explored; but is, indeed, a socio-ethical space which is signified, reflected and practised in different human encounters. These encounters are within the private and public arenas configured by personal, interpersonal, depersonal or impersonal interests. The private constitutes relationships with families and friends; the public using social institutions such as human services. However, in relation to people with intellectual disability often excluded from society, there is a blurring of private and public when these private relationships have been erased to be substituted by publicly-determined and controlled experiences such as institutionalisation. Denied or diminished familial relationships were attributes of the lives of Angela, Trudy, Simon, Desmond, Wally and Roslyn, written about previously in ‘The Quilter’s Journal’. The lack of preservation and
nurture of such artifacts as memories, histories, stories, photographs and unconditional close loving relationships are testament to that.

In many situations, therefore, inclusion is an ideal state – something imagined and sought, not yet arrived at, but continuously strived for. This research contends that not only do socio-ethical spaces of exclusion and inclusion exist, but also that ‘traditional’ socio-ethical spaces espoused to be inclusive, construe to sustain structural exclusion for people with disability, particularly intellectual disability. To elaborate, a conceptual theoretical and multidisciplinary approach will expose the implicit exclusion within traditional methods, resulting in their inadequacy and incompetency to address inclusion. The irony of this situation should not go unnoticed. As has already been articulated, non-inclusion or exclusion for people with intellectual disability has traditionally been explained because of the perceived inadequacy and incompetency of these persons to be rational individuals. However, I am suggesting that it is not a notion of impaired bodies that presents barriers to Ethical Inclusion: rather, it is impaired ethical theorising. Therefore, I assert that the fraudulence of aporetic ethical foundations in contemporary disability practices must be confronted for ethical transformation.

Profound Exclusion and the notion of inclusion mapped under the three broad categories – Technical Inclusion, Legislative Inclusion and Ethical Inclusion, embrace different dominant themes of inquiry. For example, Profound Exclusion and Technical Inclusion embrace a socio-historical positivist critique, Legislative Inclusion - a socio-political interactionist, interpretivist or phenomenological critique, and Ethical Inclusion – a socio-political-ethical-structuralist critique. Methodologically, these different themes of inquiry cannot be ignored; but rather need to be embraced and expanded to enable an adequate analysis of the conceptualisation and ethical significance of the notion of inclusion to emerge. Undertaking a complex and multidisciplinary approach recognises that the inclusion-exclusion dualism is experienced not only within socio-temporal, socio-relational, socio-visual or socio-political spaces, but also that these spaces together are components of a wider embracing, but conceivably dominant and restrictive, socio-ethical space – a space traditionally not embracing of the particularities of embodied identities. Diprose reinforces this assertion when she states that ethics is often thought of as “either the study of the logical status of our moral judgements or as setting down a set of universal principles for regulating behaviour”, assuming that “individuals are present as self-transparent, isolated, rational minds and that embodied differences between individuals are inconsequential.” Branson and Miller would contend, then, that this approach to ethics constitutes “epistemic imperialism” for its embeddedness in Western society and its propensity to organise ‘reality’ in a particular way. This, they identify, necessitates an “unitary, logocentric, phallogocentric orientation,” appropriating and devaluing ‘others’ by processes of “packaging, labeling, and controlling.” This indeed emerges as impaired ethical theorising.

On the other hand, though, Diprose contests that even if it is granted that ethics is about moral principles and moral judgment, ethics is also about location, position and place. This research will encompass this latter statement within its exploration of the ethical significance of inclusion. It is imperative that the hegemonic genesis of the traditional approaches to applied ethics and the legitimacy of their orthodoxy
and dominance be contested, and the vapidity of these approaches be exposed. Such an approach is not indefensible. It is part of a contemporary trend of methodological shifts which challenge established research paradigms. For example, Andy Knight writes in relation to multilateralism that:

... [T]he intellectual approach to multilateralism is undergoing a shift from the traditional (and problem-solving) rationalist to a reflectivist (and critical) scholarship.

Using methods of enquiry that are hermeneutic, dialectic and reflectivist, in contrast to the positivist and problem-solving approaches of rationalist researchers.¹¹⁶

Therefore, the emerging, yet constraining aporia between traditional applied ethics and the disability context is not only confronted, but commands a creative response. It will become apparent in later chapters that this aporia is not readily recognised within the established traditional paradigms of applied ethics. A fuller conceptualisation of the ethical significance of inclusion is evoked.

