A CRITICAL ANALYSIS OF A THEOLOGY OF DISABILITY IN THE
AUSTRALIAN CATHOLIC CHURCH: A QUALITATIVE STUDY INTO
CONTEMPORARY INCLUSIONARY PRACTICES

by

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for the degree of Doctor of Philosophy

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The University of Newcastle

29 June 2015
STATEMENT OF ORIGINALITY

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University’s Digital Repository, subject to the provisions of the Copyright Act 1968.

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The Supervising Committee of ZACHARIAH PATRICK DUKE certifies that this is the approved version of the following thesis:

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Dr Alex Beveridge
Emeritus Professor Terry Lovat
29 June 2015 29 June 2015
THESIS ABSTRACT

This thesis examines the role of the Australian Catholic Church, its leaders and its relevant agencies and organisations in advocating for and welcoming people living with a disability into the life of the Church. It is intended that this thesis will go beyond issues of accessibility and definitions of “disability” and instead explore developments and tensions in the Australian Catholic Church’s response to issues of disability. It is clear from the literature and the qualitative interviews examined throughout this thesis that, at the rhetorical level, the Australian Catholic Church accepts, welcomes and advocates for all people regardless of their intellectual or physical abilities. This inquiry seeks to investigate the relationship between this rhetoric and actual substantive efforts towards inclusion of people living with a disability. It finds, based on the lack of substantive evidence revealing actual inclusionary practices, that there is a significant contradiction between the policy rhetoric and practice. To this end, it will be argued that the Australian Catholic Church is not engaged in sufficient practical action to foster and support communities to genuinely welcome people living with a disability and to enhance their sense of belonging to such communities. While acknowledging some good work being conducted by individual Church agencies, based on the evidence accrued from the qualitative data gathered for this thesis, it is the contention of the researcher that there are few tangible, consistent or concrete strategies or actions towards inclusion and genuine belonging that one can point to in day-to-day practice in the Catholic Church community. It is a central concern of this research to open up a conversation, dialogue and debate that might bridge the gulf between the policy rhetoric and practice, and so foster more positive inclusionary approaches and substantive change in this area of Catholic Church life.
ACKNOWLEDGEMENTS

A wise friend once said to me that if you drink from the well, you have to remember those who built it. Now, having completed the journey of writing a doctoral thesis, I feel particularly humbled by this statement. The acknowledgements below are of a good number (although this list does not mention everyone who has assisted me along this journey – that would be an entire thesis in itself!), but this research project would not have been possible without them all. To this end, I do not know how I will ever repay everyone, but please know I remain forever grateful to you all.

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All thoughts and arguments presented throughout the thesis are my own, unless otherwise acknowledged, and are not necessarily the views and opinions of the individuals and institutions listed above. Any errors in the manuscript remain the sole responsibility of the researcher.
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DEDICATION

I wish to dedicate this thesis with love and respect to people living with a disability, known and not known to me, in the hope that, one day, your gifts will be unconditionally welcomed and treasured by all. You have taught me to listen, to be humble, to be patient and to be grateful for what we have each day. This is for you.
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### Abbreviations

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<th>Abbreviation</th>
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<tbody>
<tr>
<td>AAIDD</td>
<td>American Association on Intellectual and Developmental Disabilities</td>
</tr>
<tr>
<td>ACBC</td>
<td>Australian Catholic Bishops Conference</td>
</tr>
<tr>
<td>ACSWC</td>
<td>Australian Catholic Social Welfare Commission</td>
</tr>
<tr>
<td>DDA</td>
<td><em>Disability Discrimination Act 1992</em> (Commonwealth Government)</td>
</tr>
<tr>
<td>ESSTD</td>
<td>European Society for the Study of Theology and Disability</td>
</tr>
<tr>
<td>HREC</td>
<td>Human Research Ethics Committee, The University of Newcastle</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning (Disability and Health)</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>RHD</td>
<td>Research Higher Degree</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
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PREFACE

I have often wondered how the world would have reacted if Prince William, the Duke of Cambridge, and Princess Catherine, the Duchess of Cambridge, had introduced their baby boy, Prince George Alexander Louis, or their baby girl, Princess Charlotte Elizabeth Diana, as a child born with a severe disability. Would there have been a sense of disappointment, or would Prince George or Princess Charlotte have been welcomed with open arms?

This research project represents a profound personal interest on a number of levels. First, my father, Michael, is formally trained as a Social Educator for children and adults living with a disability and has been employed in this sector for many years. It has been his inspirational work (and that of others) that has led me to this research project. Second, disability, in the broadest sense, is an area in which I have been personally and professionally involved for most of my adult life. I am particularly passionate about advocating for social inclusion and justice for people living with a disability; and genuine care for the individual, able-bodied or not, is something on which I place great emphasis. To this end, I am constantly posing the one question: “Where does disability fit in the real world?” Third, I have always had an acute interest in hearing theological voices of marginalized and vulnerable people; this prompted me to focus on the question of refugees and asylum seekers in an earlier honours research project.

I come to my field, having introduced myself, at various times, as a practical theologian, as an ethnographic ecclesiologist and as a sociologist of religion. A lot of my work, and
indeed the focus of the thesis, is in the area of disability, with a particular focus on analysing the Catholic Church (using qualitative research methods) to propose ways in which it can become a genuine place of belonging and community – advancing from being a place where people living with a disability are merely included. When I am talking about my research to friends and foes alike, I often comment that “qualitative research is a methodology that has been neglected to a certain extent within the discipline of theology, resulting in a whole range of methodological tensions between theology and modern social science – perhaps a conversation for another day!” Well, that “other day” is today!¹

It seems quite strange to look back on the academic journey that has led me to write this thesis; however important or benign it has been, it has enabled me to be where I am today. The journey dates back to early 2006, when during my first semester of undergraduate theology study at the Australian Catholic University, students were required to complete several compulsory units, one of these being “Practical Theology as Social Criticism.” This unit enabled students to critically analyse and reflect on the theology behind the practices of the Church, and how these can impact on the world in which we live. From that moment on, it made sense that all theology should be made “practical,” that we should “get

¹ Here I do not suggest that I am the first theologian researching similar issues, but just one amongst an ever-expanding group of theologians. A testament to this has been the growing body of literature on this topic. See especially, Pete Ward, ed., Perspectives on Ecclesiology and Ethnography (Grand Rapids, MI: William B. Eerdmans, 2012) and Christian B. Scharen, ed., Explorations in Ecclesiology and Ethnography (Grand Rapids, MI: William B. Eerdmans, 2012).
something out of it,” something useful or tangible. Since when was theology ever not practical?²

As I will show later in the thesis, people living with a disability remain a largely marginalised group within the Australian Catholic Church – as arguably are youth, women, and the elderly, among many others.³ I would argue strongly, based on its own teachings on human dignity, that the Catholic Church in Australia should be at the forefront of creating and fostering inclusive communities and showing other churches and secular groups what genuine inclusion should look like! Moreover, I am motivated by the prevalence of “stigma”⁴ directly concerning people living with a disability.⁵ Too often, I open a local, metropolitan, or national newspaper to an article (or series of articles) that is exposing some sort of exclusion, discrimination, or rejection of a person or a group of people living with a disability, with headlines such as “Disabilities Report Exposes Exclusion, Neglect,”⁶ “Intellectually Impaired Aboriginal Woman Rosie Fulton To Be Freed after 21 Months in Jail with No Conviction,”⁷ “Children with Autism Caged and Abused”⁸ and

³ See Chapter Three, especially section 3.1.
“Understanding Without Words.”9 To be fair, there are just as many articles or feature stories that highlight the extent to which certain people in the community advocate and protest against exclusion, discrimination, or rejection towards a person or a group of people living with a disability. Examples can be seen in the following: “People Aren’t Broken, System Needs Fixing,”10 “Smashing the Stigma for Those with Disabilities,”11 “Organisation Makes Impact,”12 “Where the Love Runs Deep,”13 “Vinnies Puts the Focus on Inclusion by Emphasising Ability Not Disability,”14 and “Announcement of First Archdiocesan Special School.”15

There is sound evidence to suggest that society is moving towards recognising the importance of social inclusion of people living with a disability.16 In fact, whilst writing this thesis, the Commonwealth Government of Australia introduced legislation for a National Disability Insurance Scheme (NDIS). To quote directly from the legislation: “This Bill will give people with disability a right to realize their potential, and to make choices and be in control of the decisions that affect their lives.”17 As we will see as part of the

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16 See especially Chapter Two, section 2.3.4.
conclusion of the thesis, Australian legislation and government policy is aligning itself more and more with the Social Model of disability, which is overwhelmingly positive. In summary, it is important for me to note here that no matter what we do in relation to disability services, it is never going to be enough to overcome the gap between exclusion and inclusion.

THESIS INTRODUCTION

i.1. INTRODUCTION

The purpose of this chapter is to introduce the topic of this thesis beyond what has already been presented in the preface, by addressing a range of issues central to the thesis. These issues will include: the nature and development of disability theology; the prevalence of disability in Australia; and the Catholic Church’s response to disability issues. It will also identify the following features of the thesis: its methodology; and its research aims, objectives and hypotheses. It will also comment on the thesis’ significance and offer a brief outline of the thesis.

i.2. BACKGROUND TO THE THESIS

This thesis examines the role of the Australian Catholic Church in advocating for and welcoming people living with a disability into the life of the Church.

i.2.1. DISABILITY THEOLOGY

Disability theology is a sub-discipline of theology that deals with the experience of people living with a disability, in dialogue with sources of theological insight. In order to understand this approach, it is necessary first to provide some background information on people living with a disability. People living with a disability can personally grow and

18 See Chapter One, section 1.5 for a more detailed definition of disability theology.
develop, especially in faith and spirituality, regardless of their intellectual and/or physical abilities. John Swinton and Harriet Mowat share this view when they state: “those most able to inform understandings of what spirituality is, what it means, and the ways in which it functions in people’s lives, are people with learning disabilities [intellectual disabilities].”

Deborah Selway and Adrian F. Ashman argue that the lack of substantial literature in the realm of disability theology “gives the impression that there has been little interest in the spiritual lives of people with a disability or the influence of religion on their health and wellbeing.” Similarly, Linda Ward and Margaret Flynn state that “very little research has examined the goals and life experiences of people with learning disabilities [intellectual disabilities].”

---

19 John Swinton and Harriet Mowat, *Practical Theology and Qualitative Research* (London: SCM, 2006), 229. It is essential to state here that some people may not be capable of developing a faith and/or spirituality, such as people living with autism, who may not have an awareness of abstract ideas due to the nature of autism. In any case, people with learning difficulties may not have an intellectual disability as such, for example those with dyslexia. Disability is defined and understood differently across the world. See Chapter Two of this thesis for an explanation. See also Australian Catholic Social Welfare Commission, *Disability and Human Relationships*, esp. chap. 1.

20 Deborah Selway and Adrian F. Ashman, “Disability, Religion and Health: A Literature Review in Search of the Spiritual Dimensions of Disability,” *Disability and Society* 13, no. 3 (1998): 429. Furthermore, Selway and Ashman highlight this lack of understanding by stating: “Few studies exist which examine religious orientation and its effect on the acceptance of disability. [Moreover], studies focusing on the role of religion in the lives of people with a disability themselves have yet to be conducted. The relative absence of studies on the spiritual lives of people with a disability seems an oversight in terms of gaining greater understanding, awareness and appreciation of the lives of people with a disability generally.” (433–34)

When discussing disability theology, two questions arise: First, what difference does a theology of disability make? And, second, why would a theologian be interested in disability issues – theoretically? Swinton describes disability theology as:

the attempt by disabled and non-disabled Christians to understand and interpret the gospel of Jesus Christ, God, and humanity against the backdrop of the historical and contemporary experiences of people with disabilities. It has come to refer to a variety of perspectives and methods designed to give voice to the rich and diverse theological meanings of the human experience of disability.

In brief, disability theology is “the attempt by people with and without disabilities to reflect on what it means to be a human being and what it means to be a Christian, looking through the lens of people with disabilities.” Furthermore, Swinton asks: “What does it mean to be fully human and at the same time have a profound disability?” In view of this literature survey, this thesis defines disability theology as the study of transforming Christian practices towards an authentically inclusive Church. Theologians from other faith traditions are investigating disability in similar ways.

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22 This question has been adapted from the “Theology, Disability and People of God” Conference, Carey Baptist College, Auckland, New Zealand, July 1–3, 2013.
25 Swinton, “Interview.”
26 Although there is much work to be done in the area of the theology of disability, it has been researched quite aggressively over the past ten or so years. See Chapter One, section 1.5 and 1.6, for a detailed explanation of the development of the theology of disability.
27 See Chapter One, section 1.6.
i.2.2. A BRIEF STATISTICAL OVERVIEW OF DISABILITY IN AUSTRALIA: CLARIFYING THE “PROBLEM” AND THE TERMINOLOGY

As in every corner of the world, disability is very much a reality in Australia, with the National Disability Services commenting that “disability [in Australia] is a common yet varied experience.”28 Most people will experience disability in some form during their life. According to the 2011 Australian census,29 there was a population of approximately 21,783,000 in Australia, of which approximately four million people, or 18.5 per cent of the population, reported to be living with one or more disability.30 We also see documented “267,715 Catholics who had need for assistance with one or more core activities of self-care, mobility and communication, because of a long-term health condition, a disability, or old age.”31

The dominance of the Medical Model of disability services prior to the 1960s, whereby decisions for treatment were made by medical practitioners and other health professionals, would be what is considered the “planning for” program (as opposed to a “planning by” program), meaning that decisions were made for people living with a disability, not by the

29 The Australian census is run by the Australian Bureau of Statistics, is conducted every five years, and poses an extensive range of demographic questions, such as: Is the person of Aboriginal or Torres Strait Islander origin? How well does the person speak English? What is the person’s religion? Does the person ever need someone to help with, or be with them for, self-care activities?
30 National Disability Services, “Disability Data Snapshot.” Furthermore, 5,439,268 people classified themselves as being Catholic (25.3% of the total population). This was the highest ranking religious affiliation – even ahead of those classifying themselves as “no religious affiliation” (4,796,787 people, or 22.3% of the total population).
people with the disability.\textsuperscript{32} Many people were simply incarcerated in institutions, with little or no consideration for their rights, or consultation, or holistic concern for their health or welfare. Others not abandoned in institutions were kept at the family home or perhaps allowed to venture out only to “sheltered workshops” if considered capable, again this decision tending to be made by medical doctors. The attitude behind this position seemed to be one of “out of sight, out of mind.”

Thereafter, a move towards deinstitutionalisation and independent living followed and the 1970s saw the emergence of “normalisation,” which aimed to assist people living with a disability to live like others in the community. This movement of “planning with” represented a huge step forward and coincided with the \textit{Richmond Report} and with the \textit{Disability Services Act 1986} (Australian Commonwealth), designed to ensure that people living with a disability have access to the community, education and/or training, and are not unfairly excluded or disadvantaged. Much of the decision-making power was still retained by a select group of professionals and, in spite of person-centred planning being introduced, this feature remained in place.\textsuperscript{33} As it will be argued later in the thesis, this is problematic because it creates a sense of stigma and alienation.\textsuperscript{34}

\subsection*{1.2.3. \textbf{THE AUSTRALIAN CATHOLIC CHURCH AND DISABILITY ISSUES}}


\footnotesize{\textsuperscript{33} For a more detailed account of disability in Australia, see Gerard Goggin and Christopher Newell, \textit{Disability in Australia: Exposing a Social Apartheid} (Sydney: University of New South Wales Press, 2005).}

\footnotesize{\textsuperscript{34} See Louise Lawrence, \textit{Sense of Stigma in the Gospels: Depictions of Sensory-Disabled Characters} (Oxford: Oxford University Press, 2012).}
The Catholic Church has an official body of social ethics often known as Catholic social teaching, which encompasses the treatment of people living with a disability. Such teaching echoes several government and humanitarian legislation pieces, including those affirmed by the Australian Commonwealth and United Nations, though in contrast is founded on specifically Catholic teaching. At the heart of Catholic social teaching lies the belief that all human beings have an inherent dignity, and all human beings should be treated equally.

The Second Vatican Council’s Pastoral Constitution on the Church in the Modern World (Gaudium et Spes) emphasises this point by stating:

there is a growing awareness of the sublime dignity of human persons, who stand above all things and whose rights and duties are universal and inviolable. They [human persons] ought, therefore, to have ready access to all that is necessary for living a genuinely human life: for example, food, clothing, housing, the right freely to choose their state of life and set up a family, the right to education, work, to their good name, to respect, to proper knowledge, the right to act according to the dictates of conscience and to safeguard their privacy, and rightful freedom, including freedom of religion.

In accordance with the above sentiment, since Catholicism arrived in Australia during the eighteenth century, Catholics have been “one of the largest providers of social care services in Australia.” Furthermore, it is well documented that the Australian Catholic Church takes a positive position on the incorporation of disability services as part of its social care

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brief. It is clear therefore that, at the levels of teaching and the rhetoric that follows this, the Australian Catholic Church accepts and welcomes all people regardless of their intellectual or physical abilities and is active in pursuing their support. Nonetheless, the question that remains pertinent is: What is the Church actually doing in this area to ensure that these sentiments are put into practice? As will be seen in the following section, this section frames the research objectives and premises, and shows how the thesis can provide a substantial answer to this final question.

i.3. RESEARCH OBJECTIVES AND PREMISES

As outlined in the Thesis Abstract above, this research has been directed by the following aims and objectives:

1. To investigate the relationship between theological theory and practice in the Australian Catholic Church’s approach to disability;
2. To determine whether the Australian Catholic Church is, in its structures and practices, addressing the religious needs of people living with a disability;
3. To investigate the effectiveness of contemporary attempts at inclusionary practices within the Australian Catholic Church;
4. To develop, where appropriate, practical strategies and actions that might assist the Australian Catholic Church to foster communities of inclusion, belonging, friendship and

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ownership. This will include devising proposals for successful disability service provision (grounded in the Catholic tradition) that could further meet the religious needs of people living with a disability; and, finally

5. To open up a healthy conversation, meaningful dialogue and comprehensive debate that will foster more positive inclusionary approaches and substantive actions towards beneficial change.

The following premises, established in the introduction, have guided the research:

1. People living with a disability can find human fulfilment through religious practices;
2. The Australian Catholic Church recognises the dignity and rights of people living with a disability; and
3. There must be a correlation between theory and practice, and this correlation or lack thereof warrants investigation in relation to disability and the Australian Catholic Church.

1.4. SIGNIFICANCE AND OUTCOMES OF THE RESEARCH

This research is significant on a number of different levels. First, having reviewed the literature, there is insufficient scholarship from a Catholic theological viewpoint that examines the lives of people living with a disability. Second, disability theology has begun to receive more scholarly attention over the past ten years internationally,

39 See Chapter Three, especially section 3.3.
particularly in the United Kingdom, North America and Europe. Nevertheless, to date, there is no significant research exploring the Australian Catholic Church’s attitudes and practices towards people living with a disability. Third, a “stigma” relating to those people living with a disability is still evident in today’s society. This study hopes to make a contribution to eliminating such stigma. It also aims to help in supplementing the international literature and body of knowledge concerning disability and, furthermore, to fill some of the void in Australian research noted above.

As such, this research project should be of interest to theologians, social scientists, Australian Catholic Church agencies, relevant institutions and their leaders, and will hopefully clarify if there is any disconnection between the rhetoric and what the Australian Catholic Church and its agencies are actually doing to ensure that the rhetorical positive disposition is put into practice. This researcher hopes to contribute to the theological field

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40 See the Centre for Spirituality, Health and Disability at the University of Aberdeen, Scotland, under the direction of John Swinton. Its main aim is to “enable academics, researchers, practitioners and educators to work together to develop innovative and creative research projects and teaching initiatives . . . in the broad areas of (1) the relationship between spirituality, health and healing and the significance of the spiritual dimension for contemporary healthcare practices; and (2) the theology of disability.” (The Centre for Spirituality, Health and Disability, “About the Centre,” 2014, accessed May 25, 2014, http://www.abdn.ac.uk/sdhp/centre-for-spirituality-health-and-disability-182.php.) Furthermore, the Kairos Forum for People with Intellectual or Cognitive Disabilities was established in 2012, under the co-direction of John Swinton and Cristina Gangemi. The Kairos Forum seeks “to highlight and respond to the spiritual and religious needs of people with disabilities. Our aim is to facilitate the crafting and empowerment of ‘Communities of Belonging’, both within religious and secular settings.” (The Kairos Forum, “What We Offer,” 2013, accessed May 25, 2014, http://thekairosforum.com/.)


43 Refer to the Preface above for specific examples.
in determining how the Australian Catholic Church’s outreach and its relevant publications actually make the difference in turning positive discussions and resolutions into a reality. As a graduate in theology and an active member of the Australian Catholic Church and various Catholic-based social service providers, the researcher has a grasp of the practical theological issues entailed, as well as familiarity with the intricate culture of each relevant institution. Over the past ten years or so, the researcher has made a number of valuable contacts within the discipline of theology and the Catholic Church, and among other relevant individuals and groups.

i.5. SCOPE AND LIMITATIONS

As with any research project, there needs to be a specific scope (areas that are covered in the research) and a set of limitations (areas that are not covered in the research), owing to the constraints that are inherent to the pursuit of a PhD. The scope and limitations of this research project are detailed below.

i.5.1. SCOPE

The scope of this research project has taken into consideration the following elements: research objectives and premises; resources; budget; and time schedule. The research aims, objectives and hypotheses, which are included above, detail the intentions of the research and list the desired outcomes. The researcher has paid strict attention to these parameters. As with all research higher degrees, budgetary constraints and considerations have been
significant. As per The University of Newcastle’s Research Higher Degree Financial Support policy, research higher degree candidates are eligible for a sum of AU$1,500.00 per year, totalling a maximum of AU$5,250.00 for the duration of an enrolment of three and a half years. The researcher has not required the supply of any particular resources beyond this financial support. Any further research expenses, outside of the aforementioned policy, have been met by the researcher. The researcher, in consultation with the supervisory team, devised a strict time schedule to ensure the research project would be completed in the allocated time frame.

i.5.2. LIMITATIONS

The researcher has a deep and profound interest in disability issues through his academic, professional and personal involvement with disability studies and organisations that care for people living with a disability. The researcher is also a Catholic layman and attends Catholic Masses and other related services on a regular basis. It is important that these factors be acknowledged and appraised against any potential conflict of interest. To counter this potential limitation, relevant qualitative research theory has enabled the researcher to study people’s narratives about the crucial research questions concerned with inclusivity of people living with a disability in the Australian Catholic Church. The researcher has modelled this component of the study on previous investigations that are similar to this one,

in particular Swinton and Mowat,\textsuperscript{45} and those mentioned in books in the series titled \textit{Studies in Ecclesiology and Ethnography}.\textsuperscript{46}

Nevertheless, as with all methods of data collection, both qualitative and quantitative, issues of reliability come into question, perhaps more so for qualitative studies. One of the main reasons for this is that quantitative studies rely on “hard data,” for example, statistics, calculations, numbers, equations,\textsuperscript{47} while qualitative research relies on interview transcripts, field notes, reflections, and the like. Therefore, there can be a greater risk of researchers “bending” their results to suit their hypothesis or outcome.\textsuperscript{48} In the words of O’Leary: “research is an activity that needs to be approached with discipline, rigour, and a level of standardization.”\textsuperscript{49} The fact that qualitative interviews were recorded for the current research using a reputable digital voice recorder eliminated an element of interviewer recall bias.\textsuperscript{50} Reliability in terms of conducting the interviews and the processes thereafter was addressed in the design of the research methodology “in ways that are consistent, logical, systematic, well documented, and designed to account for research subjectives.”\textsuperscript{51}

\begin{itemize}
\item \textsuperscript{45}See Swinton and Mowat, \textit{Practical Theology}.
\item \textsuperscript{47}Nahid Golafshani, “Understanding Reliability and Validity in Qualitative Research,” \textit{The Qualitative Report} 8, no. 4 (2003): 597.
\item \textsuperscript{49}O’Leary, \textit{Essential Guide}, 37.
\item \textsuperscript{50}See Susan E. Kelly, “Qualitative Interviewing Techniques and Styles,” in \textit{The Sage Handbook of Qualitative Research in Health Sciences}, ed. Ivy Bourgeault, Robert Dingwall, and Ray de Vries (Los Angeles: Sage, 2010), 314.
\item \textsuperscript{51}O’Leary, \textit{Essential Guide}, 37.
\end{itemize}
oversight through the various levels of analysis added a greater depth of reliability.\textsuperscript{52} This is a point that will be covered in more detail when the methodology is discussed.

\textbf{i.6. METHODOLOGY}

The methodology for this research is more fully explained in Chapter Four, titled “Methodology and Research Design.” Nonetheless, it is important to set out, however briefly, some comments on the methodology of the thesis at this point.

This research has entailed a qualitative study of the Catholic Church in Australia in an attempt to determine the extent to which it is including and creating communities of belonging for people living with a disability. The study focused on the following key institutions, from which staff and volunteers over the age of eighteen were recruited: (1) Catholic social care agencies (for example, CatholicCare, Centacare); (2) the Catholic school system (for example, the Catholic Education Office, the Catholic Schools Office); and (3) other Catholic agencies and organisations (for example, the Australian Catholic Bishops Conference [ACBC], parish support units, parish ministry teams, archbishops, bishops, and other clergy).

The essential protocol entailed in the qualitative study can be summarised as follows:

• Interviews were undertaken in a mutually agreed-upon location, which was preferably in open public spaces, such as a municipal library or a community neighbourhood centre. However, where desired by interviewees, organisational offices were utilised. In the case of substantial geographic distance between the interviewer and the interviewee, interviews took place over the telephone or by using Skype.

• Information statements\(^{53}\) and consent forms\(^{54}\) were sent to potential interviewees from the three sample clusters in order to canvass interest.

• Interested interviewees were asked to read the Information Statement thoroughly, to understand its content, parameters and expectations, and to register their interest and participation in the research project by completing the Consent Form within two weeks of the date of the Letter of Invitation.

• A brief semi-structured interview lasting no more than sixty minutes was requested of the interviewees.

• Interviewees were afforded the opportunity to voice their personal viewpoints regarding inclusion of people living with a disability from their perspective – as a bishop, priest, educator, parish administrator, disability support worker, as appropriate.

• The interview data were transcribed by a professional transcription company (Digital Transcripts).

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\(^{53}\) See Appendix B.

\(^{54}\) See Appendix C.
• The transcripts were subjected to a thorough thematic analysis process in order to identify any recurrent patterns, themes and categories.\textsuperscript{55}

• Upon request, an edited summary report of the research was provided to interviewees at the completion of the project.

• All interview transcripts and relevant paperwork were securely housed in a locked cabinet accessed only by the principal supervisor/investigator and student researcher. The “working data” was password-protected and encrypted to protect the identity of the interviewees. This material will be stored for a minimum of five years and then destroyed by personnel of research services at the student researcher’s university.

• Individual interviewees and their place of employment were not identified at any stage throughout the data analysis and synthesis.

i.7. THESIS STRUCTURE

This thesis will be organised according to the following structure:\textsuperscript{56}

**Thesis Introduction**

The purpose of this component is to introduce the topic of the thesis. It will address a range of key issues central to it. These include: the nature and development of disability theology; the prevalence of disability in Australia; and the Catholic Church’s response to


\textsuperscript{56} See specifically the Table of Contents, for a more detailed chapter outline.
disability issues. It will also identify the following features of the thesis: its methodology and its research aims, objectives and hypotheses; and it will comment on the thesis’ significance and offer a brief outline of the thesis.

Chapter One – Bridging the Theological and Clinical Divide: Literature Review, Tensions and Controversies

Chapter One explores the question: “Why would a theologian be interested in disability – from a theological perspective?” As well as this, the chapter will investigate what we mean by the word “theology,” or, more pertinent to this particular inquiry, how we do theology? (What are the ways of theologising?) In so doing, it will make particular reference to natural theology and practical theology. The chapter will draw on the work of a selection of notable scholars who have researched or are researching in the broad areas of the theology of disability.

Chapter Two – The Disability Debate: Literature Review, Tensions and Controversies

The purpose of Chapter Two is to critically trace the sociological and historical development of disability and related theoretical frameworks. After discussing the “definability” of disability, there will follow an overview of (1) the Medical Model of disability; (2) the Principle of Normalisation; (3) Social Role Valorisation; and (4) the Social Model of disability. Some considerations will then be given to the necessity of change and its progressive character. Chapter Two will argue that there will never be a universally accepted definition of disability and will propose the need for a resolution of the tensions and controversies that result.
Chapter Three – Genealogy of, and Key Developments in, Disability in Catholic Thought: An Australian Perspective

The intention of Chapter Three is to critically explore the genealogy of rhetoric about and responses to disability within the Catholic Church in Australia, and to trace several key developments that the Church has forged in this area. A concerted focus will be on both the discourse and practical efforts in this regard. This aspect of research will prove vital when determining – at the conclusion of this thesis – whether the Australian Catholic Church has been or is an authentically strong advocate (or not) for people living with a disability. Key focus areas will include: the Australian Catholic Bishops Conference and relevant Catholic leaders and agencies within Australia and the universal Catholic Church, and papal and other Vatican documentation.

Chapter Four – Methodology and Research Design

The purpose of Chapter Four is to propose an appropriate methodology for undertaking the qualitative research that underpins the present study. A reflection on relevant ethical considerations will be put forward\(^5\) that shows that the research has been conducted in accordance with the Human Research Ethics Policies and Guidelines of The University of Newcastle and the Australian Code for the Responsible Conduct of Research.

Chapter Five – Research Findings

The purpose of Chapter Five is twofold. First, we see the research findings examined on a question-by-question basis to identify any recurrent patterns, themes and categories in the responses. In so doing, the researcher will present a text-based analysis for each of the six interview questions, accompanied by a number-based analysis (in table form) that will present how many times each of the thematic categories showed up during the thematic analysis process. Second, a critique of the five key categories that have emerged from the thematic analysis will be directed to the following five categories: (1) Attitudes and perceptions; (2) Inclusion; (3) Empowerment; (4) Rhetoric versus reality; and (5) Demonstrated action.

Chapter Six – Making Meaning of the Findings

The purpose of Chapter Six is to interrogate discrete elements of the qualitative data and to consider the data in the context of the literature and interlinked with documentary evidence published by the Catholic Church and relevant agencies and organisations.

Chapter Seven – Thesis Conclusion

The purpose of Chapter Seven is to provide an overall synthesis of the qualitative data in dialogue with the theological foundation established earlier in the thesis. In summary, conclusions and recommendations will be extended to highlight existing positive attempts towards social justice for people living with a disability, and attention will be given to identifying and tabling any gaps and inconsistencies. In particular, barriers and competing
discourses of inclusion will be outlined. The researcher will also return to the theological literature to analyse, interpret and offer critique of the findings.

i.8. ETHICAL CONSIDERATIONS

The initial application to the Human Research Ethics Committee (HREC), seeking approval in relation to the protocol, was tendered on June 1, 2012; it received endorsement and was “peer reviewed” by Dr Barry Morris. The project was considered under L2 Low Risk Research Expedited Review by the HREC Panel on July 17, 2012. As from September 3, 2012, the status of the submission was “Conditional Approval” (reference number: H-2012-0220). The application was not subject to the L3 Full Review. The application considered a number of themes, including: clarification on how the researcher would recruit participants; notification on what contingencies were in place if a participant was to become distressed during the interview; and what action would be taken by the researcher to manage this risk; and, an explanation in the Information Statement concerning how the recipient had been identified for participation. On September 5, 2012, the submission was considered under “Expedited Review” by the Chair/Deputy Chair, and the decision on the submission was “Approved” (Reference no.: H-2012-0220). For further information, please refer to Appendix B.

i.9. STYLISTIC FEATURES OF THE THESIS
The thesis has been prepared in accordance with The University of Newcastle’s Thesis Examination Guidelines.58

i.9.1. USE OF AUSTRALIAN ENGLISH

The thesis is written in Australian English. No amendments have been made to direct quotes that use another variant of English.

i.9.2. WORD COUNT

The word count of the thesis is 82,389 words. This includes the title page, all sections of the main manuscript, tables, footnotes and the bibliography. The word count, however, excludes appendices.

i.9.3. USE OF FIRST PERSON PRONOUNS

First person pronouns are used sparingly throughout the thesis to avoid making it sound informal or anecdotal. Only in rare occurrences, such as in the Preface, the Introduction and in sections where the researcher is engaged in investigator reflection (as against reporting) are first person pronouns used.

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i.9.4. USE OF TENSES

There is no exclusive rule on the use of tenses throughout the thesis. The default position is past tense, especially when citing literature and/or reporting findings. However, when the researcher is citing or reporting something that is clearly current, present tense is used.

i.9.5. USE OF HEADINGS AND SUBHEADINGS

Headings and subheadings are used extensively throughout this thesis. Given the broad nature of this inquiry, the use of headings and subheadings provide a clear and coherent structure to aid in navigation.

i.9.6. REFERENCING

This thesis uses the Turabian style of referencing. This includes the correct acknowledgement of references and resources, both print and electronic, that have been used in the research. The only exception to the use of Turabian style concerns the referencing of interview transcripts, owing to the frequency with which they are referred to. In such cases, in-text parentheses have been used instead of footnotes. For other references, full footnote citations are included the first time particular works are cited in each chapter, with a suitably abbreviated form of reference being used thereafter. All direct quotations longer than forty words are set apart, indented on the left, with single-spaced lines, in

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59 See Kate L. Turabian, A Manual for Writers of Term Papers, Theses, and Dissertations, 8th ed. (Chicago: University of Chicago Press, 2013), for further technical classifications.
accordance with Turabian style. The only exceptions to this are direct quotes from interview transcripts, which are presented in italicised font in the body of the text.

i.9.7. SPECIFIC TERMINOLOGY

It is important to note the potential difficulties with specific terminology around the word “disability.” Throughout the thesis, the following approaches will be adopted:

- Use of the term “disability”, as opposed to any other alternative notion used throughout the world, for example, “retarded,” “mentally challenged,” “handicapped,” “impaired,” “learning disabilities.”
- Use of the expression “people living with disability/ a disability,” as opposed to “people with disabilities,” as the latter suggests that all people living with a disability have more than one disability.
- Use of “people first” language, which refers to people by their first name, rather than by their disability. The terms “wheelchair-ridden” and “people bound by a wheelchair” are not appropriate as the researcher believes this kind of terminology signifies negative attitudes. People should refer to “a person who uses a wheelchair” or to “someone who happens to need a wheelchair.” (See Interviewee 8: Brianna.)
- Avoidance of the use of language such as “the intellectually disabled,” “the handicapped,” and “those suffering from disability.” Nonetheless, no amendments have been made to direct quotes that use these, or other, possibly discriminatory terms. To signify this, the researcher has simply inserted [sic] immediately after such occurrences.
Finally, when referring to “the Church,” the researcher is referring to the Catholic Church, unless stated otherwise.

i.9.8. MISCELLANEOUS STYLISTIC FEATURES

The following miscellaneous stylistic features are to be noted:

- The font style used throughout the thesis is Times New Roman and the font size is twelve for the main text and ten for footnotes.
- The orientation of the paper is portrait, and standard A4 metric paper is used (approximately 21 cm x 30 cm).
- The gutter margin size is 4 cm, the outer margin 2 cm, the top margin 3 cm, and the bottom 2 cm.
- Words in square brackets, often inserted in a direct quotation, are words that have been included or modified by the researcher.60
- Numbers under one hundred (for example, sixty-six), rounded numbers (for example, one hundred or six million) and ordinal numbers (for example, second or twentieth) have been written in words, as opposed to their numerical form. But there are some exceptions, including dates and the numbering of categories, for example.

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60 In terms of the overall presentation of the thesis, the following resources have been consulted: Howard S. Becker, Writing for Social Scientists: How to Start and Finish Your Thesis, Book, or Article (Chicago: University of Chicago Press, 1986); and Lawrence D. McIntosh, A Style Manual for the Presentation of Papers and Theses in Religion and Theology (Wagga Wagga, NSW: Centre for Information Studies, Australian and New Zealand Theological Library Association, and Australian and New Zealand Association of Theological Schools, 1995).
• Pseudonyms have been used to prevent the disclosure of the identities of research subjects and places.

• Direct quotes from interview transcripts have been italicised to make them more easily distinguishable from the main text.

i.10. CONCLUSION

In the Thesis Introduction, the topic of the thesis has been introduced and, in doing so, a range of key issues central to this thesis have been touched on, including: the nature and development of disability theology; the prevalence of disability in Australia; and the Catholic Church’s response to disability issues. This section has also signposted the mechanics of this thesis, including: its methodology, and its research aims, objectives and hypotheses; and it has described its significance and offered a brief outline. In the next chapter, the central question: “Why would a theologian be interested in disability – from a theological perspective?” will be explored. In so doing, natural theology and practical theology will be identified as ways of theologising about the topic, and a selection of notable scholars who have contributed to such theologising will be examined. These will include theologians who have researched or are researching directly in the broad area of disability theology.
CHAPTER ONE: BRIDGING THE THEOLOGICAL AND CLINICAL DIVIDE: LITERATURE REVIEW, TENSIONS AND CONTROVERSIES

1.1. INTRODUCTION

This chapter explores a question central to the focus and methodology of the thesis: “Why would a theologian be interested in disability – from a theological perspective?” As well as this, the chapter will investigate what we mean by the word “theology,” or, more pertinent to this particular study, how we do theology (what are the ways of theologising?), with a particular reference to natural theology and practical theology. Herein, the researcher relies on a selection of notable scholars whose work the researcher considers to be relevant to the topic, including the work of some scholars who have researched or are researching directly in the area of disability theology. It would be impossible within the scope of this thesis to survey everyone who has published a book or article in the area. The scholars that the chapter focuses on were chosen based on their significance in the field and ongoing discussions between the supervisors of this project and the researcher. The scholars listed throughout this chapter are surveyed in no particular order to avoid any biases and/or hierarchical structure.

1.2. THEOLOGY: “FAITH SEEKING TO BE UNDERSTOOD”¹

Theology has been both a devotional and academic pursuit since earliest times.² In fact, the word “theology” can be traced back to the early patristic period.³ Theology itself

engenders many forms, depending on how it is defined and how it is “lived out.” For example, theology is an exercise that can be done in private, such as when a person prays or engages in an adult faith course; at the same time, theology can also be an activity that is done in a communal setting, such as at Sunday Mass, among lay students completing an undergraduate theology degree program at university, or among a group of seminarians studying for the priesthood.

The word “theology” derives from two Ancient Greek words, Θεός / theos (literally meaning “god”) and λόγος / logos (literally meaning “word”). It could then be said that theology is “words about God.” However, when we look at it from a contemporary perspective, it is best understood as “the study of God” – just as biology is the study of life, anthropology is the study of humans, sociology is the study of societies, and psychology is the study of mental functionalities and behaviours.

Theology is most universally defined and understood as fides quaerens intellectum, Latin for “faith seeking understanding,” a phrase which derives from St Anselm of


\[^3\] McGrath, *Christian Theology*, 102.


\[^7\] See McGrath, *Christian Theology*, 102. See also Lovat and Fleming, *What Is This Thing?*, esp. chap. 3.

Canterbury’s *Proslogion*, or as Timothy Stanley puts it, “faith seeking to be understood.” Anselm affirmed that religious faith was a sound standpoint from which to understand God and the world around us. Then, the task of the theologian is to critically explore particular intricacies of religious belief systems and/or spiritualities, and to suggest how we can gain meaning and understanding of the transcendent, asking “Where does God fit into all of this?”

John Macquarrie, a prominent Scottish theologian and philosopher, defines theology as: “the study which, through participation and reflection upon a religious faith, seeks to express the content of the faith in the clearest and most coherent language available.” Macquarrie’s definition of theology is particularly relevant to this thesis, given that it highlights the importance of human experience and participation. Extending Macquarrie’s definition further, it is apt to mention the significance of community when understanding the task of theology. Rausch stresses this by stating: “Theology is concerned with our experience of God, particularly our experience of God as a community of faith . . . to understand and interpret the faith experience of a community, to bring it to expression in language and symbol.”

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9 See Anselm, *Proslogion*.

10 Stanley, “Theology.”

11 Dan Fleming, personal communication with the researcher, June 11, 2014.


In the next section, we survey two types (methods) of theology that distinctively relate to the realm of disability theology and provide a platform from which one might look at the questions: What constitutes a theology of disability? And why would a theologian be interested in disability issues – theologically? Additionally, natural theology and practical theology, which constitute the main theological foci in this thesis, are two distinctive ways of theologising, as are systematic theology, biblical theology, dogmatic theology, sacramental theology, moral theology, and so on.

1.3. RESEARCH SCOPE AND ITS RELATIONSHIP WITH NATURAL THEOLOGY

Medieval Scholastic philosopher-theologian, St Thomas Aquinas, was responsible for a shift in the way people understood theology, and perhaps more aptly, how people viewed the world around them. This change can be understood as a turn towards applying theology to the natural world, or simply natural theology, which can be defined as “the practice of philosophically reflecting on the existence and nature of God independent of real or apparent divine revelation or scripture.”\(^\text{15}\) Aquinas’ natural theology brought about a change in the more common understanding within Christianity that theology was mainly concerned with “revealed” phenomena, most especially through the Bible and the institution of the Church. Thomist\(^\text{16}\) natural theology suggested, rather, that among the “sacred pathways” through which God reveals the God-Self, such as the Bible and Church doctrines of Incarnation, Trinity, etc., is the


\(^{16}\) Thomism is the school of thought that arose from the work and writings of St Thomas Aquinas.
reality that we can also come to know God through our dealings with and our experience of the world. Roger E. Olsen states:

according to Thomas [Aquinas], even the most sinful person can use one’s reason to know that God exists, the soul is immortal, and the basic laws of morality are sound. One does not have to be a Christian to know these things. There are proofs of the existence of God drawn from experience of the world. Thomas’s proofs are drawn from experience of the world.

However, the questions that remain unanswered include: What relationship does this kind of natural theology have with disability? Furthermore, why might theologians use Aquinas’ natural theology as a lens through which to debate disability issues? In answer the researcher would argue that: people living with a disability are “made in the image and likeness of God” (Genesis 1:26-27), and, people living with a disability are part of God’s creation. Hence, reflection done in dialogue with their experience can provide depth and breadth to the theological project of faith seeking understanding.

1.4. RESEARCH SCOPE AND ITS RELATIONSHIP WITH PRACTICAL THEOLOGY

Practical theology is often framed as a relatively new way (method) of doing theology. However, a number of scholars, including Brian J. Kelty and Ray S. Anderson,

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18 Olsen, God in Dispute, 197.
believe that it has always been present in, and effectively grown out of, an existing method known most commonly as pastoral theology.\textsuperscript{22} As Kelty states: “Practical theology relates to an ancient and more venerable term: pastoral theology. This traditional term has a long history in Christian theology.”\textsuperscript{23} A number of definitions of practical theology that scholars have proposed in recent times are considered below.

John Swinton and Harriet Mowat define practical theology as “critical, theological reflection on the practices of the Church as they interact with the practices of the world, with a view to ensuring and enabling faithful participation in God’s redemptive practices in, to and for the world”\textsuperscript{24}; while Terry A. Veling believes practical theology offers “a choice to practice a theological way of life – a choice or a decision that doesn’t come at the end of a process like an outcome, but rather stands at the beginning, like a true test of faith: ‘Can I practice this way of life?’ ”\textsuperscript{25} Furthermore, Veling extends this point in another publication by stating:

Practical theology, as its name suggests, is less a thing to be defined than it is an activity to be done. In this sense, it resists our attempts to pin it down and define it. Practical theology is more “verb-like” than “noun-like.” In many ways, we


\textsuperscript{22} See Kelty, “Practical Theology,” 119.

\textsuperscript{23} Kelty, “Practical Theology,” 119.


would be better to speak of “practicing theology” rather than “practical theology.”

Theology is not static – it is very much “alive” in everyday life. Human beings are constantly searching for meaning, stretching their minds beyond where they are now. Theological reflection offers a methodology, within the discipline of practical theology, to achieve this. If we understand theology as “faith seeking to be understood,” as introduced above, then by the very definition of theology, it is suggesting an element of reflection, or the need to be reflective. In contrast, Patricia O’Connell Killen and John de Beer believe theological reflection “confirms, challenges, clarifies and expands how we understand the religious tradition . . . the outcome is new truth and meaning for living.”