2.5.2 Creating A Methodological Metaphor

A challenge emerges as to how a researcher can best work with seemingly disjointed fragments to construct an adequate explanation of the ethical significance of the notion of inclusion. I have chosen to use metaphor to meet such a challenge. Johnson argues, “The way we frame and categorise a given situation determines how we reason about it, and how we frame it depends on which metaphorical concepts we are using.”¹¹⁷ He writes that metaphor “is one of our principal mechanisms of imaginative cognition;” and opens up new dimensions of our moral understanding.¹¹⁸

Gareth Morgan also claims that metaphor is often used as a device “for embellishing discourse”; however, he continues, its real significance is much greater, for metaphor “implies a way of thinking and a way of seeing that pervade how we understand our world generally.”¹¹⁹ Feminist theologian, Sally McFague states, “Metaphor is a strategy of desperation, not decoration; it is an attempt to say something about the unfamiliar in terms of the familiar, an attempt to talk about what we do not know in terms of what we do know.”¹²⁰ Elsewhere she comments that metaphorical thinking is “intrinsically perspectival”; for whilst we can derive similarities, we also acknowledge dissimilarities.¹²¹ A metaphor, then, is a word or a phrase which appears to belong to one particular context, but is used in another, as a semantic tool to make visible certain traits that have remained invisible.¹²²

Lincoln and Denzin promote the methodological metaphor of the researcher as a bricoleur, who not only cobbles together a new piece from used or historical material, but who invents, like an artist, a new future through creative and innovative uses of material.¹²³ This is a similar metaphor to that evoked by critical theorist, Levi-Strauss, in the 1960s. John O’Neill explains:

The bricoleur … moves into a neighbouring craft whenever the need to improvise arises, a need able to be seen within the materials at hand although
they may not be explicitly designed for incorporation in the constructions. Given any ready-made materials, the bricoleur may be said to create structures from events, or necessity from contingency.\textsuperscript{124}

Patchwork quilting represents a feminine artform which sees women perform as bricoleurs. As well, it is a crafting process. Melissa Raphael contends that in patriarchal culture, female crafts are trivialised as hobbies, make-up or fashion, however feminists seek to “reclaim craft production as an act of spiritual-political dissent and as a form and metaphor of transformatory praxis.”\textsuperscript{125} Faith Gillespie states, “Within the power to change raw materials by our hand into things both pleasing and useful lies an intimation of the possibility of transforming our lives.”\textsuperscript{126} As a feminist researcher, therefore, I use the metaphor of a patchwork quilt as analogous to the methodological process of this research. Elizabeth Johnson illuminates the value of this choice, when she states:

\begin{quote}
Feminist artisans and poets have been designing evocative metaphors for the creative work women do. Spinning, weaving, and quilting, all taken from women’s domestic chores, provide an evocative description of scholarship as it seeks to articulate new patterns from bits of contemporary experiences and ancient sources.\textsuperscript{127}
\end{quote}

\textbf{2.5.3 Applying The Metaphor}

A patchwork quilt is made of three layers of cloth, held together by stitches or knots. The patchwork metaphor, as a methodological process, reflects a multi-paradigmatic approach which not only uses old or previous material, but reshapes and reorganises the material to form a new reality. It also introduces new discourses which add texture, and is embellished with new shades and richness. The latent is transformed to the manifest. It is a mapping process which lays out the pieces within the piece.

However, even as a craft, it would be naive not to acknowledge implicit power considerations within patchwork quiltmaking. Who designs the quilt and decides which pieces will be included? From what and whose ‘scrapbags’ are pieces drawn; and what constitutes unusable material? Are there privileged pieces that must be included; and who decides what should be treasured or discarded?\textsuperscript{128} And with the finished product, who judges its worth?

The context of this research, using the frameworks of applied ethics, allows for the creative use of a wide range of material which encompass different understandings of disability, discursive influences, and social practices. Margaret Urban Walker states:

\begin{quote}
The fabrics of social worlds through which moral understandings are woven are the works of many hands down generations meeting different strains and circumstances. Fabrics of distinct origin, or torn ones, may be joined through artful redesign or makeshift patchwork; elegance of design or appearance does not guarantee strength or durability. Moralities, like the social lives from which they are not separable, are collective more by accretion and concurrence than by concerted effort or design.\textsuperscript{129}
\end{quote}
The artistic challenge to the researcher seeking to gain a fuller understanding of inclusion is how can these socio-ethical fabrics be configured, laid out, and used in a way that may involve reshaping and rupturing, yet respecting the integrity of previous research.