In the researcher’s perspective, practical theology is about how we can make sense of one’s lived experience and the transcendent. As Pete Ward indicates in his book, *Perspectives on Ecclesiology and Ethnography*, and in other books in the series titled *Studies in Ecclesiology and Ethnography*, practical theology and qualitative research together have gained traction in only the last thirty years or so. The aim of this book

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28 Stanley, “Theology.”
series is to clearly signpost: “Here we are!” Further, Ward states (in relation to the book series):

> Now is the time to start to bring this wealth of experience together. We want not only to talk about the theological significance of empirical research, but also to reflect on the experience of doing fieldwork. We want to explore how the practice of engaging in ethnographic and qualitative research shapes the way we do theology and reflect on the church.”

Richard Osmer coins the term “empirical practical theology” in a recent book and defines it as “disciplined attention to some form of contemporary human experience with the intent of learning something new.” Patrick McArdle believes that “a practical theology of personhood may enable the Church and society to more positively celebrate the diversity of the human condition rather than at best pay it lip service as is so often the case.” McArdle appears to avoid dwelling on the inconsistencies of one’s personhood, but instead focuses on offering a perspective for celebrating the gift of God – the gift of talents, joy and sacramental mysteries. Amid all these various theological viewpoints is the experience of daily life of people living with a disability. Indeed, many people living with a disability are cast as “others” by society that often seems to treat them as though they are deficient and inferior.

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36 See McArdle, “Disability and Relationality.” According to McArdle, “personhood” can be understood as simply the state of being human. He argues that “people who live with disabilities of one form or another are among those whose personhood is routinely questioned, in practice if not always in theory. They are those who subsist precariously due to their vulnerability in terms of living; and the regard in which they are held in modern Western societies is demonstrably subordinate to those of the majority of persons.” (McArdle, “Disability and Relationality.”)
1.5. WHY ARE THEOLOGIANS INTERESTED IN DISABILITY ISSUES?

A certain narrowness in our society’s ability to accept the mentally handicapped \textit{sic} seems to be connected in part with an unclear perception of the intrinsic dignity of the disabled human being.\textsuperscript{37}

It must be understood in the context of this research project that God does not exclusively force a disability (or disabilities) upon a person; disability is a way of naming difference.\textsuperscript{38} It is crucial to the theological premise being mounted in this thesis that every human being, regardless of physical and/or cognitive ability (as well as other characteristics such as race, gender, skin colour, language used, and so on)\textsuperscript{39} is reverenced with equal dignity and respect.\textsuperscript{40} This is echoed in the opening lines of the \textit{Universal Declaration of Human Rights} (1948): “all human beings are born free and equal in dignity and rights.”\textsuperscript{41}

We are introduced to the theological concept of \textit{imago Dei} in the book of Genesis,\textsuperscript{42} where all human beings are “created in the image and likeness of God” (Genesis 1:26-


\textsuperscript{38} Swinton, “Time, Hospitality and Belonging: A Practical Theology of Disability” (public lecture, Broken Bay Institute, Pennant Hills, NSW, June 24, 2014).


\textsuperscript{40} See Zachariah P. Duke, “Transforming Theology: A Way of Enabling Quality of Life for Persons Living with a Disability” (paper presented at the 4th Biennial European Society for the Study of Theology and Disability, Lille Catholic University, France, June 27–29, 2013).


\textsuperscript{42} Amos Yong, \textit{Theology and Down Syndrome: Reimagining Disability in Late Modernity} (Waco, TX: Baylor University Press, 2007), 169–70.
This is a vivid image and is often remembered as the cornerstone of all theological understandings of the human person; it should act as the basis for all mutually enriching relationships with people living with a disability. In relation to human dignity and the value of each human person, Clark Carlton states:

No matter how dehumanizing modern life may be, it can never suppress the absolute uniqueness of the human person, for that uniqueness is the imprint of God upon us all. God calls us all to grow into His likeness, but in a way that is unique to each of us.

However, in opposition to this is the realisation that people living with a disability are often isolated, or even worse, excluded from faith communities, and there are many reported narratives of such experiences. Stephanie O. Hubach states: “People with a disability are generally outside of the body of Christ, or on the fringes of congregational life – marginalised, unappreciated and underutilised.”

Although there is much work to be done in the area of disability theology, it has been researched extensively over the past ten or so years. A testament to this is the broad range of conference themes loosely around disability and inclusion, for example:

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46 Clark Carlton, *The Life: The Orthodox Doctrine of Salvation* (Salisbury, MA: Regina Orthodox, 2000), 19. In this quote, “dehumanizing” refers to the constant stigma that people living with a disability feel on a regular basis; see Chapter Two, section 2.2.


“Divine Story – Human Context”;\textsuperscript{49} “‘Breaking Down the Dividing Wall’: On Difference and Diversity in Disability”;\textsuperscript{50} “Theology, Disability, and the People of God”;\textsuperscript{51} “‘Life in All Its Fullness?’ Theology and Quality of Life”;\textsuperscript{52} “In God There Is Diversity, but Not Division: Building Interfaith Dialogue and Collaboration through Theology and Disability.”\textsuperscript{53}

As a side note, it is my observation and view, as a friend and confidant of many people living with a disability, as well as being a weekly volunteer at a Catholic primary school catering for children living with a disability and at a few L’Arche communities, that it is indeed people living with a disability who are amongst those who have the closest relationships with God.\textsuperscript{54} Similarly, Jean Vanier has published on several occasions that people living with a disability are great teachers in this regard:

People with disabilities have taught me so much over these past forty-two years as we have lived and shared together in L’Arche as friends and companions, as brothers and sisters, as people brought together by God. In fact, they have not only taught me; they have transformed me and brought me into a new and deeper vision of humanity. They are helping discover who I am, what my deepest needs are, and what it means to be human.\textsuperscript{55}

\textsuperscript{49} European Society for the Study of Theology and Disability 2nd Biennial Conference, July 1–4, 2009, Boldern, Switzerland.
\textsuperscript{50} European Society for the Study of Theology and Disability 3rd Biennial Conference, June 29–July 1, 2011, School, The Netherlands.
\textsuperscript{51} Australian and New Zealand Association of Theological Schools Annual Conference, June 1–3, 2013, Auckland, New Zealand.
\textsuperscript{52} European Society for the Study of Theology and Disability 4th Biennial Conference, June 27–30, Lille, France.
\textsuperscript{53} Summer Institute on Theology and Disability 4th Biennial Conference, July 15–19, 2013, Toronto, Canada.
\textsuperscript{54} Swinton and Mowat, \textit{Practical Theology}, 229.
The theological notions of access, belonging and community within the Catholic tradition find their roots in Catholic social teaching. Theologically, there should be no basis for people living with a disability being considered “non-human,” which only stresses the importance of there being appropriate access to the Church and relevant activities and gatherings, and of their feeling as if they belong and are embedded within the Church community. All human beings, regardless of cognitive and/or physical ability, share a common humanity through the Incarnation of Jesus the Christ.\(^56\) As Pia Matthews illustrates: “each human being has a part to play in God’s plan of salvation for humanity.”\(^57\)

For a person living with a disability to feel part of a Church community, he or she must first be able to access\(^58\) the place of worship and feel as if he or she is genuinely accepted into that community.\(^59\) Now, this does not mean being merely included and welcomed by means of physical accessibility\(^60\) (although convenient accessibility provided by the architecture of the church building is obviously important) for, as Matthews argues, “merely removing barriers so that the disabled are included”\(^61\) is not enough. Genuine acceptance goes further than this.\(^62\)

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\(^56\) Yong, *Theology and Down Syndrome*, 157.


\(^59\) Matthews, “Participation,” 428.

\(^60\) By accessibility, I am referring to the aspects of Church life that affect respective parishioners or visitors either physically or materially or both, including the provision, or not, of large-print biblical texts, Braille text, wheelchair ramp access, and large pew spacing.

\(^61\) Matthews, “Participation,” 428.

In the context of this research, it is important to ask the following question, so that the theological critique may be situated more appropriately: Why have people living with a disability been excluded and discriminated against, even within Christian communities, for so long, when this contradicts their own theology of personhood? There are no doubt various answers to this question, including: lack of knowledge around disability and issues faced by people living with a disability; the difficulty of coming to terms with difference; inability and/or awkwardness to communicate or know how to engage with people living with a disability; and the fact that people living with a disability are often seen as a burden on society. Perhaps also people living with a disability may be regarded as having something wrong with them. In response to this position, Dietrich Bonhoeffer makes a very worthwhile observation in his writings, Life Together,\(^{63}\) that “every Christian community must realise that not only do the weak need the strong, but also that the strong cannot exist without the weak. The elimination of the weak is the death of fellowship.”\(^{64}\)

At various points of the qualitative interviews, as well as in the literature that has been surveyed throughout this research, there have been a number of stories in which people living with a disability (along with their families and carers) have not felt as though they belong in a Church community.\(^{65}\) Therefore, people living with a disability are seen as not being the same as “able-bodied” people and as being in need of special treatment. As argued earlier, this attitude seems to be driven by a lack of understanding of what

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65 See especially Interviewee 4: Melinda.
disability is, or perhaps it is driven by outdated and/or preconceived ideas that align with the Medical Model of disability.\footnote{See Chapter Two, especially section 2.2.1.} For example, one of the interviewees, Melinda offered the following reflection: “But a lot is to do with attitude. It’s all to do with attitude and not being aware or understanding what the issues are. So it’s lack of understanding.” (Interviewee 4: Melinda) Furthermore, the following reflection from Greg was offered:

\begin{quote}
Bishop [. . .] always uses a wonderful example of a jigsaw puzzle and he says, you know, “You only have to have one piece, if you have a jigsaw puzzle of 100 pieces and 1,000 pieces, if there’s just one piece missing it’s not complete. You look at it and you know immediately there’s something wrong with this picture and it’s only one tiny little piece” and he says, “It’s the same for people – for parishes. If there’s a person in the community who wants and desires to be a member of that parish community – an active member of that parish community but they can’t because of barriers that are there then that parish is not complete” and I think that’s a wonderful example. (Interviewee 6: Greg)
\end{quote}

In order to achieve the full participation of people living with a disability, “a shift of mindset needs to occur from service for people living with a disability to service \textit{with} people living with a disability.”\footnote{Cristina Gangemi, “A Place to Belong: Stewards in a Human Story” (available from c.gangemi@abdn.ac.uk).} An essential ecclesiological function of the Church is to create and foster a sense of community. Vanier defines community as “a place where communion is made manifest and where we grow in communion. To be a true community we must, from time to time, come together and share something personal, something of ourselves.”\footnote{Jean Vanier, \textit{Signs of the Times: Seven Paths of Hope for a Troubled World}, trans. Ann Shearer (London: Darton, Longman and Todd, 2013), 95.} Vanier established L’Arche as a prime model of community
and participation for core members, assistants, volunteers and other members of the community to be together equally, where no-one is superior to the other.

The community life we live at L’Arche with people who are weak is rooted in simple, material things: cooking meals, spending time together at table, washing the dishes, doing the laundry and the housework, helping meetings to go smoothly, organizing the house so that it is a happy, welcoming place: thousands of little things that all take time.

We hear from one of the interviewees, Melinda, who illustrates a fine example of a person living with a disability participating as a valued member of her Church community: “you would want your people, families with disability and the siblings and all of that, to be participating in and ensuring they do the communion, take the communion up. Or take the money. It doesn’t matter what it is. The altar service, you know? [A lady] has shown me many a video of people with Down syndrome being altar service [sic]. It’s absolutely marvellous. I mean, 20 years ago, it wouldn’t have been heard of. So those sorts of things. Those participatory things. For everyone to participate and be included, treated with equity.” (Interviewee 4: Melinda)

Some theologians, including some who are external to those researching specifically in disability theology, argue that the Church must be more inclusive, using the Christian Scriptures’ portrayal of Jesus the Christ’s life and ministry as a model. This is

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69 A core member is a person who lives with a disability and who lives in the L’Arche community.


significant and highlights the intersections between theological reflection and disability. Further, it speaks volumes about the current state of play and the importance of including people living with a disability into our faith communities.

1.6. SURVEY OF A NUMBER OF THEOLOGIANS WHO HAVE EXPLORED DISABILITY THEOLOGY

Theologians researching disability do so from varying theological perspectives. Indeed, there are systematic theologians, biblical scholars, liturgists and ethicists, as well as natural and practical theologians, researching disability from a theological perspective. It goes without saying that other professionals, such as anthropologists, sociologists, physicians and psychologists, are researching disability according to their own disciplinary perspectives. As is the case with all disciplines, theologians come to their research from different standpoints, including in this case, different religious standpoints. Even Christian theologians come from differing Christian denominations, while there are theologians coming from a range of different religious belief systems and/or spiritualities, with sometimes opposing influences and intentions. It is the researcher’s aim to highlight some of these different approaches to disability theology, and then to focus on a sample of renowned theologians who have explored the issue. Furthermore, the sample of renowned theologians throughout time include: St Thomas Aquinas, an eminent medieval theological ‘voice’, to Karl Rahner, a prolific Catholic theologian from the 20th century, to more contemporary theological perspectives in Jean Vanier, Hans S. Reinders, Stanley Hauerwas, John Swinton, Brian Brock and Amos Yong. It is noted that some of the material covered in this section is dated,
although it would not be reputable to investigate their work without interrogating their primary sources. As mentioned above, the next section will introduce various theologians, from different eras and perspectives, who have explored disability theology.

1.6.1. ST THOMAS AQUINAS

St Thomas Aquinas is one of the most prominent theologians in the Catholic tradition; however, “his influence and importance is by no means limited to the Catholic tradition, and the last generation has seen a new flowering work drawing on Aquinas from across the spectrum of Christian theological traditions.”\textsuperscript{72} It would be timely to note here that Aquinas’ theological anthropology and morality has enduring significance today. Aquinas is considered a pioneer of natural theology in Christianity and he felt closest to God “out in the world,” as distinct from exclusively in revelation, such as Scripture. It was Aquinas’ view that the more we understand life, the more we will understand God. It is evident from a close reading of Aquinas that our contemporary understanding of disability is not specifically explored; \textsuperscript{73} Aquinas does, however, “address questions of human impairment at all levels.”\textsuperscript{74}

\begin{flushright}
\textsuperscript{73} Aquinas does not specifically mention the word “disability” in his works, similar to the Scriptures; however, Aquinas does mention “impairment” and “corporeal infirmity.” “Corporeal infirmity,” according to Aquinas and as defined by Miguel J. Romero, is “when a body has been rendered weak by damage, dysfunction, or decay.” (Miguel J. Romero, “Aquinas on the \textit{Corporis Infirmitas}: Broken Flesh and the Grammar of Grace,” in \textit{Disability in the Christian Tradition: A Reader}, ed. Brian Brock and John Swinton (Grand Rapids, MI: William B. Eerdmans, 2012), 103.
\textsuperscript{74} Berkman, “Persons,” 96.
\end{flushright}
According to Aquinas, “all human beings are somewhat impaired.” It is almost certain that all human beings will experience disability at some moment of their lives, either directly or indirectly. Aquinas emphasised that God does not directly impose physical or intellectual disability on any individual, but rather, “they become part of the human condition as a result of original sin.” After a close reading of Aquinas and a number of notable and specialist Thomist scholars, it seems that Aquinas was more concerned about “moral and spiritual impairment than about mental or physical impairment.” Furthermore, Aquinas avoided using the Ancient Greek method of “evaluating the character of the person by their physical features.”

The burning question that remains (considering that Aquinas draws on Aristotelian thought) concerns how an individual living with a disability, especially someone living with a profound cognitive disability that forbids capacity for rationality, receives salvation. This is in the context of noting that the common Christian path to salvation is a close relationship with God along with living a just and righteous life. In summary, as Olsen states: “Thomas may have been controversial during his lifetime, but later he would be named the Angelic Doctor by the Catholic hierarchy, and his theology would become the norm for all Catholic thought. Every Catholic theologian in good standing with the Church is some kind of Thomist.” Aquinas provides a methodology by which God’s revelation can be encountered in the natural world – a creature, by its very existence, is already giving glory to God. This provides a rich opportunity for exploring

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75 Berkman, “Persons,” 84.
77 Berkman, “Persons,” 84–85.
78 Berkman, “Persons,” 85.
79 Berkman, “Persons,” 86.
80 Olsen, God in Dispute, 197.
how someone living with a profound disability may still experience and enters into relationship with God, thus providing an important avenue for a theology of disability.

1.6.2. KARL RAHNER

Karl Rahner is one of the most eminent theological thinkers of the twentieth century; in fact Karen Kilby describes Rahner as “one of the giants of twentieth-century theology.” Rahner was a German Jesuit priest who wrote extensively on a broad range of theological themes in fundamental theology, including soteriology, eschatology, transcendental Christology and theological anthropology. His most notable publications, *Foundations of Christian Faith* and *Theological Investigations*, are still widely used in seminaries and theological institutes today, having been published some thirty or more years ago, and his writings had a significant impact on how the documents of the Second Vatican Council were formed. It is difficult to summarise Rahner’s contribution to theology in such a short space, and Kilby warns against doing this due to the “recurrent and to some degree interlocking, elements in his thinking.”

It is through Rahner’s theological anthropology that we find his reflections on disability, as we describe it today. Rahner often reflected on profound theological anthropology questions, such as: What does it mean to be human? What does it mean to be created in God’s image? Rahner’s understanding of theological anthropology lies in the mystery of

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84 Kilby, “Rahner,” 97.

God: “A person knows explicitly what is meant by ‘God’ only insofar as he allows his transcendence beyond everything objectively identifiable to enter into his consciousness, accepts it, and objectifies in reflection what is already present in his transcendentality.”

William Waldron explores the work of Rahner and the notion of loneliness among people living with a learning disability in his doctoral dissertation, “‘I Came that They May Have Life, and Have It Abundantly’: Reimagining Life-Giving Responses to the Problem of Loneliness among People with Learning Disabilities.” Waldron states: “we need to understand what it means to be human in the eyes of God who created us, God’s desire for his creation, and how we should respond to the mystery that we are God’s people in the ‘concrete.’”

Rahner’s emphasis on the human person as always-already in relationship to God, regardless of rational understanding of this relationship, provides another fruitful avenue of investigation or foundation for creating a theology of disability.

1.6.3. JEAN VANIER

At the time of writing this thesis, Jean Vanier is residing in the grounds of the original L’Arche community in Trosly-Breuil, just north of Paris, offering retreats and

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86 Rahner, Foundations, 44.
87 William Waldron, “‘I Came that They May Have Life, and Have It Abundantly’: Reimagining Life-Giving Responses to the Problem of Loneliness among People with Learning Disabilities” (PhD thesis, The University of Aberdeen, Scotland, 2012).
88 Waldron, “I Came,” 183.
89 “L’Arche” is French for the word “ark.”
supporting the work of L’Arche Internationale. Vanier is arguably the most notable Catholic working in the area of disability and one of the most prolific philosophers and theologians of the current era.\textsuperscript{90} Vanier is known internationally for establishing the L’Arche communities,\textsuperscript{91} and is widely respected for his scholarship as well as for his practical work. His actions speak louder than words. Apart from his many accomplishments, he has previously been nominated for the Nobel Peace Prize; in 2013, he was awarded the \textit{Pacem in Terris} Peace and Freedom Award; in 2015, he was awarded the Templeton Prize; and he has received other awards too. Vanier was awarded the Templeton Prize for his “advocacy of belonging and social justice”\textsuperscript{92} and was described in the most positive terms:

By recognizing the importance of every individual, regardless of their station in life, Jean Vanier underscores how each of us has the ability not only to lift up others, but also ourselves. His powerful message and practice of love has the potential to change the world for the better, just as it has already changed the lives of countless individuals who have been touched by this extraordinary man.\textsuperscript{93}

Vanier has published extensively on a range of different themes and concepts, including, but certainly not restricted to: community, Christian spirituality, peace, friendship and, of course, the establishment and stories of L’Arche. His most notable publications include \textit{Community and Growth},\textsuperscript{94} \textit{I Meet Jesus: He Tells Me “I Love


\textsuperscript{91} See Jean Vanier, \textit{An Ark for the Poor: The Story of L’Arche} (Toronto: Novalis, c.1995) for more details on the L’Arche communities.


\textsuperscript{93} Templeton Prize, “Current Winner.”

You”: Story of the Love of God through the Bible, I Walk With Jesus, From Brokenness to Community: The Wit Lectures, Becoming Human, and Befriending the Stranger to highlight all but a few of his most notable publications, some of which have been translated into twenty-nine languages. Vanier has had a lasting impact on a number of notable people, including especially Henri J. M. Nouwen, who lived in a number of L’Arche communities throughout his lifetime and is known for his spiritual classics.

L’Arche is an international web of communities with a universal mission to foster and build unique relationships between people living with a disability and people living without a disability. In 1964, the L’Arche communities were founded by Vanier and a few friends in Trosly-Breuil, France. The L’Arche communities were originally established in the Catholic tradition; however, the communities have taken on a new form in our secular, pluralist and globalised world and, in doing so, have spread across the world, branching into thirty diverse countries with an ever-growing community base and “despite this emerging diversity, all the communities remain united around

100 Henri J. M. Nouwen has not perhaps been as prominent as Jean Vanier; however, Nouwen was a close friend of Vanier’s and his most notable works include: The Road to Daybreak: A Spiritual Journey (New York: Doubleday, 1988); The Return of the Prodigal Son: A Story of Homecoming (New York: Doubleday, 1992); and Adam: God’s Beloved (Maryknoll, NY: Orbis Books, 1997).
101 Michael Hryniuk, Theology, Disability, and Spiritual Transformation: Learning from the Communities of L’Arche (Amherst, NY: Cambria, 2010), 92–93.
the knowledge that the humanising contribution of people with an intellectual disability to our societies becomes apparent in mutual relationships.”

The story of L’Arche’s formation is unique in the sense that, one day, Vanier opened the doors of his own house and welcomed three severely intellectually disabled men, Raphael, Philippe and Dany, “and so, the adventure of L’Arche began.” How such a small gesture – Vanier opening his door to Raphael and Philippe – can transform the way people living with a disability are cared for in the Church is extraordinary; and this has guided the very mission of L’Arche over the past fifty-odd years, that is, for communities to open their doors and nurture and support people living with disability and their respective families and/or guardians. As Cushing and Lewis suggest: “it [L’Arche] is generally a safe place in which people with disabilities can live, grow, and from which they can step forward as they choose.” This is accomplished by operating, under the leadership of a Community Leader, houses where people living with a disability live together in a communal nature, participating in activities such as prayer sessions, crafts and picture boarding, and where a community would compile a list of words relating to their own experiences. Vanier notes that:

105 In Australia, L’Arche has established fourteen community houses and two friendship networks. The community houses are spread across the major cities and regional centres. There are three houses in Sydney, two in Brisbane, five in Canberra, three in Hobart and one in Melbourne. The friendship networks are located in the Hunter region (New South Wales) and Perth (Western Australia). For further information on L’Arche in Australia, see L’Arche Australia, “Who We Are,” 2014, accessed February 1, 2015, http://www.larche.org.au/.
the community life we live at L’Arche with people who are weak is rooted in simple, material things: cooking meals, spending time together at the table, washing the dishes, doing the laundry and the housework, helping meetings to go smoothly, organizing the house so that it is a happy, welcoming place: thousands of little things that all take time.\textsuperscript{108}

Vanier believes that the theology of disability is primarily about creating genuine places of belonging,\textsuperscript{109} and then, “community life becomes a school of love.”\textsuperscript{110} This is a similar view to that held by John Swinton, who will be introduced below. Vanier states:

belonging is the place where we grow to maturity and discover what it means to be human and to act in a human way. It is a place we need in order to live and to act in society in justice, in truth, without seeking power, privileges and honours for our own self-glory. It is the place where we learn to be humble but also audacious and to take initiatives in working with others. It is the place where our deepest self rises up into our consciousness and so we become more fully ourselves, more fully human.\textsuperscript{111}

Vanier’s theology is radiated through stories and actions, “which offer nuggets of wisdom about the beauty of disabled lives, the meaning of human relationships-in-community and the love of a God who values vulnerability and weakness.”\textsuperscript{112} Throughout his writings, “the way of the heart”\textsuperscript{113} (the idea of putting people first; above their abilities and disabilities)\textsuperscript{114} is often repeated, and this is significant to his theology of disability.

\textsuperscript{110} Vanier, \textit{Heart of L’Arche}, 57.
\textsuperscript{111} Vanier, \textit{Becoming Human}, 59.
\textsuperscript{113} Vanier, \textit{Becoming Human}, 88-91 and Swinton, “Jean Vanier: An Embodied Theology”.
\textsuperscript{114} Vanier, \textit{Becoming Human}, 88.
1.6.4. HANS S. REINDERS

At the time of writing this thesis, Hans S. Reinders is Bernard Lievegoed Professor of Ethics and Mental Disability at the Free University of Amsterdam. Reinders has published widely in the area of theology, ethics and disability. Although his book, Receiving the Gift of Friendship, should not be discounted, his chapters “Being Human” and “Being Disabled II” are particularly relevant to this research project.

Reinders indicates that the Catholic position on being human can be shown to be a mixture of Eberhard Schockenhoff’s theology of genesis, as origin, and the Greek term telos, translated as “the end.” Reinders addresses the belief emanating from the Aristotelian-Thomist tradition that suggests one can be fully human only if one has a developed capacity to reason and intellect. This then may lead to a conclusion that people living with a disability cannot be regarded as “fully human beings.” Boethius, a sixth-century thinker held a similar viewpoint whereby a human being is naturae rationali sindividua substantia (or rationalis individua), Latin for “an individual substance of a rational nature.” Once again, one may pose the question, how do people living with a disability fit into this paradigm?

In responding to this question, Reinders anchors his theorising in the day-to-day context of the Church community and stresses that the Catholic tradition has many significant

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116 Eberhard Schockenhoff is a German Catholic priest and Professor of Moral Theology in Freiburg and his landmark publication is: Eberhard Schockenhoff, Natural Law and Human Dignity: Universal Ethics in a Historical World, trans. B. McNeil (Washington, DC: Catholic University of America Press, 2003).
117 See Schockenhoff, Natural Law, 12.
118 Reinders, Receiving the Gift, 92.
119 Reinders, Receiving the Gift, 94.
unanswered questions relating to the inclusion of disabled persons in the Church community, namely how one with an intellectual disability “participates in our final end as a human being”¹²⁰ or, as Aristotle puts it, “The perfection of its own nature is the end of every object.”¹²¹ In response, Reinders uses the writings of Pope John Paul II to suggest that human beings are “called to the ‘fullness of life.’”¹²² All human beings are born onto this Earth to share God’s abundant grace and mysteries, and may share in the fullness of life regardless of intellectual capacities.

The crux of Reinders argument is clearly evident in the word “gift”; hence its inclusion in the title of his ground-breaking book, *Receiving the Gift of Friendship.* He states:

> Approaching the question theologically [that is, how do individuals with intellectual disabilities achieve the status of being “fully human,” when they do not have developed capabilities of reason and will?] this explanation suggests, at least mitigates the problem of undeveloped capacities, since the ultimate end of human life is clearly not dependent on them, but is a gift – an unexpected and undeserved gift.¹²³

Reinders’ theology of disability suggests that inclusion needs to be received as much as it is given,¹²⁴ and how the nature of friendship develops our understanding of what inclusion should look like.¹²⁵

¹²⁰ Reinders, *Receiving the Gift*, 92.
¹²³ Reinders, *Receiving the Gift*, 97.
1.6.5. STANLEY HAUERWAS

At the time of writing this thesis, Stanley Hauerwas is Gilbert T. Rowe Professor Emeritus of Divinity and Law and a Senior Research Fellow at the Duke University Divinity School, Durham, North Carolina, United States of America, and has a personal chair in Theological Ethics at The University of Aberdeen, Scotland. Hauerwas has published extensively on a broad range of theological topics, including: Christian ethics, biblical theology, systematic theology and disability theology. He is renowned for interweaving his theological research with the humanities and social sciences, and is often introduced as “one of the finest theologians of our time.”

Many general readers will assume that he writes strictly in systematic theology and ethics; however, his interest in disability spans over forty years – from well before disability theology came to greater prominence in the early 2000s. His most notable publications in the area of disability theology are: Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church, Christian Existence Today: Essays on Church, World, and Living in Between, Hannah’s Child: A Theologian’s Memoir, and his collaborative works with Jean Vanier, such as Living Gently in a Violent World: The Prophetic Witness of Weakness.

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127 See Stanley Hauerwas, Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church (Notre Dame, IN: Notre Dame University Press, 1986).
There is no doubting that Hauerwas is influenced significantly by Jean Vanier and his writings.¹³¹ A testament to this is his ongoing collaborations with Vanier and the way Hauerwas emphatically praises the work of the L’Arche communities, claiming they are vehicles of peace: “By seeing the realization of peace in the communities of L’Arche, we are better able to see and enact peace in our own lives.”¹³²

God’s face is in the face of the retarded [sic]; God’s body is the body of the retarded [sic]; God’s being is that of the retarded [sic]. For the God we Christians must learn to worship is not a God of self-sufficient power, a God who in self-possession needs no one; rather ours is a God who needs a people, who needs a Son. The Absoluteness of being or power is not a work of the God we have come to know through the cross.¹³³

Hauerwas’ theology of disability is built on the premise that people living with a disability, especially a profound intellectual disability, do not require “special justification”¹³⁴ – all people, regardless of their abilities, are “gifts bearing gifts”.¹³⁵

1.6.6. JOHN SWINTON

At the time of writing this thesis, John Swinton is Professor of Practical Theology and Pastoral Care at The University of Aberdeen, Scotland. Swinton brings a pastoral dimension to his writing, somewhat unique among the writers around him. This is

¹³³ Hauerwas, Suffering Presence, 178.
¹³⁵ Swinton, “The Importance of Being,” 519.
perhaps due to his being a Church minister and having experienced working with people living with a disability, and to his being a registered nurse and mental health chaplain. In his journal article, “Building a Church for Strangers,” Swinton develops his study based on personal experience to explore society’s unjust attitudes toward people living with a disability.136 More particularly, he integrates his relationship and close friendship with Stephen, “a young man who has Down’s [sic] syndrome,”137 who “keeps on smiling in the face of circumstances that would defeat most of us.”138 Swinton initially questions why society and the Church “frequently place reason, intellect and rationality above emotion, intuition and experience.”139 By drawing on real-life case material, Swinton raises the importance of daily social interaction. He highlights the hopes, the dreams and the aspirations shared by all peoples.

Moreover, Swinton stresses that people living with a disability, like Stephen, constitute the ideal example of a human being living in communion with God.140 Interlinked with the literature explored earlier, Swinton’s critique sharply analyses the society around the disabled person; he targets society as having the learning disability, rather than Stephen.141 It is at this intersection that Swinton questions his own faith.142 In summary, Swinton stresses the importance of being able to be loved:

141 Swinton, “Building a Church,” 27.
people are people. And that to be human is to be loved. It’s not to have capacities, it’s not to do or not do something; it’s to be able to be loved. Disability in all of its forms is simply another way of being human. ... Once you learn about people with disabilities, you realize they’re no different from yourself. You could get rid of the term “people with disabilities” and just talk about people.143

As it will be argued in Chapter Five, Swinton stresses the importance of “naming things properly.”144 Swinton contextualises this for us with an example of a person living with schizophrenia: “The problem is that once you have a diagnosis that becomes your name. And as soon as you’re schizophrenic, you’re on a really strange social tangent, not because of the way that people see and understand that particular name.”145 Swinton uses the example of a psychiatrist and how psychiatrists are constantly diagnosing people with various mental health illnesses and other related forms of disability.146 A problem arises once the diagnosis comes – the diagnosis becomes a label and then the label takes over one’s life. Affording a person with a label means that his or her story gets lost and it is difficult to understand anything other than the label. Swinton speaks positively about the L’Arche model, whereby everyone has a chance to tell his or her story and labels are often forgotten!147

Swinton (with Vanier) stresses the importance of moving beyond mere inclusion, to creating communities of belonging: “for a person to be present, they need to be

144 Swinton, “Time, Hospitality.” See also Vanier and Swinton, Mental Health.
145 Swinton, “Time, Hospitality.”
146 John Swinton, “Spirituality and Disability: Vulnerability, Dependency and Interdependency” (paper presented at the Australia L’Arche Jubilee Conference, Parkville, VIC, October 2-4, 2014). I do not intend here to blur the lines between mental health and disability: they are two different things.
147 Swinton, “Spirituality and Disability.”
missed,” or “To belong you need to be missed. To belong others need to long for you like the Prodigal Son’s father as he anxiously surveys the horizon, searching eagerly for signs of his son.” The notion of creating communities of belonging is central to Swinton’s theology of disability.

1.6.7. AMOS YONG

At the time of writing this thesis, Amos Yong is Dean of the School of Divinity and J. Rodman Williams Professor of Theology at Regent University in Virginia Beach, United States of America. Yong is an American Pentecostal theologian who has published extensively in the areas of Pentecostal theology, interfaith dialogue, political theology and disability theology. His most notable publications relating to the theology of disability include: *The Bible, Disability and the Church: A New Vision of the People of God,* Theology and Down Syndrome, and “The Virtues and Intellectual Disability: Explorations in the (Cognitive) Sciences of Moral Formation.”

It must be noted that Yong’s interest in disability theology developed from his relationship with his brother, Adam, who was born with Down syndrome. Yong

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148 Swinton, “Interview.”
149 Vanier and Swinton, *Mental Health.*
150 It is appropriate to mention how close Swinton’s theology of disability mirrors that of Vanier’s, see especially Swinton, “Jean Vanier: An Embodied Theology”.
152 Amos Yong, *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco, TX: Baylor University Press, 2007).
154 See Yong, *Theology and Down Syndrome,* particularly the preface, for a detailed account of his relationship with his brother, Mark.
comes from the Christian Pentecostal tradition and introduces the term “Disability Enabling Theology,” which challenges people that “the way we read biblical texts, not the Bible itself, is what causes us to marginalize persons with disabilities.” Yong is constantly inspiring faith communities to become more inclusive of people living with a disability.

1.6.8. BRIAN BROCK

At the time of writing this thesis, Brian Brock is Reader in Moral and Practical Theology at The University of Aberdeen, Scotland. Among other theological topics, Brock has published extensively in the area of disability theology and his key publications include: Theology, Disability and the New Genetics: Why Science Needs the Church (edited with John Swinton), Disability in the Christian Tradition: A Reader (edited with Swinton), and “Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ”. Brock states that he was: “involuntarily thrust into the world we today call disability” through the birth of his first son, Adam, who was born with Down syndrome – a similar situation to Yong, whom we mentioned above.

155 Yong, “Disability Enabling Theology.”
156 Yong, Bible, Disability, back cover.
157 See Yong, Bible, Disability.
162 Brock, “After Dark.”
Brock’s approach to disability theology is borne from an underlying premise of seeking to discover the meaning of faith in practical life. Brock argues that St Paul’s account of the Body of Christ as depicted in 1 Corinthians 12 has become a key focus for theologians looking to define inclusion theologically. Throughout his writings, Brock reminds his readers that humans are dependent on others.

1.7. SUMMARY OF THEOLOGICAL CONTRIBUTIONS

As alluded to earlier, disability theology has gained significant momentum over the past ten years, and one of the main reasons for this has been the growing number of contemporary Christian theologians (and philosophers) interrogating “key writings on disability by thinkers from all periods of Christian history.” In the preceding section, we have surveyed a number of different approaches to disability theology and how eight renowned theologians, namely Aquinas, Rahner, Vanier, Reinders, Hauerwas, Swinton, Yong and Brock have explored the theology of disability. In the landmark book, Disability in the Christian Tradition: A Reader, the editors and their collaborators offer a more comprehensive account of what key theologians and philosophers from the Christian tradition, including the early fathers, St Augustine, St Thomas Aquinas, St Julian of Norwich, Martin Luther, John Calvin, Georg Hegel, and others, have contributed to the field of disability theology.

165 Brock and Swinton, eds., Disability in Christian Tradition, back cover.
166 See Brock and Swinton, eds., Disability in Christian Tradition.
169 See Romero, “Aquinas on Corporis Infirmitas.”
Soren Kierkegaard, Willem Van den Bergh, Dietrich Bonhoeffer, Karl Barth, Sarah Coakley, Nancy Eiesland, Rosemary Radford Ruether, Jean Vanier and Stanley Hauerwas have said about disability.

Although it is outside the scope of the thesis, it is important to note that other religious traditions, including Judaism, Islam, Buddhism and Hinduism, are

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179 See Bennett, “Women, Disabled.”
180 See Bennett, “Women, Disabled.”
181 See Reinders, “Being with the Disabled.”
182 See Swinton, “The Importance of Being, 512–45.
184 See Mohammad Ghaly, Islam and Disability: Perspectives in Theology and Jurisprudence (London: Routledge, 2010); and Kristina Richardson, Difference and Disability in the Medieval Islamic World:
investigating the topic of disability and how this phenomenon is “lived out” within the sacred texts, histories, narratives, laws and ethics of these traditions. The researcher and others believe that by religious traditions investigating the nature of disability from their own religious perspective, the issue will receive the wider attention that it deserves.

1.8. A BIBLICAL BACKGROUND AND DISABILITY

It is important to acknowledge that, in order for the Scriptures to be studied at doctoral level, one needs to be competent with the biblical languages and equipped with a particular set of intricate methodologies and skill sets. Although the researcher has not studied Scripture at doctoral level, a brief look at how disability is perceived in the Scriptures is important for this inquiry. It is significant to note the number of biblical scholars who are researching disability as portrayed throughout the Scriptures,


189 Clarke, review of Islam and Disability, 355.
Whilst disability is never considered systematically in the Scriptures, nevertheless the theme of “disability” appears through references to illness, blindness, leprosy, sickness, disease and paraplegia are common themes of the biblical narrative. Many characters in the Bible are described by their disability, for example, Jacob, Leah, Miriam, and Isaac. As argued by Abrams, Eiesland, Black, Yong and others, disability is overwhelmingly portrayed negatively in the Scriptures. The emphasis is often on healing the disability, rather than on accepting the person and his or her disability, for example: “Jesus Cleanses a Leper” (Luke 5:12-16; Mark 1:40-45); “Jesus Heals a

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194 See Yong, Bible, Disability.
197 Morris, “Church as Sign,” 50; Yong, Theology and Down Syndrome, 20; and Schipper, Disability and Suffering Servant, 14. “Disability” is a “relatively recent construction”, according to Morris, “Church as Sign,” 49.
198 Vanier, Heart of L’Arche, 17.
199 Vanier, Heart of L’Arche, 17.
200 Abrams, Judaism and Disability, 23.
203 Yong, Bible, Disability, 53.
Paralytic” (Luke 5:17-26; Mark 2:1-12; Matthew 9:2-8); “Jesus Heals the Epileptics and Paralytics” (Matthew 4:24); “Jesus Heals on the Sabbath” (John 5:3; 9:1-41); and “Jesus Heals a Blind Man” (Mark 8:22-25). This is the basis of Yong’s book, *The Bible, Disability, and the Church*, where Yong pleads for readers to welcome people living with a disability *just as they are*.205 In some instances, disability is portrayed in the Bible “as a curse and as a result of disobedience, unbelief, and ignorance.”206 This can be seen in Leviticus 26:14-46 and Deuteronomy 28:15ff, where disability is a penalty for disobedience.207 One wonders if these have had at least some influence on why people living with a disability have been treated as “others” and therefore as not worthy of being accepted by the general Church community.

Furthermore, there are numerous instances, within both the Hebrew Scriptures (Old Testament) and Christian Scriptures (New Testament), where “disability” (or equivalent conditions) is referred to in a negative way, for example: “debased mind” (Romans 1:28); “the lame walk” (Matthew 11:5), and “For no one who has a blemish shall draw near, one who is blind or lame, or one who has a mutilated face or a limb too long, or one who has a broken foot, or a hunchback” (Leviticus 21:18-20). On the other hand, there are examples where “disability” (or equivalent terms) is illustrated in a positive way, for example “[Jesus said] ‘When you give a luncheon or a dinner, do not invite your friends or relatives or rich neighbours. But when you give a banquet, invite the poor, the crippled, the lame, and the blind’ ” (Luke 14: 12-14), and “The Spirit of the Lord is upon me, because he has anointed me to bring good news to the poor. He has

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205 Yong, *Bible, Disability*.
sent me to proclaim release to the captives and recovery of sight to the blind” (Luke 4:18-19).

The Hebrew Scriptures also highlight the appropriate ethical conduct one should observe towards people living with a disability. They stress the vital importance of humanity caring for the ill, sick and vulnerable; for instance, “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) and “Cursed be anyone who misleads a blind person on the road” (Deuteronomy 27:18). An argument could also be mounted for specific excerpts in the Christian Scriptures, especially the many examples of Jesus Christ’s ministry for people living on the margins.208 As Yong states: “a disability reading of scripture has religious and even theological benefits beyond the disability community, for instance, St Paul and his literature is beneficial for people living with or without disability.”209 The other point to note here is that the general injunction to protect “the poor, the widow, the orphan” is a paradigm to refer to all vulnerable people.210

1.9. CONCLUSION

In this chapter, the central question “Why would a theologian be interested in disability – from a theological perspective?” has been explored. As part of this, the word “theology” and how we do theology has been investigated, with particular reference to

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208 See Beates, Disability and the Gospel, 48; and Jennie Weiss Block, Copious Hosting: A Theology of Access for People with Disabilities (New York: Continuum, 2002), esp. chap. 7.
natural theology and practical theology. It was argued that the theological notions of access, belonging and community find their roots in Catholic social teaching and there should be no basis, theologically, for people living with a disability to be considered “non-human.” A number of different approaches to disability theology have been surveyed, and the work of several notable theologians who have explored disability theology has been highlighted. Finally, a biblical background to disability has been presented. In the next chapter, the sociological and historical development of disability and related theoretical frameworks will be traced and critically appraised. As it will be outlined in the next chapter, it is possible that there will never be an agreed upon definition of disability – given that people and professions have defined it differently over time. The historical development of disability has brought about a significant change in the way we view disability and the four main developments will be surveyed: (1) the Medical Model of disability; (2) the Principle of Normalisation; (3) Social Role Valorisation; and (4) the Social Model of disability. Nancy Eiesland believes that: “Justice for people with disabilities requires that the theological and ritual foundations of the church be shaken.”211 The next chapter will propose the need for a resolution of the tensions and controversies around the indefinability of disability.

The final words of this chapter go to Cristina Gangemi, who at the time of writing this thesis, is Co-Director of The Kairos Forum, a team of academics and practitioners who facilitate and create opportunities for people living with a disability to be empowered:212

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211 Eiesland, Disabled God, 111.
The theology of disability advocates that within the life and mission of the Church and world, a paradigm cultural shift should occur, from a culture of doing for disabled people to a culture of doing with disabled people and then together towards a common mission of presenting the full and varied image of God to the world.213

213 Gangemi, “Place to Belong.”
CHAPTER TWO: THE DISABILITY DEBATE: LITERATURE REVIEW, TENSIONS AND CONTROVERSIES

2.1. INTRODUCTION

The purpose of this chapter is to critically trace the sociological and historical development of disability and related theoretical frameworks. After discussing the “definability” of disability, there will follow an overview of (1) the Medical Model of disability; (2) the Principle of Normalisation; (3) Social Role Valorisation; and (4) the Social Model of disability. Some considerations will then be offered concerning the reasons for change and its progressive character. The chapter will argue that there will never be a universally accepted definition of disability and will propose the need for a resolution of the tensions and controversies that result. As noted in the Thesis Introduction, the scholars surveyed here will be representative – but not exhaustive – of this field of study.¹

2.2. DISABILITY: IS IT UNDEFINABLE?

The definition of “disability” is widely debated² amongst academics across the world, including among the main proponents of disability studies, such as Michael Oliver.³

¹ An informal discussion between the supervisors of this project and the writer was the method of selecting which scholars to survey. The scholars listed throughout this chapter are surveyed in no particular order, to avoid any biases and/or hierarchical structure.
Colin Barnes, Errol Cocks, Tom Shakespeare, Robert Perske, Sally French, and Wolf Wolfensberger. Those involved in this area of research wrestle with their interpretations and personal insights, attempting to define and recontextualise the precise nature and essence of disability. The range of professions and bodies of research involved is very broad, including psychologists, sociologists, anthropologists, medical practitioners, philosophers, theologians, physicians, political scientists, ethicists, human geographers, and social workers. Moreover, it is evident that the term “disability” is defined in different ways by these individuals and groups from differing


11 Oliver and Barnes, Disabled People and Social Policy, 14.
perspectives, which reflects their differing theoretical backgrounds and presuppositions.\textsuperscript{12}

For example, The American Association on Intellectual and Developmental Disabilities (AAIDD),\textsuperscript{13} as a collective entity, has released/published, to date, eleven editions of its manual on the definition and classification of disabilities.\textsuperscript{14} AAIDD was established in 1876, making it the first professional organisation in the world to research intellectual disabilities.\textsuperscript{15} Its first manual defining and classifying disabilities was released in 1908.\textsuperscript{16} Oliver and Barnes stress "definitions of disabilities are frequently vague, malleable and used interchangeably."\textsuperscript{17} For example, an anthropologist is not necessarily going to agree with the definition a sociologist puts forward, and conversely. Lindsay believes the different positions and contentions\textsuperscript{18} are due to the fact that “disability services [and disability studies] is a very complex area of social policy [and

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\item[13] The American Association on Intellectual and Developmental Disabilities was previously known as The American Association on Mental Retardation.
\item[16] See the American Association on Intellectual and Developmental Disabilities, “FAQ on Intellectual Disability,” 2010, accessed June 30, 2011, http://www.aamr.org/content_104.cfm. The fact there have been eleven editions to date suggests the profound complexities when defining “disabilities.” There may also be new syndromes “discovered.”
\item[17] Oliver and Barnes, \textit{Disabled People and Social Policy}, 14. Additionally, Barnes, Campbell, and Oliver illustrate that “in an effort to overturn traditional negative assumptions and attitudes surrounding disability, organisations controlled and run by disabled people developed definitions and terminology of their own.” (Oliver and Barnes, \textit{Disabled People and Social Policy}, 14; see also Barnes, \textit{Disabled Imagery}; Jane Campbell and Michael Oliver, \textit{Disability Politics: Understanding Our Past, Changing Our Future} [London: Routledge, 1996].)
\item[18] See Deborah Marks, \textit{Disability: Controversial Debates and Psychosocial Perspectives} (London: Routledge, 1999), for a detailed outline of the controversies surrounding the disability world view.
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rife with political contests, both because of the size and diversity of the target population and because of the range of individuals, organisations and governments involved.