These decisions are enmeshed in analogy. Similarities include the creative tensions between aesthetics and function; interrelatedness and uniqueness; public and private; individualism and corporateness; open-endings and boundaries; passion and order. This research, as a creative process, can be likened to a birthing process of craft. As well as embracing realism and suspicion, excitement and uncertainty, expectation and mystery, it is also tedious, yet intentional. As such therefore, it involves a process which culminates with the tenacity of labour and action to present a product of incomplete possibilities—a process that necessitates structural rupture and severing for transformation, reconstruction and refigurement.

Mary Catherine Hilkert, who promotes the use of the patchwork quilt metaphor in feminist scholarship, draws attention to another aspect when she states:

While the quilting process is clearly creative, the pieces come from the earlier fabric of one’s life. The art involves collaboration ... The pieces they work with come from that past, but the inspiration and art come in designing something new.  

Women’s stories are woven within quiltmaking. Although stories are sometimes recorded in other forms such as autobiographies, anecdotes, personal essays, biographies, and interviews in periodicals, their presence within the quilt reflects an expression of the quiltmaker’s experience. Narratives are “not merely information storage devices.” According to Jerome Bruner, the “cultur uly shaped cognitive and linguistic processes that guide the self-telling of life narratives achieve the power to structure perceptual experience and organize memory in their role to segment and purpose-build the very ‘events’ of life.” The self-telling of life narratives is part of a creative process. The writer takes control: to participate in transformatory processes which create new selves, new stories, and new social realities.

Narratives woven into a patchwork quilt are autobiography in fabric. Barbara Hillyer describes autobiography:

... as a selective retelling of one’s story, reordered, retrospective, and biased by both the requirements of form and changes in the writer’s understanding of the meaning of what she remembers.

Braham speaks of women’s autobiography as always understanding the need to compose a life from the bits and pieces of the past which are “marinated in memory, resurrected by the imagination and imbued with meaning.” Hillyer warns that autobiographies can be seen as suspect as sources of academic research, for the “biases of writer and reader are assumed to contradict the ethic of scholarly objectivity.” However in the context of, and intersection with, disability, a woman’s autobiography enables one to think about what is known or can be known about disability “as women experience it in its complex, multiform, disorganized dailiness.” Women’s narrative in disability embraces the intimacy and risk of
relationships; and in so doing, exposes the rigidity of the metanarrative of the Enlightenment for its unashamed exclusion founded on the capacity of abstract, arelational reasoning. The narrative challenges the tradition to treat thought as an “instrument of reason” by which its efficacy is “measured against the laws of logic or induction”; and by which its form is “reducible to machine computability.”

My narrative prologuing this research is an expression and interpretation of my unique experience, my unique positioning, and my unique relationships. The interpretations of these inform and illustrate, and invoke the use of the imagination for a different social reality. My narrative embraces Bruner’s notion that “a life as led is inseparable from a life as told” or life is not only how it was, but how “it is interpreted and reinterpreted, told and retold.” For a metaphorical patchwork quilter, the narrative is not separate to the quilt - in the same way as one cannot tell “the dancer from the dance”. The narrative is the very essence of the quilt.

Arthur Frank highlights the implications for ethics in the sharing of narrative when he states, “Narrative teaches that being human is the perpetual finding out of what is good and virtuous, whether the process of that moral inquiry is called the examined life or reflexive monitoring.” Guy Widdershoven and Maree-Josée Smits declare that, although narratives can illuminate understanding of participants’ experience, their capacity to make an ethical evaluation is somewhat opaque. However, they also contend that stories are not just literary creations: they are a central element of life itself. Accordingly, stories embody actions and practices, in which teleological notions are considered and evaluated for their usefulness in contributing to the common good and living with others in social conditions that are just. Narratives evoke moral witnessing, which, in turn, continually configure the moral self. Frank states:

The moral imperative of narrative ethics is perpetual self-reflection on the sort of person that one’s story is shaping one into, entailing the requirement to change that self-story if the wrong self is being shaped.