Below is a review of the similarities and differences in definitions of “disability,” as proposed by various academics and commentators.

Perhaps a helpful starting point is the observation of Deborah Marks: “Disability studies emerged as an academic discipline out of the pioneering work of disabled scholars and activists, who found that disability, as a socially constructed phenomenon, was not being critically addressed within the traditional academic disciplines.” Such disabled scholars and activists (not necessarily all to be considered ‘pioneers’ of the disability movement as noted by Marks above) have included Michael Oliver, Colin Barnes, Jenny Morris, Vic Finkelstein, Christopher Newell, Paul Abberley, Simon Brisenden, and Mark Sherry, who have been significantly involved in advocating greater inclusion amongst their respective communities.

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19 There exist competing interests concerning the rights and needs of people impacted by disabilities.
21 It is the researcher’s intention here to provide a snapshot of these similarities and differences, in order to gain a wider understanding of the current literature and research in this area. This will then lay the foundations for this research and will be built upon especially in the qualitative research.
22 Marks, Disability, x. Here Marks suggests the need “for a new, cross-disciplinary approach, which drew upon different levels of analysis.” (Marks, Disability, x.)
Historically, especially in Western countries, it is suggested that “disability” had been viewed as the distinction between those individuals who were unable to work and those who were unwilling to work.\(^\text{29}\) Goggin and Newell stated that disability, according to this view, “is something that we would rather not have, do anything to avoid, and try to prevent.”\(^\text{30}\) To this end, Davis stated:

The average, well-meaning “normal” observer feels sorry for that disabled person, feels awkward about relating to the person, believes that the government or charity should provide special services, and gives thanks for not being disabled (as in “I cried that I had no shoes until I met a man who had no feet”).\(^\text{31}\)

However, “throughout the twentieth century, the process of categorisation [of disabilities] has become ever more sophisticated.”\(^\text{32}\) This is mainly due to advances in medical technology,\(^\text{33}\) the emergence of disability studies as an academic discipline, and “the involvement of a seemingly never ending list of professional ‘experts.’”\(^\text{34}\)

### 2.3. THE HISTORICAL DEVELOPMENT OF THE CONCEPT OF DISABILITY: THE MODELS OF DISABILITY AND THEORETICAL FRAMEWORKS

In beginning the mapping of the historical development of the concept of disability, Oliver states:


\(^{30}\) Goggin and Newell, *Disability in Australia*, 23.


\(^{32}\) Oliver and Barnes, *Disabled People and Social Policy*, 14.


\(^{34}\) Oliver and Barnes, *Disabled People and Social Policy*, 14.
Disabled people have existed in all societies and at any given historical period. However, the kinds of disabling restrictions that existed and the experiences of disabled people, both individually and collectively, have varied from society to society and from age to age.\textsuperscript{35}

By examining four models we will be able to get a sense of the historical trajectory of the developing understanding of disability.

2.3.1. THE MEDICAL MODEL OF DISABILITY

The United Nations \textit{Declaration of the Rights of Disabled People} (1975)\textsuperscript{36} emphasised that people living with a disability have an inherent right to respect from others and to enjoy a decent life that is as normal and satisfying as possible. At a time when society’s regard for and definition of disability was being challenged and reconsidered, one commentator noted that “the medical profession constituted an ensemble of power, that is, it either seeks to cure, rehabilitate, or destroy”\textsuperscript{37} and if it was not able to do so, then it sought to “control.”\textsuperscript{38} This stands in stark contrast with the Social Model of disability, which is less prescriptive and more cooperative, as we will see below.\textsuperscript{39}

The Medical Model of disability was at the forefront of disability service provision until the late 1980s and early 1990s. The model “views disability as a problem of the person,


\textsuperscript{38} Meekosha, “Changing Discourses.”

directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals.”  

Disability according to the Medical Model was: “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being,” and the assumption was that people living with a disability always require medical assistance. Roy McCloughry and Wayne Morris extended this further: “[The disability] is a lack, a deficit, an inability, which must be restored by medical or surgical means wherever possible.”

Alternatively, Cocks refers to the Medical Model of disability as “the Clinical Paradigm.” He defines the clinical paradigm as:

a condition which is essentially within the individual, in a manner similar to an illness or disease. The [clinical paradigm] approach is based upon the diagnosis of intellectual disability by highly trained professionals, usually working in a multi-disciplinary context, under the direction of a physician.

This approach was expressed throughout the centuries as “personal pathology.” Furthermore, rather than taking into consideration the myriad of social forces impacting on the individual, society and its growing professions sought to “blame the victim.”

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42 McCloughry and Morris, Making a World, 9.
43 Cocks, Introduction, 10.
44 Cocks, Introduction, 10.
Australia, since the implementation of the *Disability Services Act 1986*, people living with a disability have been viewed as being “different,” “negative and separate” or “objects” of protection, treatment and assistance. Against this view, academics such as Oliver and Barnes, McArdle and Cocks strongly affirm that people living with a disability should be treated as individuals with the normal range of human rights.

People living with a disability were often denied equal access to those basic rights and fundamental freedoms that most non-disabled people take for granted, including, but most definitely not restricted to, healthcare, education, the right to vote, employment, the development of lasting relationships and, in some instances, reproduction and the parenting of children. People living with a disability were simply not allowed to participate in these pursuits, whether subconsciously or (perhaps more often than not) consciously.

Within Australia, from the enactment of the *DSA*, there has been a dramatic shift in disability services that reflects a shift in thinking about the rights of people living with a

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47 The *DSA* was one of the first pieces of legislation passed, acknowledging and defending those with disabilities. It can be heralded as Australia’s first piece of legislation to protect people who live with a disability and who are under the auspices of human service organisations.

48 Mike Duggan, *Confidence and Capacity: Parish Communities Knowing and Supporting People with Disability* (Brisbane: Catholic Archdiocese of Brisbane, 2003), 21.


50 At times, people are viewed as statistics and commodities within an algorithmic trend, rather than respected as human beings.


53 Cocks, *Introduction*, 1. Cocks affirms this by stating: “People with disabilities are people first and foremost. They are developing people in need of social and educational experiences and opportunities, and typical life experiences. They are entitled to be accepted as valued, worthwhile citizens with the associated rights and responsibilities, and able to make a real contribution to their communities.” (Cocks, *Introduction*, 1.)
disability. Additionally, society is progressively emerging from a long era where most people with an intellectual disability were forced to live, socialise and learn in special facilities and institutions separate from and often in isolation from mainstream communities. As Barnes, Mercer and Goffman state: “large numbers of disabled people were ‘put away’ in segregated institutions on the grounds that it was for their own good and to stop them being a burden on others.” In this context, institutions could be understood as special facilities where medical professionals would force people with disabilities to be segregated from mainstream society and to “get better.”

Institutions had long been regarded as the most efficient state-endorsed method of housing people living with a disability – as some would suggest, “warehousing the ‘undesirable other.’” Although many institutions throughout the centuries began with goals that were initially deemed positive for their intended residents, there is evidence to suggest that negative and inhumane treatment were often the consequences of their foundation. Barnes and Mercer state: “institutional regimes were often harsh, and long-term residents were liable to be ‘written-off’ as ‘socially dead’ while awaiting the ends of their lives.” Most routines in these institutions were rigid and production-line

56 Goggin and Newell, Disability in Australia, 124.
like in their delivery and provision, while the recognition of individual needs was virtually non-existent, evidenced by everyone eating the same meal, at the same time, etc., under the constant watchful eye of staff who may have been interested only in the completion of the next set task. After all, it is conformity, rather than flexibility, that is a major requirement of the operation of a large institution. In such a Medical Model involving institutions, we see that there was little to no space for expressions of individuality and/or the exercise of personal rights.

Contact with family, guardians and extended friends was minimal and discouraged, once again in the interests of control. In most instances, families were happy to be relieved of their “burdens.” History has shown that these draconian measures, as described by Cocks, Allen and others, indicate that people living with a disability have been discriminated against, oppressed, and too often denied their basic human rights. Thompson sums it up in the following way: “Disability provide[d] a clear example of

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60 See Marks, Disability, 64, who, according to Sheila C. Hunt and Anthea Symonds, alludes to a “factory production process.” (Sheila C. Hunt and Anthea Symonds, The Social Meaning of Midwifery [Basingstoke: Macmillan, 1995], 139.)
61 See Amos Yong, Theology and Down Syndrome: Reimagining Disability in Late Modernity (Waco, TX: Baylor University Press, 2007), 54.
62 Christopher Williams, Wolf Wolfensberger, Sally French, and Mark Sherry paint a vivid picture of some of the draconian practices evident in institutions across the years. See especially Williams, Invisible Victims: Crime and Abuse against People with Learning Disabilities (London: Jessica Kingsley, 1995); Wolfensberger, Origins and Nature; French, “Institutional and Community Living”; and Sherry, “Hate Crimes.”
63 Cocks and Allen provide examples of practices used by institutions since their introduction. Many were, and still are, considered as necessary treatments, managements and cures for the “patients” within the respective institutions. Most of the practices were used to inflict punishment or to assert superiority and control over the “prisoners.” These practices included hydrotherapy, where an individual was placed in iced water; “territion,” an experience created to terrify or intimidate people; the use of restraining devices, such as straitjackets, bellybands and chains; mass feeding and hosing down; and the use of medications and injections to tranquillise or even end the lives of the “patients.” (Cocks and Allen, “Discourses,” 230–32.)
64 Duggan, Confidence and Capacity, 21.
66 French, “Institutional and Community Living,” 56.
the process of discrimination and its oppressive consequences. Disabilities act[ed] as a social division, dividing one group of people off from the mainstream, thereby creating a minority.”

This “social division” was facilitated through the widespread use of institutions. This then leads to the question of human growth and development. How can anyone, especially someone with a disability, develop physically, cognitively, socially, emotionally, spiritually, if one is continually rejected, oppressed and devalued?

Institutions were also commonly referred to in derogatory terms as “funny farms,” “nut houses,” “psycho centres.”

In addition, several theories of human development, including Jean Piaget’s cognitive development theory, Lev Vygotsky’s sociocultural theory, Erik Erikson’s psychosocial theory, Albert Bandura’s social learning theory, and James W. Fowler’s faith development theory, rely on growth at various stages throughout a

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68 Thompson, Promoting Equality, 107. According to Thompson, people with disabilities confined in institutions are constantly oppressed by these processes of discrimination, namely stereotyping, marginalising, infantilising, welfarism, medicalising, dehumanising, and trivialising. (See Thompson, Promoting Equality, 107–8.)
69 See Hempel, “Impact,” 17–33; and Barnes and Mercer, Disability, 3.
73 See Mooney, Theories of Childhood: An Introduction to Dewey, Montessori, Erickson, Piaget and Vygotsky (St. Paul, MN: Redleaf, 2000).
74 See Crain, Theories, esp. chap. 9.
person’s lifespan, and the nature of institutionalisation is such that this growth does not
occur or is minimal, with very little success in the terms of these theories. Each theory
describes the critical need for close social interaction and intervention to guide and
“coach” all human beings, regardless of their cognitive abilities. There is a need for
nurture and support, as John Bowlby argues.76 This was never a high priority for
institutional life, even though it may have been an original goal for some in the
introduction of this system.

The theorists, either directly or indirectly, highlight the importance that relationships
(especially within the immediate family) and community play within one’s growth and
development. Jardine and Viljoen propose that Erikson’s psychosocial theory is
foundationally constructed on “acquiring new skills and interacting with others.”77
Further, Osche summarises Erikson’s theory in the following way:

Every individual is genetically determined to pass through a sequence of eight
life stages, during each of which he becomes physically equipped and/or
biologically impelled to enter into a new form of social interaction – and each
new form of social interaction affects the development of a specific component
of personality. This means that during each stage a certain personality
component is developing relatively more than other aspects of personality and is
especially vulnerable to internal and external forces.78

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76 See John Bowlby, *Child Care and the Growth of Love*, 2nd ed. (Harmondsworth: Penguin, 1965); John
77 Marlene M. Jardine and Henning G. Viljoen, “Fowler’s Theory of Faith Development: An Evaluative
and Viljoen, “Fowler’s Theory,” 77.
While institutionalisation is widely regarded as an outdated social service system and is less common nowadays, as Johnson states, we still see many people living with a disability in these facilities that are not connected to mainstream living.\(^\text{79}\) Duggan states:

> The voices have needed to grow stronger, because of the long history of people with disability being perceived as so different and so negative, that it was decided they needed a world of their own – separate places to live (institutions), separate schools to attend (special schools), separate places to work (sheltered workshops). It was thought that people with disability needed protection from society and that society needed protection from people with disability.\(^\text{80}\)

Gradually, as will be argued in the following discussion, society is moving to find alternatives for institutions’ inmates and to eradicate these “homes.”\(^\text{81}\) This process is known as deinstitutionalisation and is defined by Barry S. Willer and James Intagliata as follows:

> the reduction in the number of admissions to public institutions, the development of alternative community methods of care, the return to the community of those individuals capable of functioning in a less restrictive environment and the reform of public institutions to improve the quality of care provided.\(^\text{82}\)

Sadly, many of those new living arrangements sometimes mirror what they are supposed to replace. They may in fact become “mini institutions.”


\(^{80}\) Duggan, *Confidence and Capacity*, 21.


There are many reasons that the Medical Model of disability was so prominent until the 1970s. First, there is its historical significance, and its success in many areas, most notably those concerning disease eradication and control, physical impairment\textsuperscript{83} and discoveries of genetic or inherited syndromes. Second, this thesis argues that there was a vested interest in the Medical Model by powerful people and organisations (medical professionals, wealthy individuals and drug companies); hence a strong proliferation. Third, it was a specific and clear model, that is to say, people (including those with disabilities) had a sense of feeling safe and at ease with the idea that they could rely on the explanatory models that it had to offer; and, finally, all people, but especially those with a disability, required documentation that could be supplied only by medical professionals for any number of legal and everyday needs. Indeed, the medical profession constituted the central gate-keeper that determined and legitimated an individual’s access to social services and financial assistance.

While acknowledging these aspects of the Medical Model, there are other considerations, as we have discussed above. According to Alan E. Kazdin: “the unmistakable benefits of eliminating institutionalisation are shared learning opportunities and socialisation processes afforded by schools, work experiences, community integration and community living.”\textsuperscript{84} Moreover, other negative aspects of the Medical Model in relation to disability included: incorrect views around its causes and characteristics; the categorising of people as “abnormal”, dysfunctional, disabled,


inadequate, requiring surveillance and monitoring, treatment or hospitalisation; and a focus on their inabilities or limitations, their alleged deficits, perpetuating and prolonging the views around the “patient”.

The effect was to create an enhanced sense of disability within an individual via a process of continually emphasising and highlighting a person’s incapacities rather than seizing upon what an individual could achieve, such as might result when strengths rather than deficits are highlighted. Although limited, there were some advantages of the Medical Model, including professional treatment with medical training being beneficial in some instances, but even then, it should have been taken as part of a whole and not been the be-all and end-all of the solution.

Indeed, according to the Office of the United Nations High Commissioner for Human Rights, there are four core values of human rights law that are of particular importance to the context of disability and that were not adhered to in the parameters of institutionalisation. They were: the dignity of each individual, who is deemed to be of inestimable value because of his/her inherent self-worth, and not because s/he is economically or otherwise “useful”; the concept of autonomy or self-determination, which is based on the presumption of a capacity for self-directed action and behaviour, and requires that the person be placed at the centre of all decisions affecting him/her; the inherent equality of all people regardless of difference; and, the ethic of solidarity,

which requires society to sustain the freedom of the person with appropriate social supports.⁸⁶

Beatrice A. Wright, Michelle Fine, Adrienne Asch, and Susan Wendell strongly affirm that all definitions of disability must start with United Nations documentation. Wendell states: “The UN definition of disability is widely used and tends to be favoured by disability activists and other advocates of greater opportunities for people with disabilities.”⁸⁷ Furthermore, Wendell provides two reasons why she believes the UN definitions of disability are most favoured.⁸⁸ This means society has an obligation to uphold the right of all individuals with regard to these values, including people living with a disability in institutions, but which cannot and does not happen. In sum, the Medical Model is the product of its own historical context and, whilst it retains some value, it has serious deficiencies. As such, we continue now to consider the Principle of Normalisation.

2.3.2. THE PRINCIPLE OF NORMALISATION

Prior to the implementation of the DSA, disability services were dominated by a Medical Model,⁸⁹ where crucial decisions were made by medical practitioners and other

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⁸⁸ See Wendell, Rejected Body, 13.
⁸⁹ Barnes, Mercer, and Shakespeare, Exploring Disability, 67.
related medical professionals.\textsuperscript{90} Whilst this model flourished in the 1970s, societies across the world saw the need to move away from institutions, where: “many thousands of people with learning difficulties were living.”\textsuperscript{91} We then witnessed the emergence of what is described as “normalisation,”\textsuperscript{92} which aimed to assist people with a disability to live like others in their respective communities; it was the same movement that was behind the emergence of the DSA.

The Principle of Normalisation has its origins in Denmark in 1959 with Nils Bank-Mikkelsen. Its charter is “to enable mentally retarded [sic] people to live in a manner as close to normal living conditions as possible”\textsuperscript{93} and to afford them “the same legal and human rights that all others have.”\textsuperscript{94} This Principle of Normalisation was significantly refined by Bengt Nirje, who thought of the principle as “making available . . . patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.”\textsuperscript{95} Furthermore, he qualified the definition by adding the expectations of “normal rhythms of the day, week, year and life cycle, and normal

\textsuperscript{90} Quite a few people living with a disability were simply told (or forced) to do something at the whim of the medical professionals, such as being incarcerated in institutions or “homes” with little or no rights or consultation with family and carers – no real concern for their health and genuine welfare. This can be compared to a paradigm of “out-of-sight, out-of-mind”. Barnes, Mercer, and Shakespeare also say that “over the last two centuries, disabled people have been kept more ‘out of sight, [out of mind]’ and disability has almost been a ‘taboo’ subject.” (Barnes, Mercer, and Shakespeare, \textit{Exploring Disability}, 37–38.) Harold H. Wilke also suggests that throughout the world, countries have a “history of keeping [disabled persons] ‘out of sight, out of mind.’” (Wilke, “Mainstreaming the Alienated: The Church Responds to a ‘New’ Minority,” 1977, accessed July 15, 2011, http://www.religion-online.org/showarticle.asp?title=1146.)


\textsuperscript{94} de Corte and Weinert, eds., \textit{Encyclopedia}, 73.

\textsuperscript{95} Nirje, “Normalization Principle,” 57.
opportunities to receive the respect of others, live with whomever they choose, live in
typical housing and experience financial security.”

In its earliest form, the Principle of Normalisation acted as a guide for disability service
provision, rather than as a way of offering concrete theoretical frameworks, especially
in Denmark, where it originated. It is important to emphasise that Denmark along with
Sweden committed a large proportion of gross domestic profit to fund such liberating
and forward-thinking programs. Other countries, such as Australia and the United States
of America, were more reluctant to outlay such large amounts. This has had huge effects
and ramifications that are still experienced today.

In 1972, Wolf Wolfensberger proposed an updated definition. Wolfensberger stated:
“Normalization is the utilization of means which are as culturally normative as possible
in order to establish and/or maintain personal behaviours, experiences, and
characteristics which are as culturally normative as possible.” Again, the disability
rights movement was actively advocating change during the late 1960s; it was the initial
force behind the changes to disability service provision and practice. This is suggested
by Swinton and Mowat, who state: “disability rights researchers have challenged this
professional domination of research goals and are calling for disability research which is

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96 de Corte and Weinert, eds., Encyclopedia, 74. The researcher would agree with de Corte and Winert
that the majority of people living with a disability are not afforded the opportunity to “live with
whomever they choose” (de Corte and Weinert, eds., Encyclopedia, 74). Accommodation arrangements
for people living with a disability are often made by a family member or the person’s disability service
provider.
and Michael S. Chapman (Baltimore: Paul H. Brookes, 1980), 39. This quote also appears in Stalker et
99 Note especially the advocacy work of Paul Steven Miller, Tom Shakespeare, Nancy Eiesland, and
many others.
based on the experiences of people with disabilities and has a benefit to people with disabilities.”

Wolfensberger believed that the very disability services that aimed to care, support and empower people living with a disability worked to achieve the exact opposite. Wolfensberger argued: “human services, while having [the] stated aim of providing humane care and treatment, in reality [the human services] segregate and ‘dehumanise’ people.” Herein, there was a notion of “stigma” and shame whereby family and friends ensured appropriate disability services were in place in order to hide their shame and disgrace away in the appropriate institution. As Thomas and Wolfensberger have stated, however, “the devaluing of people who are perceived as different from others in some negative way” was to view them as less than human. Furthermore, “People with intellectual disabilities [we]re likely to be cast, en masse, into particular social roles, [for example] those with learning difficulties having variously been regarded as subhuman, menaces, objects of ridicule or pity, and so on.” From these various debates emerged Wolfensberger’s theories on devaluation of vulnerable people, theories

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105 Stalker et al., “Models,” 7. Note terminology of “learning difficulties” as opposed to “intellectual disability.”
that evolved into the ground-breaking Social Role Valorisation theory,\textsuperscript{106} which is the next topic.

There are a group of scholars, namely Alan Walker, Carol Walker and Stanley Hauerwas, who are critical of the Principle of Normalisation, especially when applied to older people living with an intellectual disability. Walker and Walker state:

\begin{quote}
Is it reasonable to ask what is “normal” for any particular group in society? Is what is regarded as “normal” or widely accepted as such, a desirable optimum or the result of historical development or just a matter of resource constraints? What is “normal” is not necessarily ideal or even appropriate . . . the limitations of the normalisation concept are clearly demonstrated with regard to older people with learning difficulties because the experiences of their reference group – in this case older people – are themselves often limited and restricted by society’s attitudes. Thus, the goals set for older people with learning difficulties and the service responses offered to them will, in turn, be restricted by the socially constructed stereotype of old age as a period of dependency.\textsuperscript{107}
\end{quote}

Moreover, Hauerwas has offered a number of strong theological critiques of the Principle of Normalisation namely that society wanted to “normalise” people living with a disability so that “they [sic] can become part of the agenda of those who basically want to deny the existence of mentally handicapped [sic]”\textsuperscript{108} and this obviously has implications for St Paul’s vision of the Body of Christ.

We now consider Social Role Valorisation as a historical concept and framework of disability.

\textsuperscript{106} See Thomas and Wolfensberger, “Overview.”
2.3.3. SOCIAL ROLE VALORISATION

The word “valour” derives from the Latin valere meaning “to be strong” or “to be well and healthy.”\(^{109}\) The original meaning of “valorise” is to fix and maintain an artificial price for a commodity by governmental action.\(^{110}\) Wolfensberger, who coined the term and developed the theory, meant for it to be “the valuing of the person him/herself.” His reworked new term for normalisation, Social Role Valorisation, was defined as “the enablement, establishment, maintenance, and/or defense of valued social roles for people – particularly for those at value risk – by using, as much as possible, culturally valued means.”\(^{111}\)

Wolfensberger observed that vulnerable people, perceived as devalued and deviant,\(^{112}\) were burdened with “wounds,” equating to rejection, loss of control, impoverishment and brutalisation. From this, he deduced life areas to address these wounds and protect them from this wounding. As a result, he applied “the knowledge generated by the substantial body of study and theory on social roles, role expectancies and role performance to the plight of socially devalued people in a unifying fashion.”\(^{113}\) Furthermore, Social Role Valorisation states “that the two major strategies to counter


\(^{110}\) Michael Duke, personal communication with the researcher, June 8, 2015.

\(^{111}\) Cocks, Introduction, 28.

\(^{112}\) See also Barnes and Mercer, Disability, 3.

\(^{113}\) Thomas and Wolfensberger, “Overview,” 125. See also Barnes and Mercer, Disability, 3.
social devaluation are to enhance the social image of vulnerable people and to enhance their competencies."

Significant for Social Role Valorisation is the pursuit, capture and retention of valued social roles, where no-one’s worth is disparaged or lessened due to disability, so, for example, people living with a disability can make a significant contribution in the workforce. Once accepted by society, Social Role Valorisation powerfully impacts upon the image of an individual in the following ways: status and reputation are enhanced; acceptance from others increases one’s sense of belonging; associations and relationships are increased; there is a new-found autonomy and freedom; personal growth and development occur; opportunities to make contributions with others are facilitated; and the material and financial aspects of life and lifestyle may be engaged.

As stated previously, this has been an extremely important concept for the improvement of living conditions for people with disability, with many new ideas and themes introduced, that, when implemented correctly, greatly benefit such people. We now consider the Social Model of disability.

2.3.4. THE SOCIAL MODEL OF DISABILITY

One of the main reasons why the Social Model of disability\textsuperscript{115} is at the forefront of disability services provision today\textsuperscript{116} is the work and advocacy of a group of people

\textsuperscript{114} Cocks, Introduction, 65.
\textsuperscript{115} There are various academics, such as Shakespeare and Chappell, who believe the Social Model of disability does not fit the current paradigm and should be further updated. See Shakespeare, “Social Model”; Anne L. Chappell, “Still Out in the Cold: People with Learning Difficulties and the Social Model of Disability,” in The Disability Reader: Social Science Perspectives, ed. Tom Shakespeare (London: Cassell, 1998); and Anne L. Chappell, Dan Goodley, and Rebecca Lawthorn, “Making Connections: The
with disabilities in England during the 1960s/1970s. This group was known as the Union of the Physically Impaired Against Segregation, and it began to develop the Social Model of disability. They defined “disability” as “the disadvantage or restriction caused by contemporary social organisations which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.”\(^{117}\) Further, in the late 1980s and early 1990s, Michael Oliver, a pioneer of the Social Model of disability, conceived the problem as “societal and/or attitudinal, or environmental restriction placed upon people with physical and/or mental impairments.”\(^{118}\) He suggested that society disables or impairs people living with a disability, “preventing [them] from exercising their civil liberties.”\(^{119}\) Albrecht and Levy also shared this view:

> We contend that disability definitions are not rationally determined but socially constructed. Despite the objective reality, what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments. Certain disabilities become defined as social problems through the successful efforts of powerful groups to market their own self interests. Consequently the so-called “objective” criteria of disability reflects the biases, self-interests, and moral evaluations of those in a position to influence policy.\(^{120}\)

For the purposes of this thesis, the researcher has subsumed the minority group model of disability with the social model of disability. The minority rights model was

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116 This radical shift from the Medical Model of disability to the Social Model of disability has generally been regarded as “a positive one.” (Wayne Morris, “Church as Sign and Alternative: Disabled People in the Churches,” *Journal of Religion, Disability and Health* 14, no. 1 [2010]: 49.)


119 Gregory et al., *Dictionary*, 178.

developed in the United States of America and was based on a civil rights approach to difference (similar to other civil rights in America such as the African-American Civil Rights Movement). In Australia, as Rachel Carling-Burzacott rightly points out: “Disabled people are a minority group with a long history of struggle for liberation, a history that has been largely overlooked and ignored in historical writings and dominant discourse.”

Further, Carling-Burzacott argues that the minority rights model of disability has had minimal impact within the Australian context:

When contrasted with the impact of feminist and anti-racist movements, the Disability Rights Movement’s achievements in Australia appear to be low key at best. This leads me to question how the Disability Rights Movement can learn from other social movements. This transferring of learning can be facilitated through research.

Munford and Sullivan commented that people’s perceptions cause a social construction of disability that underpins “the discriminatory practices which socially create disabled people.” The Social Model of disability is in obvious direct opposition to the Medical Model, which “sees disability as ‘not normal’ and disabled people as ‘deviant others,’” whereas the social approach sees the disablement of society as the main concern. From this, Oliver stated: “Ironically, that is precisely what the social model insists, disablement is nothing to do with the body. It is a consequence of social

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124 Gregory et al., Dictionary, 179.
125 See Schipper, Disability and Suffering Servant, esp. chap. 1, for an analysis of the Social Model of disability and the Hebrew Scriptures.
oppression.”\textsuperscript{126} It is a phenomenon anchored in social processes and interactions. Additionally, “Culture, therefore, is both a source of oppression and of liberation for disabled people.”\textsuperscript{127}

There are distinct similarities between the Social Model and Social Role Valorisation, which are of consequence to disability service practice.\textsuperscript{128} Both theories “identify and attempt to remove disability barriers; they challenge prevailing assumptions on attitudes; they agree that most of the oppressive and discriminatory treatment . . . is socially ascribed; and both strive to fight oppression and achieve equality.”\textsuperscript{129}

While there is some resistance to the application of the Social Model, possibly because of its confrontation with the Medical Model and the forces that oppose it, it does have achievable goals that can benefit everyone involved, provided that the overbearing mindset shifts and particular barriers are removed.\textsuperscript{130} There are also disability scholars, such as Tom Shakespeare and Nicholas Watson, who believe that “the time has come to move beyond this position”\textsuperscript{131} and criticise the use of the Social Model due to “the issue of impairment, the impairment/disability dualism, and the issue of identity.”\textsuperscript{132} Albrecht succinctly defines disability within the Social Model as the condition of being “disabled

\textsuperscript{126} Oliver, \textit{Understanding Disability}, 35. Michele Moore, Sarah Beazley, and June Maelzer suggest that “disability is socially constructed.” (Michele Moore, Sarah Beazley, and June Maelzer, \textit{Researching Disability Issues} [Buckingham: Open University Press, 1998], 13.)


\textsuperscript{130} This also includes the assumption that rigid support systems are in place and all people have access and control over their own lives and destiny. For a detailed criticism of the Social Model of disability, see Marks, \textit{Disability}, 87–89.


by society, not by our bodies.” Mostert concurs with Albrecht’s view when he states: “At the very core of how persons with intellectual disabilities are viewed and treated, it is the notion of difference that is most problematic.” Further, as Riddell, Watson and Oliver argue:

We now feel that only a critical approach to disability research, rooted firmly in social model discourse and practice, enables a human rights perspective to be given to issues which shape disabled people’s lives. It is only with this approach that research can explore the extent to which fundamental rights, such as equal access to equal opportunities and to full inclusion in society, are recognised and promoted in the face of prejudice and excluding practices. Research which is structured in relation to the social model of disability is not “disabled people blaming” but calls a disabling society to account.

It is worth noting that there have been significant advancements from disability scholars in other models of disability, such as the cultural model of disability where disability functions not as an identification of an impairment or abnormality but rather as a tool of cultural diagnosis. The deaf community for example have developed this model in various ways.

In 1992, the Australian Commonwealth Government responded to vigorous protesting and pressure from disability advocacy bodies and associations to update and renew its disability legislation. Consequently, the Disability Discrimination Act 1992

135 Moore, Beazley, and Maelzer, Researching Disability, 13.
136 See Goggin and Newell, Disability in Australia, esp. chap. 5, “Reinstitutionalising Disability,” 121–39. There is no doubt this pressure was triggered by radical shifts in how disability was understood, particularly the establishment of the Social Model of disability. Some of the disability advocacy bodies are: Advocacy for Inclusion Incorporated, People with Disability Australia Incorporated, and Action for More Independence and Dignity in Accommodation Incorporated.
(Commonwealth Government) \textit{(DDA)} was introduced.\textsuperscript{137} The main purpose of the \textit{DDA} is to “provide protection for everyone in Australia against discrimination based on disability.”\textsuperscript{138} Furthermore, “it encourages everyone to be involved in implementing the Act and to share in the overall benefits to the community and the economy that flow from participation from the widest range of people.”\textsuperscript{139}

This piece of legislation was passed by both Houses of Parliament and received support across all sectors of the political spectrum.\textsuperscript{140} In his recommendation for the legislation to be passed, the then Minister for Health, Housing and Community Services, Brian Howe stated:

\begin{quote}
Our vision is a fairer Australia where people with disabilities are regarded as equals, with the same rights as all other citizens, with recourse to systems that redress any infringements of their rights; where people with disabilities can participate in the life of the community in which they live, to the degree that they wish; where people with disabilities can gain and hold meaningful employment that provides wages and career opportunities that reflect performance; where control by people with disabilities over their own bodies, lives and future is assumed and ensured; where difference is accepted, and where public instrumentalities, communities and individuals act to ensure that society accommodates such difference. Only then will we be able to say that justice has been achieved.\textsuperscript{141}
\end{quote}

The main problem with all four models of disability is that no matter how positive and beneficial they aim to be, they rely on a fundamental commitment to practising and delivering high quality disability services that are “shaped by our values and our vision

\begin{footnotes}
\item[\textsuperscript{137}] Prior to this legislation being passed, the state and territory governments enforced legislation limited to their own jurisdictions, in relation to the protection of those people living with a disability.
\item[\textsuperscript{139}] Australian Human Rights Commission, “D.D.A. Guide.”
\item[\textsuperscript{140}] See Goggin and Newell, \textit{Disability in Australia}, 37.
\end{footnotes}
of the sort of world in which we wish to live.” Further, adequate funding must match the rhetoric, otherwise nothing will substantively change. Real change requires real action and this has funding implications.

From our discussion of disability – its definition and the four models – what is apparent is that the concept and understanding of disability has altered considerably throughout history, but attitudes and perceptions of non-disabled people towards people living with a disability have not necessarily changed. As has been shown, the concept and understanding of disability has moved from a medical/clinical model to a more socially inclusive model. Simpson, and Stalker et al., believe “that ‘medical and institutional’ theories are now generally rejected by those working in community-based services as having little to offer.” Further, Jackie Leach Scully states: “The social model’s most fundamental criticisms of the medical model is that it locates ‘the problem’ of disability in the individual and neglects the social and structural.” We now consider why there has been such a radical shift, and in so doing we will acknowledge the major catalysts for such change.

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142 Cocks, *Introduction*, 89. The following analogy is similar here. Regardless of how well the textbook is set out and written, it essentially relies on the teacher’s pedagogy to deliver, and ensure the students understand, the content. Further, Wayne Morris states: “the problem with any model of disability is that it tends to homogenize the experiences of people with disabilities.” (Morris, “Church as Sign,” 49.)

143 Where people living with a disability are integrated wholeheartedly into mainstream society.


2.4. CHANGE, DEVELOPMENT AND PROGRESS: SOME

CONSIDERATIONS

Cocks, Whitehead, Perske, and Stalker et al. share the common belief that one of the main reasons for the radical shift, as reflected in the evolving pattern of the four models we have outlined, has to do with the after-effects of and responses to World War II. Cocks and Perske point out:

the horrors of world wars, concentration camps and nuclear weapons have led us to the discovery that: all of us have gaps in our minds; all of us are unfinished; some of us can hide our deficiencies better than others; none of us will ever achieve perfection; and those of us who think we are closest to perfection may be most likely to drag the human race to new lows. [Further, Perske] believes that this realisation has contributed to a more accepting attitude towards people who are disadvantaged.

Alternatively, Leach and Ellis argue that the positive sweeping shift has been due to the implementation and success of the disability rights movement across the world. Leach points out: “until then [the establishment of the disability rights movement], disabled people had been largely politically invisible.” It could be

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149 See Perske, Hope, 14.
154 Morris, “Church as Sign,” 49.
156 Leach, “Disabled People,” 89. Moreover, “When disabled people began to assert their rights they often used as their model the theories and tactics of other groups (for example, women, black people, the gay community) that were fighting for political influence.” (Leach, “Disabled People,” 89.)
observed that the “visibility” of those once “politically invisible” is reflected in the emergence of legal advocacy for people living with a disability. This is another factor in the development and progress in the disability area. There are many definitions of advocacy that can be applied to vulnerable and marginalised people.\textsuperscript{157} Robert Adams says it is “the activity of negotiating or representing on behalf of a person,”\textsuperscript{158} while Wolfensberger\textsuperscript{159} adds “in order to promote, protect and defend”\textsuperscript{160} the interests, human rights, well-being and citizenship of that particular person (or group).

Although an individual’s disability may restrict him or her from one or a number of different activities, his or her intellectual ability may be unimpaired, leaving him or her quite capable of determining his or her own destiny.\textsuperscript{161} This points to another influence in changing perceptions, namely, that when human interaction becomes involved, people perhaps tend to perceive people living with a disability differently. Individuals and society in general often forget that people living with a disability are human beings with the same basic rights, feelings, needs and dignity that are afforded to every other individual.\textsuperscript{162} Catholics, in particular, should be mindful that every person has a unique

\textsuperscript{159} Supported by Cocks, Armstrong, and others, while interestingly adopted by the Disability Advisory Council of Australia.
\textsuperscript{160} Wolfensberger, \textit{Principle of Normalization}, 86.
\textsuperscript{161} Cocks, \textit{Introduction}, 1.
\textsuperscript{162} Deborah Selway and Adrian F. Ashman, “Disability, Religion and Health: A Literature Review in Search of the Spiritual Dimensions of Disability,” \textit{Disability and Society} 13, no. 3 (1998): 431. Furthermore, Selway and Ashman argue that, “in some cultures, having a disability was viewed as a distinct liability.” (Selway and Ashman, “Disability, Religion and Health,” 431). See also Martha C. Nussbaum, \textit{Frontiers of Justice: Disability, Nationality, Species Membership} (London: Belknap Press of Harvard University Press, 2006), 15. Nussbaum attacks the social contract theory, especially the Rawlsian tradition. She affirms that the social contract theory enables an unsatisfactory account of justice towards those intellectually disabled (Nussbaum, \textit{Frontiers of Justice}, 16). Further, Nussbaum argues there are two distinctions to be made here in terms of the social contract theory. Firstly, “by who are society’s basic principles designed?” and secondly, “for whom are society’s basic principles designed?” (Nussbaum, \textit{Frontiers of Justice}, 16).
dignity, and therefore, every person has equal rights to be treated in accordance with this dignity, regardless of whether or not a disability is involved.

It is also important to note the radical linguistic shifts in relation to the notion of “disability” throughout history. Here we see society moving towards political correctness when defining “disability.” Although accepted in years gone by, it is not acceptable nowadays to refer to people living with a disability as: “handicapped,” “mental,” “mad,” “deformed,” “defective,” “decrepit,” “hunchback,” “simpleton,” “psycho,” “abnormal,” “cripple,” “spastic,” “retarded,” “mongol,” “idiot,” “mute,” “moron,” or “imbecile.” If these terms were to be used in scholarship today and/or everyday language, they would be regarded as highly offensive and politically incorrect, according to Oliver and Barnes, Mercer and Sztompka. Further, W. Daniel Blair suggests that “labelling often has a debilitating effect on their sense of identity.” It is, however, still common for discourses in England to make reference to “mental retardation” or “mental handicap,” when defining “disability.” This is certainly not accepted language and terminology within the Australian context, as prescribed in the DDA. The DDA states that “it is an offence for a person to commit an

164 Oliver and Barnes, Disabled People and Social Policy, 14.
165 Barnes, Mercer, and Shakespeare, Exploring Disability, 6.
166 Oliver and Barnes, Disabled People and Social Policy, 14.
167 Cocks, Introduction, 41.
168 See Oliver and Barnes, Disabled People and Social Policy, 14.
172 Note particularly the scholarship originating from the United Kingdom, including but not restricted to, that of Oliver, Mercer, and Swinton.
act of victimisation towards another person with the use of language."\textsuperscript{174} In support of this, Walmsley explores the context of linguistics when defining “disability.” She affirms that the concept is heavily influenced by several self-advocacy organisations expressing their preference about how to understand “disability.” She uses the example of “learning disability” throughout the United Kingdom, as influenced by the National Learning Disability Strategy, in comparison with Australia’s reference to “intellectual disability.”\textsuperscript{175}

Cocks integrates this exclusivist viewpoint by suggesting that “idiot, moron and imbecile”\textsuperscript{176} were traditionally the three ways of describing the extent of a disability. Besides, Cocks states “[the terms: idiot, moron and imbecile] now are very outdated and are particularly negative. Unfortunately they still appear in some mental health acts and criminal codes, but rarely nowadays.”\textsuperscript{177} In more recent years, since the early 1990s, as Shakespeare suggests,\textsuperscript{178} societies across the world, including Australia,\textsuperscript{179} have moved to adopt a fully inclusive language, rather than use demeaning terminology.\textsuperscript{180} Furthermore, community organisations focused on empowering people living with a disability, such as L’Arche, stress that: “Respectful terminology to describe the people who are at the heart of L’Arche and for whom L’Arche was founded varies from one

\textsuperscript{175} Walmsley, “Normalisation,” 189.
\textsuperscript{176} Cocks, Introduction, 41.
\textsuperscript{177} Cocks, Introduction, 41.
\textsuperscript{178} Shakespeare, “Disability, Identity,” 103.
\textsuperscript{179} Cocks, Introduction, 44.
\textsuperscript{180} This strongly aligns with how the models of disability have progressed through history, whereby, once again, people living with a disability are viewed as drivers of their own destiny rather than as being at the whim of medical practitioners and other professionals. However, Cocks provides several reasons why Australian disability services have faced “roadblocks” over the years. (Cocks, “Roadblocks,” 75–82.)
country to another.”

The L’Arche community state: “We invite you to substitute the terms used on this website with those that are used and accepted in your society.”

There is also the impact of political activity and the government sector in developments with regard to disability. Since 2007, Australia has been noteworthy in ensuring greater social inclusion for those who are marginalised, vulnerable and frail. This is evident through the Rudd Government’s implementation of a Social Inclusion Board, a Social Inclusion Unit in the Department of the Prime Minister and Cabinet. More notably, there was the associated appointment of a Minister for Social Inclusion and a Parliamentary Secretary for Social Inclusion and the Voluntary Sector. In other words, as Silverstein sums it up: “the government maintained that social inclusion was a whole-of-government agenda.” Furthermore, at the higher education level, a number of Australian universities have acknowledged that social inclusion is an issue that must be addressed. This is through the appointment of senior academics to executive portfolios. Universities have reacted thus in response to the Review of Australian Higher Education (the Bradley Review), in March 2008, by Emeritus Professor Denise Bradley.