A patchwork quilt is also multivocal, for practices and narratives involve different voices. The quilt in an ethical context, whilst capturing and expressing stories of its maker; must also be obliged to upholding the integrity of the participants of the stories. Christopher Newell warns that potential misuse and unethical use of the narrative in appropriating ethical decision-making, can lead to injustice and misappropriation to those whose stories are encountered. Newell challenges us and reminds us of the inherent danger of treating the participants of the narrative as means to an end, rather as an end in themselves. To be ethically responsible, then, requires that although the quilter’s voice frames the context, it must be sensitive to the challenge of not speaking for others, but speaking out for others with the respect of mutuality. To emphatically espouse my position, I do not presume that my interpretation of the events of my narrative are confluent with the memories and interpretations of others within the story; and I, at no point would want it assumed that I speak for these others. However, I do ‘speak-up’ for them, by telling stories which break the silence about their lives, and the obscurities of their histories.
CHAPTER 2

In the context of illness, Frank describes three different forms of narrative - restitution, chaos and quest. He states:

Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on, they accept illness and seek to use it. (Author’s emphasis)\textsuperscript{149}

However, in regard to people with intellectual disability and inclusion, narratives may take other forms such as abandonment, segregation, and irrelevance, or acceptance, presence and integrality. To the degree that these narrative forms exist, or maybe dominate, as well as counterstories are formed,\textsuperscript{150} will be explored in later chapters.

As well as embracing stories, patchwork quilting, as an artform, is often culturally embedded. At times, this embedding can be a counter-culture within a dominant culture. For example, Eve Granick writes of the Amish quilt tradition in Northern America, describing such “objects of art” as being crafted within a specific purpose to reflect a distinct culture.\textsuperscript{151}

John Silber further elaborates:

Amish quilts served many purposes, and they represent many levels of meaning – practical, aesthetic, ritual and interpersonal. ... The more we know about the Amish and their lives, the deeper is our understanding of how this particularly rich form of expression came to be and what it means.\textsuperscript{152}

Analogies can be drawn from the Amish tradition of quilt-making to the design of this research. The notion of ‘counter-culture’ is present. First, there is the artform of a methodological process of this research embedded in the constructed and marginalised culturation of disability. Second, patchwork quilting is seen as a subversive artform of women to the traditions of male-dominated art of architecture, engineering, painting, sculpture and so on. Using the quilting metaphor, allows for articulation of the process of women challenging traditional notions of ethics, to be likened to engagement in a subversive act of crafting. The latter is indeed laced with irony for, as it will be explored later, women’s immorality has been an historical – sometimes even contemporary – and dominant theme in aetiology and practices concerning intellectual disability.\textsuperscript{153}

Quiltmakers in the Amish tradition are committed to the disciplines of design and humility. The quilt reflects a responsibility to the tradition of stark and geometrical form, and the use of rich luscious colours and sweeping curves, subtly being softened by the embellishment of thousands and thousands of minute stitches.\textsuperscript{154} Therefore, Amish quilts express harmony and contrasts. They appear simple, but they require discipline and persistence, commanding and demonstrating highly developed skills and sensibilities of the quiltmakers.\textsuperscript{155} These are crafters who are disciplined and responsible to the tradition of essence, but nonetheless challenge the orthodoxy of substance. In a like manner, such is the methodological requirements of this research. Whilst the researcher must be committed to the integrity of the research project at hand, the substance of the process requires innovation and...
creativity to move beyond methodological constraints and orthodoxies uncritically applied in this field in the past. Whilst contributions from positivism, interpretivism, critical theory, postmodernism, poststructuralism and feminist theory cannot be denied as strands of prefigurement, the methodological process to conceptually refigure the notion of inclusion as ethically signified for people with intellectual disability requires similar skill and sensibility to those of the imaginative quiltmaker, who dares to perform, and then create, the ‘what if’ quilt.

I have conceived that the quilt being constructed in this research is an adaptation of an Amish Bar quilt, traditionally featuring seven or nine vertical bars, surrounded by a thin border before featuring a larger external border (See Figure 1). This

![An Amish 7/9 Bar Quilt](image)

*Figure 1. An Amish 7/9 Bar Quilt*

CHAPTER 2

research quilt will feature six bars - three sets of two bars. These represent various aspects of inclusion named as Profound Exclusion, Technical Inclusion and Legislative Inclusion, and the shadow-tones representing ambivalences found in each construction. The six bars are defined, surrounded and contained by the patriarchal and kyriarchal Selvedges of Definition. A small surrounding border representing ‘A Transformatory Ethic of Inclusion’, an instrument of rupture to the patriarchal boundedness of the bars, links the external fabric constituting Ethical Inclusion by rupturing the Selvedges of Definition. (See Figure 2)

The piecing and design of a quilt is imagined and constructed by an individual, while the finishing is often a corporate activity when individuals gather in groups for the pleasures and mutual support of the ‘quilting bee’.157 So it is with the presentation of this research. I imagine the piecing and design to form the pattern of the patchwork surface of the top layer.