In considering the factors contributing to changing perspectives on disability, let us return to how it is named and the implications of recent social, cultural and legal

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182 L’Arche, “L’Arche.”
184 Such as Ms Evelyn Woodberry, Pro Vice-Chancellor (Students and Social Inclusion), University of New England, NSW, among others.
changes on language and attitudes. We noted earlier a variety of definitions. For instance, American philosopher Amundson defines the term “disabilities” as “the absences of basic personal attributes.” 186 Again, Cocks states that a “disability” is “a condition which is essentially within the individual, in a manner, similar to an illness or disease. The condition is seen as originating at, or before, birth in most cases. The condition is likely to be lifelong and incurable.” 187 Several other researchers, including Oliver, Barnes, Mercer, Shakespeare, Swain, Finkelstein, French, Riddell and Watson, affirm that “disability is linked to notions of inequality of power and human interdependence.” 188

Grappling with a definition of “disability” also entails the categories of disability. Disability is not restricted to one type or class. Evolving in understanding means that, in defining “disability,” we need to be clear about what kind of disability we are referring to. One definition will not suit all when we are considering cognitive, intellectual, physical and psychiatric disabilities. 189 It is imperative not to forget the plurality of disabilities existing in today’s society. 190

So, in the light of advances in knowledge, according to Marks 191 and Wendell, there is distinct tension and controversy when “disability” has to be grouped into four broad

187 Cocks, Introduction, 11.
188 Riddell and Watson, Disability, Culture, 6. See also, Oliver, Politics; Oliver, Understanding Disability; Barnes, Mercer, and Shakespeare, Exploring Disability; and John Swain, Vic Finkelstein, Sally French, and Mike Oliver, eds., Disabling Barriers – Enabling Environments (London: Sage, 1993).
189 Cocks, Introduction, 28.
190 The four categories will be critically explored in alphabetical order to avoid any bias.
191 See Marks, Disability, esp. chap. 6, “Causes, Complexity and Process of Categorising ‘impairment,’ ” 114–36.
categories: cognitive, intellectual, physical and psychiatric disabilities. Wendell highlights some of these tensions:

Some of the initial opposition in disability rights groups to including people with illnesses in the category of people with disabilities may have come from an understandable desire to avoid the additional stigma of illnesses[192]. . . people with physical disabilities often insist that they are not mentally disabled [not intellectually disabled], because of the additional stigma of psychological or developmental disabilities in most societies. Nevertheless . . . many people with physical disabilities also have developmental or psychological disabilities.[193]

What Wendell is alluding to here is that it is not uncommon for an individual to walk up to an intellectually disabled person and ask whether they need any assistance. While this is no doubt well intentioned,[194] it can nevertheless be perceived as offensive, as an individual with an intellectual disability does not necessarily have any limitations in completing everyday tasks. Additionally, Mostert believes “judgments of intellectual ability have traditionally been the province of the non-disabled foisted on those with intellectual disabilities either as a way of marginalizing them or as a kind-hearted if somewhat patronising way of assisting and supporting their needs.”[195] Lennox and Diggens make clear that “not all people with developmental disability also have an intellectual disability. For example, cerebral palsy is a developmental disability; however, not all people with cerebral palsy have an intellectual disability.”[196]

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195 Mostert, review of *A Transformatory Ethic*.
Finally, to return to the specific aims of this thesis, it is important here to investigate the connection between demographics, that is, people classifying themselves as “Catholic,” and living with a disability. There is no doubt that religion and/or New Age spiritualities\(^{197}\) play a significant role in the lives of millions of people in Australia and abroad. In fact, the 2011 Australian census states that over twenty-five percent of the population in Australia nominated themselves as being Catholic.\(^{198}\) This statistic, aligned with the demographic data regarding persons living with a disability cited earlier, mean that high percentages of Australia’s population identifying with a religion means that a significant portion of people living with a disability will also have a religious commitment of some sort.

To further support this claim, one just needs to have a close reading of the speech of Bill Shorten, former Parliamentary Secretary for Disabilities and current Leader of the Opposition, which was delivered on April 1, 2009, at the National Press Club in Canberra, titled “The Right to an Ordinary Life.”\(^{199}\) Statistics within that speech included: “[in the Australian landscape] there are approximately 1,145,000 people with either a profound or serious disability – this is similar to that of the population of Adelaide; such a disability affects about 1 in 24 children aged up to 14 years; and over 50 per cent of the 319,000 children with disability have profound or severe core activity

\(^{197}\) David Tacey explores New Age spiritualities in his resource, *The Spirituality Revolution*, to which he ascribes “the worldliness of [one’s] spiritual expression, the refusal of authoritarian styles of religion, and the breakdown of conventional dualities such as internal/external, heavenly/earthly, and spirit/matter.” (David Tacey, *The Spirituality Revolution: The Emergence of Contemporary Spirituality* [Sydney: HarperCollins, 2003], 67–68.)


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To put this into context, in a congregation attendance of one hundred people, you can expect twenty people to have some form of disability.

2.5. CONCLUSION

In this chapter, the sociological and historical development of disability and related frameworks were traced. The term “disability” has been defined differently across the professions and tensions and controversies have arisen out of this. The four main developments in the sociology of disability were surveyed: (1) the Medical Model of disability; (2) the Principle of Normalisation; (3) Social Role Valorisation; and (4) the Social Model of disability. The researcher is aware of other thinkers in the broad interdisciplinary field of disability studies, such as Judith Butler, Martha C. Nussbaum, and Nikolas S. Rose. Owing to space constraints, however, their literature will not be examined in this thesis. To conclude, Don Grimes, a former Australian politician, provides a snapshot into the current thinking of people living with a disability, which encapsulates the essence of this chapter:

In recent years people with disabilities have begun to speak out and be heard in the Australian community, both as individuals and through consumer

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200 Shorten, “Right to an Ordinary Life.”
203 See Nussbaum, Frontiers.
organisations and self-help groups. They have made it clear that they want to be treated as people first – people whose abilities matter more than their disabilities. They do not want to be seen as sick or different and they do not want all decisions to be made for them by other people.\textsuperscript{205}

In the next chapter, the genealogy of disability within the Catholic Church in Australia will be explored, along with several key developments of the Catholic Church in Australia in this area. As it will be argued throughout the thesis that this aspect of research will prove vital when determining whether the Catholic Church in Australia has been or is a strong advocate for people living with a disability. The investigation will include a look at the Australian Catholic Bishops Conference and relevant Catholic leaders and agencies within Australia and the universal Catholic Church, and papal and other Vatican documentation.

CHAPTER THREE: GENEALOGY OF, AND KEY DEVELOPMENTS IN, DISABILITY IN CATHOLIC THOUGHT: AN AUSTRALIAN PERSPECTIVE

3.1. INTRODUCTION

The intention of this chapter is to critically explore the genealogy of rhetoric about and responses to disability within the Catholic Church in Australia and to trace several key developments in this area in the Church. A concerted focus will be on both discourse and practical efforts. This aspect of research will prove vital when determining – at the conclusion of this thesis – whether the Australian Catholic Church has been or is a strong advocate for people living with a disability.1 Key focus areas will include: the Australian Catholic Bishops Conference and relevant Catholic leaders and agencies within Australia and the universal Catholic Church, and papal and other Vatican documentation.


Since Catholicism arrived in Australia during the eighteenth century, Catholics have been “one of the largest providers of social care services in Australia.”2 This provision

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1 This is generally done by instigating and fostering inclusive communities.
has included education, social care (through the work of the St Vincent de Paul Society, the Catholic Social Welfare Commission, Catholic Social Services Australia, Caritas Australia, etc.), social justice and health care (through the work of the Sisters of Charity, Catholic Healthcare Community Services, Catholic Health Australia, etc.), along with the provision of services by various other religious traditions, charities, care groups and governmental agencies.³

It has been well documented that the Australian Catholic Church classifies itself as being actively involved in disability services.⁴ In 2006, the Australian Catholic Bishops Conference⁵ underwent a review and the bishops decided to establish the Australian Catholic Disability Council, under the newly formed Bishops Commission for Pastoral Life. Soon after, they appointed a Disability Projects Officer to act on requests from the Australian Catholic Bishops Conference, dioceses and parishes.⁶

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⁵ The Australian Catholic Bishops Conference is defined as “the assembly of the bishops of a country or a particular territory, exercising together certain pastoral offices for Christ’s faithful of their territory. By forms and means of the apostolate suited to the circumstances of the time and place, it is to promote, in accordance with the law, that greater good which the Church offers to humankind.” (Australian Catholic Bishops Conference, “About Us,” accessed May 1, 2014, http://www.catholic.org.au/about-us.australian-catholic-bishops-conference. See also Code of Canon Law, canon 447.)

Furthermore, on numerous occasions, Catholic agencies have lobbied governments for a greater allocation of the budget to be streamed into disability service provisions.\(^7\) These recorded efforts to secure better services and resources notwithstanding, the overarching questions that remain are: To what extent were they token efforts? To what extent did the burgeoning growth of Catholic social care services require a greater slice of the overall government welfare expenditure? It would seem that, according to the rhetoric that will be noted below, the Australian Catholic Church is a champion of disability services and accordingly accepts and welcomes all people regardless of their intellectual or physical abilities. But the pertinent question nonetheless is: What is the Church actually doing in this area to ensure that this positive regard for others is put into practice? Or, more critically, one could ask: How does the Church community accommodate people living with a disability? Does the Church adopt a model of disability and care which aligns with the position it advances about human dignity, as described in Chapter Two.

The evidence would suggest that the Church is not always as good as its words when it comes to championing the rights of minorities. There are many people and groups of people that experience marginalisation within the Australian Catholic Church, including but not restricted to youth, women, the elderly, people who are gay, lesbian, bisexual or transgender, and indigenous peoples, among others. Before we analyse the Church’s key documents and developments, it is important to note when the first explicit

reference to disability was made by the Australian Catholic Church. Although the Australian Catholic Church established a National Catholic Steering Committee for Disabled People in 1981, the first published reference to disability came in May 1985, when the Australian Catholic Social Welfare Commission (ACSWC) released a publication titled *Listening and Responding to Disabled People.* It is also worth noting that the United States Conference of Catholic Bishops acknowledged this pastoral issue in 1976, some nine years earlier, with the release of its *Pastoral Statement on People with Disabilities.*

3.2.1. LISTENING AND RESPONDING TO DISABLED PEOPLE (ACSWC, 1985)

This document was prepared by Sr Jeanie Heininger, who, at the time was employed as a Project Officer for the Australian Catholic Social Welfare Commission. The publication was the result of an extensive action-based research project. As Bishop Eric G. Perkins, President of the ACSWC at the time of publication, noted: “Much still remains to be done as this study undertaken by the ACSWC clearly shows.”

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11 This commission responded to a number of social care concerns that affected the Catholic Church, not just disability.
12 An action-based research project is a participatory pursuit to improve the status quo.
This short sixty-four-page publication was exploratory in terms of the Australian Catholic Church and disability issues, as noted in the preface: “In the absence of directly relevant research this study was necessarily exploratory in nature.”14 The document is broken up into five chapters with the purpose of providing a response to the evident rejection, discrimination and isolation that people living with a disability had been experiencing in the life of the Church and wider society. The themes and topics covered include: definitions, classifications and myths that surround disability (chap. 1); a selection of narratives of what people living with a disability want the Church to be (chap. 2); a response from the Church highlighting the various ministries available to people living with a disability (chap. 3); a selection of practical strategies that parishes can adopt to involve people living with a disability more fully (chap. 4); and further elaboration on specific programs and services that may assist people living with a disability (chap. 5). This book would have been quite revolutionary at the time it was published. Nonetheless, although it would have “told us a great deal about the situation and the needs of disabled people in the Australian Church today,”15 it missed the target on providing the wider Church community with details about how to create communities of genuine belonging and acceptance.

3.2.2. DISABILITY AND HUMAN RELATIONSHIPS: CHRISTIAN VALUES IN PERSONAL DEVELOPMENT (ASCWC, 1990)

In 1986, Pope John Paul II visited Australia and specifically spoke about the Catholic Church’s involvement with people living with a disability.\textsuperscript{16} Although it is not explicitly stated, this visit could have influenced the Australian Catholic Social Welfare Commission to publish the 1990 document \textit{Disability and Human Relationships: Christian Values in Personal Development} as a key resource on inclusiveness in relation to people living with a disability.

As we see, this book follows the Australian Catholic Social Welfare Commission’s \textit{Listening and Responding to Disabled People}, which we surveyed earlier.\textsuperscript{17} Interestingly, in the introduction, reference is made that “this book reinforces and adds an important further dimension to the Commission’s 1985 document. Many felt that the issues faced by those with disabilities had somehow become divorced from the Christian journey that others were experiencing.”\textsuperscript{18} The aim of this latter book was to:

consider the very real challenges that those with disabilities and their families face in the area of personal development. It seeks to affirm the place and role of people with disabilities within the Church and the wider community, to share in

\begin{itemize}
  \item \textsuperscript{16} On December 3, 2000, the United Nations International Day for Disabled Persons, Pope John Paul II spoke about the distinct importance of the Catholic Church’s involvement in disability issues, marking the twenty fifth anniversary of the United Nations’ \textit{Declaration of the Rights of Disabled People} (United Nations, \textit{Declaration of the Rights of Disabled People}, 1975, accessed June 24, 2015, http://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfDisabledPersons.aspx.) Pope John Paul II stressed: “The Ecclesial Community also listens respectfully; it senses the need to question itself about the strain in so many of your lives, mysteriously marked by suffering and by the discomfort of harmful events, whether congenital or acquired. It would like to draw closer to you and to your families, knowing that inattentiveness sharpens suffering and loneliness, whereas faith shown in love and generosity gives strength and meaning to life.” (John Paul II [Pope], “Homily of John Paul II: Jubilee of the Disabled,” 2000, accessed July 10, 2011, http://www.vatican.va/holy_father/john_paul_ii/homilies/documents/hf_jpii_hom_20001203_jubildisable d_en.html, my italics.)
  \item \textsuperscript{17} See Australian Catholic Social Welfare Commission, \textit{Listening and Responding}.
\end{itemize}
their quest to discover more about the meaning of life and its responsibilities, and to suggest ways of helping them to lead happier and more fulfilling lives.19

This book highlights the importance of human relationships for people living with a disability and the understanding that people living with a disability personally develop like any other people. The key premise of the book is a challenge: “we are called to walk with persons with disabilities [sic] and their families to help them experience the reality of God’s love in the Christian community through care, support and understanding we give them.”20 Key concepts and topics that are explored throughout the twenty-one-page booklet include: how people living with a disability are perceived in society (chap. 1); the importance of human relationships, including sexual relationships, marriage, family relationships and other relationships (chap. 2); the fact that people living with a disability, “can be more vulnerable than most persons to becoming objects of sexual encounters”21 (chap. 3); the responsibilities of the Church, including providing access to Catholic schooling and religious education for people living with a disability (chap. 4); and the “sacredness and uniqueness of human life”22 (chap. 5).

Although this booklet is full of good intentions – “[this booklet] should make parishioners and other members of the community more aware of the needs of these people”23 – it misses the mark of providing a tangible resource to overcome the gap between exclusion and the inclusion of people living with a disability. The reality of

23 Australian Catholic Social Welfare Commission, Disability and Human Relationships, foreword. Note the language used here, especially “these people”, which implies that they are different from people living without a disability.
people living with a disability being sexually abused has been a concern, not only for churches, but for other institutions over many years, so this section is to be applauded; but the purpose of including notes on sexual relationships and self-control (masturbation) is somewhat perplexing and it explores terrain unnecessarly.

3.2.3. I HAVE A STORY: PEOPLE WITH DISABILITY AND THEIR FAMILIES PARTICIPATING FULLY IN PARISH LIFE (ACBC, 2004)

In 2004, the Australian Catholic Bishops Conference released a pastoral document with the main title, I Have a Story. The main objective of this document was to acknowledge the lack of recognition for people living with a disability within the Australian Catholic Church community and to “summon our parishes to be communities that gladly welcome people with disability and their families.”

Furthermore, this document makes it clear that the non-inclusion of people with a disability and their families had been an “issue” in various parishes. This document recommends relating to “people for their gifts and ability, not their disability.” The document is constructed adopting a “personal touch” approach – similar to Swinton’s journal article, “Building a Church for

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24 Australian Catholic Bishops Conference, I Have a Story: People with Disability and Their Families Participating Fully in Parish Life (Canberra: Australian Catholic Bishops Conference, 2004), 3. Furthermore, the following endnotes from the bishops’ document should be noted:

This pastoral document has been developed by the Australian Catholic Bishops Conference. The Bishops of Australia acknowledge with gratitude the people from every state and territory of Australia who contributed to the development of this document through consultation in 2003. The document is available on request in large print, Braille and audio recording. A Disability Working Party was established by the Australian Catholic Bishops Conference in 2002 to develop a pastoral document, which would be representative of people with disability and their families. To ensure the authenticity of the document, the Working Party conducted a broad consultation, whereby responses to certain questions could be used in the development of the pastoral document, the main aim of the consultation was to collect ideas and stories from people with disability and their families. Opinions and comments on how they saw their membership within the parish and the Church were sought. The objective was to discover what was happening in parishes and how people were participating in the faith life of the Church, while being aware of the difficulties that still exist. People were invited to comment on the barriers, as well as give constructive suggestions for parishes. This pastoral document is the culmination of the 357 responses received from dioceses in every state and territory of Australia. (Australian Catholic Bishops Conference, I Have a Story, 20).

25 Australian Catholic Bishops Conference, I Have a Story, 4.
Strangers,” which we investigated above. The ACBC document features a range of responses from various people living with a disability and their families. Respondents had been asked a number of key questions, such as: “How is this parish community liberating for all members?” “How does everyone contribute?” “How do we build relationships in this community?” “How can we learn about the experience of people with disability?”

During his 1986 visit, Pope John Paul II stated:

No one born into this world is free from human frailty – whether it be physical, emotional or spiritual. Each of us must personally come to terms with this frailty . . . But in the providence of God a different life does not mean a less important life. It does not mean a life with less potential for holiness or for contributing to the well-being of the world.

When comparing the Australian Catholic Church’s teachings and attitudes towards people with intellectual disabilities to the historical development and advancement of disability theory, it can be concluded from an initial assessment that the Australian Catholic Church had been far behind the progression of other social science disciplines in emphasising the social relevance of disability. This is based on the fact that the abovementioned documents, whilst they progress in their understanding of disability, do not nearly match the progress achieved in the models of disability explored in Chapter Two. Additionally, the Australian Catholic Church’s viewpoints and practical responses appear to have been markedly minimalist compared with those in other contexts, such as the proactive attempts at inclusion by the Catholic Church in the United States,

driven by the *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities.*\(^{28}\) All of this change correlates with the increasing observance of the rights of people living with a disability in general and with the growing literature supporting these changes. It is reasonable to suggest that these changes developed from increased recognition of rights from other groups, for example, women and indigenous peoples.

The Australian Catholic Church has set a challenge to its community in an attempt to “demystify disability”\(^{29}\) and to cease the negative “attitudes and prejudices”\(^{30}\) against persons, and groups of persons, with a disability. The crux of this challenge is summarised in the following: “Let us all commit ourselves to take up this call and challenge, given by people with disability, to be communities where all can use their gifts.”\(^{31}\) The Australian Catholic Bishops Conference stresses that instead of implementing a blanket or universal set of doctrines, it is essentially up to local parishes and dioceses to become more inclusive communities,\(^{32}\) by, among other things, involving people living with a disability. To reiterate and emphasise a comment elaborated on earlier, what is critically important is action rather than mere rhetoric.

The booklet *Disability and Human Relationships: Christian Values in Personal Development* was the first explicit reference that the Australian Catholic Church made

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\(^{29}\) Australian Catholic Bishops Conference, *I Have a Story*, 6. Moreover, Duggan affirms “Church communities are called to take a lead, rather than mirror what happens in society.” (Duggan, *Confidence and Capacity*, in Australian Catholic Bishops Conference, *I Have a Story*, 2.)

\(^{30}\) Australian Catholic Bishops Conference, *I Have a Story*, 7.

\(^{31}\) Australian Catholic Bishops Conference, *I Have a Story*, 3.

to anything regarding “disability”. The basis of this document was essentially to acknowledge that the Australian Catholic Church welcomes those experiencing disabilities and challenges the wider Australian Catholic Church: “to walk with persons with disabilities [sic] and their families to help them experience the reality of God’s love in the Christian community through care, support and understanding we give them.”33

It is interesting to clarify that the booklet did not attempt to define “disability”, but rather to “provide its readers with a realistic appreciation of personal development and human relationship issues encountered by Christians in an increasingly secular society.”34 The document considers the real battles and tensions that people living with a disability face in everyday life. It suggests (but does not demand) that people living with a disability do in fact have a place in the Church.35

We clearly see from the responses from interviewees quoted in the booklet that, in most cases, disabled persons’ cognitive faculties are regarded as being inferior to the norm; nevertheless, this does not mean they do not want to participate in Church life. Throughout the document, we continually see responses from an anonymous person with an intellectual disability about his or her positive and meaningful experiences of attending church on a regular basis. These include choice words and phrases, such as “It’s very important for me to go to church,”36 “It [Church] makes me feel

34 Australian Catholic Social Welfare Commission, Disability and Human Relationships, foreword.
36 Australian Catholic Bishops Conference, I Have a Story, 2.
independent,”37 “[I] sing with everyone,”38 and “Someone to welcome me, someone who knows me.”39

The document also highlighted a number of negative experiences of Church life. For example:

Our recent experience in our parish was interesting. We didn’t feel particularly welcome or acknowledged at all – but the priest recently dropped by to give us music for the weekend liturgy and said how good it was to have our family in the parish and that people talk about really liking having us and that our family inspires them. We had no idea about this. Which makes us think that perhaps the “welcome” in many parishes is disguised by them not knowing what to do and by the silence which is often associated with disability.40

This response is not necessarily negative. People are sometimes not sure what to do when confronted with disability and so do nothing. Additionally, respondents with a disability articulated the desire for greater involvement throughout the Mass, through assuming responsibility for certain roles and duties, including those of choir member, altar server, Scripture reader, usher, or special minister of the Eucharist. The Australian Catholic Bishops Conference states: “we [the ACBC] are concerned that there were responses from some parents stating that some children are still not being included in sacramental programs and Catholic education.”41 In essence, the Australian Catholic Bishops Conference realised that a document needed to be released in acknowledgement of this growing societal disjunction.