The rest of the research is committed to this activity, which will include examining the structure of socio-ethical fabrics of the Judeo-Christian context in which inclusion is embedded. However, the scope of this research is also limited to the preparation of the top layer. The quilting, as embellishment and counterpoint, must be a communal activity as the quilt is subjected to the scrutinies of other interested parties. Therefore, this work will conclude as an unfinished quilt, ready for corporate involvement and engagement, both for finishing and usefulness.

Figure 2: A Metaphorical Quilt – ‘A Transformatory Ethic of Inclusion’

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2.5.4 Constructing A ‘Research Quilt’

Although a design has been indicated, numerous steps are required to prepare the top layer.

Firstly, there is the choice of fragments, which considers the particular textures of the fabrics. What constitutes the threads of disability theories and practices, how implicit values act, what is influenced by the controlling ethics, and how boundaries constrain and define are necessary textual considerations. These will be explored in Part Two of this research.

After considering the texture, the second step is to consider how the fragments may be patterned according to ethical frameworks or ethical templates of understanding.

Ethical discourses such as bioethics and rights are prevalent in the disability context. However, decisions need to be made as to whether these are the most appropriate templates by which to explore and ethically signify inclusion, and if not, then to offer an alternative framework. This exploration occurs in Part Three.

Having chosen an appropriate framework, the third step is to lay out the patterned fragments of Profound Exclusion, Technical Inclusion and Legislative Inclusion. These are fragments which also contain ethical ambivalences that need to be identified. Using the same framework for patterning, then, the form of Ethical Inclusion can be contemplated. However, it will be shown that Ethical Inclusion not only has a different texture, but is embedded in a different socio-ethical fabric.

‘A Transformatory Ethic of Inclusion’ is conceived as an instrument of rupture by which the notion of integralty can be conceptualised, and ethically defended. This third exploration occurs in Part Four of this research.

After these steps, the top layer is prepared.

2.6 SUMMARY

In this chapter, I have attended to two objectives. Firstly, I have introduced an exploration of the conceptualisation and ethical significance of the notion of inclusion in relation to people who are marginalised in Western Judeo-Christian society, particularly people with intellectual disability. Secondly, I have developed a methodology by which to adequately explore the topic.

I have indicated how so called ‘care’ for disabled people in a post-Enlightenment and post-industrial Western Judeo-Christian society has predominantly been provided in segregated contexts, often resulting in physical placement in institutions. Recent developments in disability policies and practices challenge such exclusionary practices to promote deinstitutionalisation and inclusion. However, I suggest that it would be futile to continue to shape inclusion policies and practices without giving due attention to redefining the structures of signification, that is, the frameworks of meaning and valuation where the momentum of hidden ontological and epistemological assumptions keeps people with intellectual disability in particular socio-ethical positions within Judeo-Christian subcultures.

Therefore, I highlight the significance of purposefully choosing Judeo-Christian society for exploration, because, I argue, such a context serves not only as an
ethnographic focus for analysis, but also as a locus for social change. Two specific reasons are outlined: (1) descriptions of, and responses to, ‘impairment’ as described in the theological narratives recorded in the Hebrew Scriptures and Christian Scriptures have shaped practices of how ‘people of God’ perceived, treated, and lived with people with disabilities; and (2) Christian churches, in the past and in the present, represent a large body of responders of care and service-providers, and therefore, provide not only a site for historical reflections of ‘traditional’ practices, but also a site for creative refiguration of disability practices using contemporary scholarship.

How Judeo-Christian beliefs and practices have intersected with philosophical notions of the superiority of the mind, the orthodoxy of reason, the primacy of rationality, and the control of the body is also noted. I describe how some humans 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. Therefore, I contend that ethical debates of personhood and human status must necessarily inform discussions of inclusion and exclusion.

A scan of the literature suggests that in recent times, two approaches have dominated practices and scholarship about inclusion: the technical approach and the legislative approach. However, I propose another approach – an ethical approach, which challenges exclusion as well as the inadequacy of technical and legislative processes; and identifies hidden assumptions which cause flaws and problems for people with intellectual disability in particular. I assert that there is an implicit requirement to also understand notions of profound exclusion – exclusion practised ontologically as well as socially.

Therefore, this research undertakes a conceptual theoretical analysis of the ethical significance of the notion of inclusion for people with disability as conceptuated in Western Judeo-Christian society. It becomes apparent that the hegemonic genesis of the traditional approaches to applied ethics and the legitimacy of their orthodoxy and dominance be contested for their implicit exclusion of people with intellectual disability. I suggest that it is not a notion of impaired bodies that presents barriers to Ethical Inclusion: rather, it is impaired ethical theorising.

However, a challenge emerges as to how a researcher can best work with seemingly disjointed fragments to construct an adequate explanation of the ethical significance of the notion of inclusion. I choose to meet such a challenge by using metaphor. First, I adopt the metaphor of the researcher as a bricoleur, and then, I invoke the metaphor of a patchwork quilt by which to describe how the methodology of this research can be conceived.

I describe how, as a feminine artform, patchworking embraces creativity, multimethod, narrative and counterculture – elements that I identify as necessary to explore the multifaceted nature of inclusion.

Finally, in determining the metaphorical process, I indicate how the top layer of the quilt will be prepared. Therefore, I identify three steps to be undertaken: attention to texture, choice of an appropriate ethical framework, and the laying out of all the fragments.
PART TWO: CONFIGURING THE WEAVE OF THE FRAGMENTS OF INCLUSION

The quiltmaker can approach a project in two ways. One way is to be committed or attracted to a particular master design or meta-narrative, and then to find the appropriate fabrics to enhance and serve the design’s purpose. Therefore, the design, as a chosen preference of the maker, is the dictating force of the textual formation, which creatively constructs the texts to defend the principles within the design. The other way is to select fragments of fabrics for their inherent value, worth and symbolic representation, and to then use a design that captures and makes full significance of the fragments’ contextual importance.

This research adopts both approaches, but gives significant attention to the latter approach to construct a quilt which reflects a complex conceptualisation of the ethical significance of inclusion for people with intellectual disability. I contend that the fragments, which will constitute three apparent socio-ethical fabrics of inclusion – Profound Exclusion, Technical Inclusion, and Legislative Inclusion – are configured by particular threads. I claim, then, that these are fragments of ethical melange, made of fabrics configured by the warps of theories, definitions, assumptions and understandings of disability, interlaced with the wefts of values, beliefs and perceptual framings of social practices.

However, I also assert that the foundational ethical significance cannot be constructed and situated outside of the texture like an overlaid pattern. It is present within the weave of diverse strands and mingled colours. As well, the ethical significance is contained within intentional borders presenting as Selvedges of Definition, which, I have asserted, are constructed from matrices of patriarchal philosophy and theology. Therefore, it is in the holes of the weave that ethical significance is present, yet calendared, that is, influencing, yet concealed. This research contends that the configuration of the weave, which includes the holes between the threads, propones and supports expressions of an Ethic of Normalcy and an Ethic of Anomaly.

Part Two outlines meaningful components which constitute three fragments of the fabrics of inclusion. Chapter Three highlights one set of ‘Threads of Configuration’, by exploring the warps of theories, definitions, assumptions and understandings of disability. Chapter Four highlights another set of threads by exploring the wefts of values, beliefs and perceptual framings of social practices of disability services with which the warps are interlaced. Chapter Five, ‘Wiping Away The Calendering For Ethical Understanding’ explores the constructions of the Selvedges of Definition which bind an Ethic of Normalcy and an Ethic of Anomaly. Figure Three diagrammatically outlines the weave of the fragments of the fabrics of inclusion.
‘Threads of Configuration - 1’
Warps of theories, definitions, assumptions and understandings of disability

‘Wiping the Calendering’
An Ethic of Normalcy and An Ethic of Anomaly present in the spaces between the Warps and the Wefts, and bounded by the Selvedges of Definition.

‘Threads of Configuration - 2’
Wefts of values, beliefs and perceptual framings of social practices of disability.

Selvedges of Definition

Figure 3. The weave of the fragments of the fabrics of inclusion.