37 Australian Catholic Bishops Conference, I Have a Story, 2.
38 Australian Catholic Bishops Conference, I Have a Story, 2.
39 Australian Catholic Bishops Conference, I Have a Story, 2.
40 Australian Catholic Bishops Conference, I Have a Story, 7.
41 Australian Catholic Bishops Conference, I Have a Story, 1.
3.3. THE UNIVERSAL CATHOLIC CHURCH: PAPAL AND OTHER VATICAN DOCUMENTS

During the Second Vatican Council, the Church Magisterium promulgated several historic documents relating to its place and function in the modern world. Here, although no documents directly relate to “disability” per se, it is crucial to examine other key teachings, such as those about the dignity of the human person and about human anthropology. The Dogmatic Constitution on the Church (Lumen Gentium) proclaimed by Pope Paul VI, on November 21, 1964, disseminates the idea of the Church being the “Universal Sacrament.” While this may have a multifaceted meaning, it points towards a collective collaboration, with the rituals, the prayers, the teachings, the sacred texts, the sacred symbols, the clergy and the entire parish community, including people living with a disability, unified in Christ. The document proposes:

Since the Church, in Christ, is a sacrament – a sign and instrument, that is, of communion with God and of the unity of the entire human race – here it proposes, for the benefit of the faithful and the entire world, to describe more clearly, and in the tradition laid down by earlier councils, its own nature and universal mission.

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42 The Second Vatican Council occurred between 1962 and 1965, and was opened by Pope John XXIII and closed by Pope Paul VI.
43 The Church Magisterium is simply the teaching authority of the Church, including the Bishop of Rome (the Pope) and other bishops from around the world.
44 Historic in the sense that the Second Vatican Council was the first ecumenical council of the Catholic Church since the Council of Trent (1545–63), some four hundred years earlier. Pope John XXIII used the term aggiornamento, Italian for “updating,” to articulate the essential path he wanted the council to take. Since then, the council has been remembered as the “Call to Renewal.” (Veronica Lawson, “Vatican Council II: Call to Renewal,” in Foundations of Christian Faith: An Introduction for Students, ed. Damien Casey, Gerard Hall, and Anne Hunt [Southbank, VIC: Social Science, 2004], 51–59). See also Joseph A. Komonchak, “The Significance of Vatican Council II for Ecclesiology,” in The Gift of the Church, ed. Peter C. Phan (Collegeville, MN: Liturgical, 2000).
The Pastoral Constitution on the Church in the Modern World (Gaudium et Spes), another document of the council, makes clear that Catholics must seek an active role in pursuing and defending the rights of all human beings.\(^{47}\) Furthermore, all issues that impact upon the vulnerable, sick, disadvantaged and marginalised, are concerns for the Church. Pope John Paul II reiterated the importance of this almost forty years after the council by stating:

> The starting point for every reflection on disability is rooted in the fundamental convictions of Christian anthropology; even when disabled persons are mentally impaired or when their sensory or intellectual capacity is damaged, they are fully human beings and possess the sacred and inalienable rights that belong to every human creature.\(^{48}\)

An important question here that concerns the presence of people living with a disability in the life of the Church is whether it is plausible to exclude such people from access to the sacraments. The term “sacrament” derives from the Latin sacramentum, and means “a visible sign, instituted by Christ that communicates and reveals God’s grace.”\(^{49}\) The Catholic Church recognises seven sacraments, each with an equal yet unique significance. These are: baptism, reconciliation (penance), Eucharist, confirmation, matrimony, anointing of the sick and holy orders. A lay person’s understanding of this question would pose many challenges and encourage much debate. Throughout the ancient traditions and practices of the Catholic Church, there is no canonical law that excludes an individual with a disability from access to the Catholic sacraments. Rather,


“all Catholics have a right to access the sacraments and no person with a disability can be denied a sacrament because of their disability.”

Furthermore, in support of this, Huels states:

All the baptised have a right to the sacraments, a fundamental, constitutional right that exists in virtue of their baptism into Christ’s Church. This right cannot be restricted unless there are clear legal grounds for doing so. We will see that, indeed, there are no clear legal grounds for denying Catholics with developmental disabilities access to the liturgical rites in question.

There are a number of instances, however, both published and garnered from the interviews of this study, that report priests trenchantly refusing to baptise children living with a disability. Hence, one can see here an instance of there being a gap between the rhetoric or aspiration of inclusion, on the one hand, and, on the other, actual practice. Even in instances where attempts are made to include the marginalised, the very process can be stigmatising and bring into sharp focus the reality of “otherness.”

Additionally, the sacraments bond Catholics closer together by mutual experiences. For example, if two people are baptised Catholic, they share a common understanding that allows for a sense of belonging and identity, where Catholics can relate these sacraments to human experiences and life in general.


51 Huels, “Canonical Rights,” 95. Although allegations of sexual abuse were made against him in 1994, Huels’ writings, nevertheless, remain influential in the scholarly world. At the time of writing this thesis, Huels is a Professor of Canon Law at Saint Paul University in Ottawa, Canada. He has written extensively on the relationship between canonical law and access to the sacraments in the Catholic Church.

52 See the transcripts of the researcher’s interview with Interviewee 3: Tracey; Interviewee 4: Melinda; and Interviewee 13: Janine.

53 Additionally, sacraments have profound ethical implications for a Catholic, so far as offering them a source of guidance and/or justification by which they should live their life.
and Claude Duchesneau broaden the understanding of sacramentality to stress the importance of what might be referred to as living a sacramental life:

There is a real sense in which, when any one of us chooses to act as Jesus was known to act, we too become living sacraments in our world. Sacraments are a revelation of God, a presence of God in our affairs.\(^{54}\)

In support of this, Gascoigne states: “the fulfillment of human persons, created in the image of God, is to make a communion or community of life possible, in many different forms and contexts.”\(^{55}\) Such theological frameworks (building a sense of belonging and identity), however, need a point of tangible translation, a point at which they are realised in real actions in the lives of people. Otherwise such aspirations are mere tokens.

Trevor Whitney states: “Amidst the frailty and brokenness of human life, the critical issue becomes the need to be affirmed sacramentally in the realization that one is loved, indeed embraced, by God.”\(^{56}\) Therefore, as Whitney suggests further, “The God who reaches out to and expresses love to these people [with intellectual disabilities] through the sacrament of Communion defines worth in terms of unconditional acceptance, not intellectual achievement.”\(^{57}\)


In Chapter One, the importance of the dignity of the human person was introduced. The intention of the current section is to frame this idea with reference to the Catholic tradition. This theological and anthropological concept (dignity of the human person) is grounded in the biblical tradition, especially in the Hebrew Scriptures, where all human beings are “created in the image and likeness of God” (Genesis 1:26-27). Additionally, a key feature of the Pontifical Council for the Family’s publication, *Conclusions of the Vatican Conference on the Family and Integration of the Disabled*,\(^{58}\) is that “the disabled person ‘is a fully human subject,’ endowed with ‘a unique dignity’ as a human being.”\(^{59}\) Furthermore, the notions of access (acceptance), belonging (friendship) and community (participation) find their roots in Catholic social teaching.

At the centre of Catholic social teaching is teaching around the common good. In this context, however, it will be proposed that the common good is an ethical concept that relies on worthwhile contributions from human beings, in a range of facets, to ultimately achieve the result of a peaceful and joyous society. The most prominent exploration into the meaning of the common good can be drawn from the Second Vatican Council’s document, Pastoral Constitution on the Church in the Modern World (*Gaudium et Spes*),\(^{60}\) which defines it as: “the sum total of social conditions which allow people, either as groups or as individuals, to reach their fulfilment more fully and more easily.”\(^{61}\)

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\(^{59}\) Pontifical Council for the Family, *Conclusions*.


The common good is central to this argument in many ways. In any given society unless the people within it make valuable contributions, it will falter at its very core. It is of paramount importance that people living with a disability be included in this paradigm. As Pope John XXIII explored in his encyclical, “On Establishing Universal Peace in Truth, Justice, Charity, and Liberty” (Pacem in Terris), it is generally accepted today that the common good is best safeguarded when personal rights and duties are guaranteed.

3.4. CONCLUSION

In this chapter, a historical and contextual backdrop of the Australian Catholic Church and the subject of disability has been provided, including a close investigation of the Australian Catholic Bishops Conference and relevant Catholic leaders and agencies as well as the universal Catholic Church, together with papal and other Vatican documentation. It was stated that the Catholic Church in Australia have provided care for people living with a disability since the eighteenth century. The final words of this chapter will go to Richard B. Steele, an American Methodist theologian, who strongly believes that those who “intend to minister faithfully and effectively to and with persons with disabilities [sic] ought to have reverence for human life [and in turn, dignity for all

69, for another definition of the common good. Further, the common good is a term that is closely related to several facets of human existence – facets that affect the individual, such as ethics, human rights, individual freedom, human purpose and politics/political theory.

62 See Hollenbach, Common Good, esp. chap. 8, 212–44.
65 John XXIII (Pope), Pacem in Terris.
human beings].” In the next chapter, the methodology for undertaking the qualitative research that supported the preparation of the current thesis will be outlined. This will include a reflection on relevant ethical considerations that have helped to ensure that the research was conducted in accordance with the Human Research Ethics Policies and Guidelines of The University of Newcastle and with the Australian Code for the Responsible Conduct of Research. Looking further ahead, in Chapter Five the results of this research will be disseminated, and then in Chapter Six they will be critiqued in dialogue with the theological positions explored in this chapter and the models of disability explored in the previous chapter.

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66 Steele, “Christian Virtue,” 28. To argue further, the Pontifical Council for the Family document, 
Conclusions of a Vatican Conference on the Family and Integration of the Disabled, stresses that “this dignity cannot be rejected, nor can it be lost; no one’s dignity can be taken away; it remains the same to the last minute of one’s life.”
CHAPTER FOUR: METHODOLOGY AND RESEARCH DESIGN

4.1. INTRODUCTION

The purpose of this chapter is to describe the methodology that was used for the qualitative research that underpins the present study. A reflection on the relevant ethical considerations that helped to ensure that the research was conducted in accordance with the Human Ethics Policies and Guidelines of The University of Newcastle and with the Australian Code for the Responsible Conduct of Research will be put forward. Earlier a brief explanatory account was articulated for the methodology of the thesis in the Thesis Introduction. However, this chapter will be more comprehensive in outlining the methodology chosen for this research project, and more precisely, in outlining the various intricacies of researching qualitatively.

4.2. METHODOLOGY: RESEARCHING QUALITATIVELY

When someone undertakes research, whether as an educator, sociologist, biologist, historian, psychologist, physician or a theologian, the main objective is always to make a significant contribution to a body of knowledge in his or her area. Qualitative research is used extensively in the social sciences, especially in sociology, anthropology, education and psychology; however, it has been a methodology that has been neglected to a certain extent within the discipline of theology. Pete Ward notes

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how theologians “appear to be more and more interested in practice, culture, and the embodied social nature of doctrine and the church. Yet, whether through inclination, disciplinary convention, habit or methodological prejudice, theologians have tended to avoid fieldwork.”70 As a result, many theologians remain, he says, “very often divorced from any real or sustained engagement with actual churches and communities.”71 Ward is clearly right. It is my argument here, in response to his challenge, that ethnography, action research, qualitative research and other social-cultural studies can supply a theologian with sufficient concrete resources to test theological assertions through fieldwork. Theologians may not all be able to use the research methods listed above, dependent on their particular focuses, but they can engage with them and understand them, just as they do with history and the other disciplines we need in order to practise ecclesiology.

Norman K. Denzin and Yvonna S. Lincoln affirm that:

Qualitative research is multi-method in focus, involving an interpretative, naturalistic approach to its subject matter . . . qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.72

John McLeod offers the following definition:

Qualitative research is a process of careful, rigorous inquiry into aspects of the social world. It produces formal statements or conceptual frameworks that provide new ways of understanding the world, and therefore comprises knowledge that is practically useful for those who work with issues around learning and adjustment to the pressures and demands of the social world.\textsuperscript{73}

It is interesting to note how McLeod’s definition of qualitative research can be linked to the research scope and its relationship with natural theology, especially Aquinas’ methodology by which God’s revelation can be encountered in the natural world – a creature, by its very existence, is already giving glory to God.\textsuperscript{74}

In terms of qualitative research, it is essential that methodological clarity be established from the outset, for “if we do not know how people went about analysing their data, or what assumptions informed their analysis, it is difficult to evaluate their research.”\textsuperscript{75} Further, Michael Quinn Patton states: “The motivations of social scientists have become suspect, as have our methods.”\textsuperscript{76}

In the project at hand, this researcher has precisely used qualitative interviewing to gather a large bulk of the data. Qualitative interviewing, according to Susan E. Kelly, refers to the intricate “interviewing techniques that provide qualitative (textually rich) data.”\textsuperscript{77} It has been the intention of the researcher, as it should be for anyone

\textsuperscript{73} John McLeod, \textit{Qualitative Research in Counselling and Psychotherapy} (London: Sage, 2001), 3.

\textsuperscript{74} See Chapter One, section 1.3 and section 1.6.1.


undertaking qualitative research, to structure and execute the interviewing process in a way that upholds the integrity and rigour of qualitative interviewing technique, while providing enough space to reverence the interviewee.\textsuperscript{78} The interviews were constructed in a way that reached the heart of “those things we cannot directly observe.”\textsuperscript{79} The interviewing process enabled the interviewees to tell their personal narratives, stories and/or reflections around semi-structured questions, with the aim of “enter[ing] into the other person’s perspective.”\textsuperscript{80} Extending on this further, Patton argues that: “evaluators must learn how to listen when knowledgeable people are talking.”\textsuperscript{81}

It is also important to note here that the interviewer did not enter into the space of the interview as an expert in the field. The emphasis was based around adopting a co-constructionist approach, where both the interviewer and the interviewee participate in a mutually enriching dialogue with one another around the subject and specific questions. Perhaps the only thing that made the interviewer a little apprehensive about presiding over the interviews was the possibility of not acquiring enough information, or even worse, not making the interviewees feel sufficiently comfortable.\textsuperscript{82} For the interviewer soon came to realise that “the quality of the information obtained during an interview is largely dependent on the interviewer.”\textsuperscript{83} The researcher is grateful in this regard to his supervisors and qualitative research mentors,\textsuperscript{84} all experts in this field, for taking him

\textsuperscript{79} Patton, \textit{Qualitative Research}, 340.
\textsuperscript{80} Patton, \textit{Qualitative Research}, 341.
\textsuperscript{81} Patton, \textit{Qualitative Research}, 341.
\textsuperscript{83} Patton, \textit{Qualitative Research}, 341.
\textsuperscript{84} Who were named in the Acknowledgements above.
through the “ins and outs” of qualitative research, and in particular, for helping him to practise qualitative interviewing techniques before commencing the actual interviews.

Patton proposes three methodologies for collecting data: the informal conversational interview approach; the general interview guide approach; and the standardised open-ended interview approach.\textsuperscript{85} For the purpose of the thesis, all three methodologies were drawn upon to essentially make a hybrid methodology, “tailor made” to best suit this research project. The key to the way the methodology was constructed and executed, the interviewing process was guided by the foundational semi-structured interview questions (which, using Patton’s analysis, constitutes the general interview guide approach), while allowing enough freedom and space for interviewees to “open up” and re-tell their personal narrative, stories and/or reflections (which could be considered as deriving from a mixture of the informal conversational interview approach and the standardised open-ended approach).

Finally, it is important to note that the methodology for this study was formulated from within an anti-oppressive ideology and research approach that aimed to respect and uphold the dignity of people living with a disability. Swinton and Mowat stress the importance of doing this by stating that qualitative research should “enable people with learning disabilities [intellectual disabilities; or any disability for that matter] to retain their autonomy and power and to gain the opportunity of articulating their experiences clearly and openly with as little cultural bias as possible.”\textsuperscript{86}

\textsuperscript{85} See Patton, \textit{Qualitative Research}, 342, for a detailed analysis of each interviewing method.
\textsuperscript{86} John Swinton and Harriet Mowat, \textit{Practical Theology and Qualitative Research} (London: SCM, 2006), 233.
4.3. RESEARCH DESIGN: THE QUALITATIVE PARADIGM

This qualitative study of the Catholic Church in Australia is a major part of this thesis, determining the extent to which the Church is including and creating communities of belonging for people living with a disability. The study focused on the following three key operational areas, and staff and volunteers over the age of eighteen within these operational areas were invited to participate: (1) Catholic social care agencies (for example, representatives from CatholicCare, Centacare); (2) the Catholic school system (for example, representatives from the Catholic Education Office, the Catholic Schools Office); and (3) other Catholic agencies and organisations (for example, representatives from the Australian Catholic Bishops Conference, parish support units, parish ministry teams, archbishops, bishops, and other clergy). The qualitative study took the form of an interview and was centred on questions about the inclusivity of people living with a disability in the Australian Catholic Church. Moreover, it sought to determine the tangible philosophies, values and practices that facilitate such inclusion.  

This researcher acknowledges and appreciates the value of participation. The project aimed to create a meaningful experience for the researcher and the interviewees. The end result was to highlight existing positive attempts towards social justice and inclusion for people living with a disability and also the gaps between current practice and the theological rhetoric of the Australian Catholic Church, as noted in Chapter Three. Furthermore, at the outset, it was anticipated that this project would generate a

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87 See Figure 2 for greater detail and clarity.
conversation, dialogue and debate that might potentially foster more positive inclusionary approaches and substantive actions towards change within the Australian Catholic Church.89

As noted above in Chapter One, the interdisciplinary research of meshing theology and qualitative research has gained significant traction in the past thirty years.90 There are an increasing number of theologians using empirical-based methodologies – such as qualitative research and ethnography – to investigate theological issues and contexts, as Ward suggests: “the ethnographic [and qualitative research] ‘voice’ demands our attention because it has the potential to make a significant and urgently needed contribution to the contemporary discussion of the church.”91 Brett Webb-Mitchell, for example, conducted a nine-month ethnographic case study of a L’Arche community in London, of which the synthesis can be found in his book God Plays Piano, Too: The Spiritual Lives of Disabled Children.92 Moreover, Sarah Dunlop and Mark Cartledge are conducting an ethnographic investigation of the social engagement of London’s megachurches,93 and Yutaka Osakabe has conducted an extensive qualitative study of Japanese Evangelical Churches after the Fukushima nuclear disaster.94

89 As stated throughout this thesis, the Australian Catholic Church by its very nature and mission should indeed be “leading the way” in disability ministry. Action rather than mere rhetoric is of importance.
92 See Brett Webb-Mitchell, God Plays Piano, Too: The Spiritual Lives of Disabled Children (New York: Crossroad, 1993). Webb-Mitchell believes that the “goal of ethnography is to describe the participants, rituals, interactions, and the physical setting so clearly the image produced is a verbal photograph.” (Webb-Mitchell, God Plays, 10.)
4.4. RESEARCH PROCESS

In order to complete the research within the prescribed time frame, it was essential that the research process take account of this constraint. In a doctoral program, the scope, time duration and refinement are limited. The research process detailed below provided the foundation for how the research was approached.

Step 1: Literature Review

The researcher conducted a discourse and conceptual analysis of relevant literature in the following three categories:

1. Bridging the theological and clinical divide (what is theology? how do we do theology, with particular reference to natural theology and practical theology? why would a theologian be interested in disability – from a theological perspective? what difference does a theology of disability make?).95

2. The disability debate (“definability” of disability; the sociological and historical development of disability; the change, development and progress of disability).96

3. The genealogy of, and key developments, in disability thought in the Catholic Church (survey of Australian Catholic Bishops Conference and relevant

95 See Chapter One.
96 See Chapter Two.
Catholic leaders and agencies; and of the universal Catholic Church, including papal and other Vatican documentation). 97

The purpose of the literature review was to establish a framework in which the thesis would sit and to verify that this research should be carried out, that is, go some way to filling the void in Australian research, as noted above in the Thesis Introduction, section i.4.

**Step 2: Qualitative Interviews**

The researcher developed a database of potential interviewees and made contact with them in the form of an Information Statement and Consent Form. Potential interviewees were pooled from three key operational areas and staff and volunteers over the age of eighteen within these operational areas were invited to participate. Participants came from: (1) Catholic social care agencies (for example, CatholicCare, Centacare); (2) the Catholic school system (for example, the Catholic Education Office, the Catholic Schools Office); and (3) other Catholic agencies and organisations (for example, the Australian Catholic Bishops Conference, parish support units, parish ministry teams, archbishops, bishops, and other clergy). Interested interviewees were asked to read through the Information Statement thoroughly and understand its content, parameters and expectations and register their interest and intended participation in the research project by completing and signing the Consent Form within two weeks of the dated Letter of Invitation. A brief semi-structured interview lasting no more than sixty minutes was asked of the interviewees. Interviewees were afforded the opportunity to

97 See Chapter Three.
voice their personal viewpoints regarding inclusion of people living with a disability from their perspective – as a bishop, priest, educator, parish administrator, or disability support worker and so on. Interviewees were warmly thanked for their participation and honest insights.

Step 3: Reporting on the Research Findings: Analysis, Synthesis and Making Meaning of the Qualitative Data and Research Findings

The interview data was transcribed by a professional, external transcription company (Digital Transcripts). The transcripts were then subject to a thorough thematic analysis process to identify any recurrent patterns, themes and categories. In Chapter Five, we will see the research findings examined on a question-by-question basis and a critique of five key categories that emerged from the thematic analysis: (1) Attitudes and perceptions; (2) Inclusion; (3) Empowerment; (4) Rhetoric versus reality; and (5) Demonstrated action. We will also see links back to the theological literature in that chapter. In brief, the researcher will perform a systematic analysis of the qualitative data. Additionally attempts will be made to draw contrasts and comparisons between each organisational participant – discrete elements of the data will be interrogated and considered in the context of the literature and interlinked documentary evidence promulgated by the Church and its community welfare organisations.

Step 4: Conclusion

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98 See Braun and Clarke, “Thematic Analysis.”
The researcher will bring the data together to explore the various debates emerging from
the inquiry. Recommendations will be extended to highlight existing positive attempts
towards social justice for people living with a disability, and attention will be given to
tabling the identified gaps and inconsistencies. In particular, barriers and competing
practices and discourses about inclusion will be outlined. The researcher will return to
the question posed in Chapter One: “Why would a theologian be interested in disability
– from a theological perspective?” to determine how these theologies of disability are
fruitful for these conclusions.

4.5. DATA COLLECTION

The interviews were conducted over a period of eight months from February to
September 2013. The interviews were made possible after the researcher identified a
range of potential interviewees and made contact with them by sending through an
Information Statement99 and a Consent Form100 that had been approved by The
University of Newcastle’s Human Research Ethics Committee.101 After the interviews
were completed, a letter of appreciation was sent to each interviewee and each
interviewee requested to be sent a summary report at the conclusion of the research. The
researcher anticipated that interviews would last no more than thirty minutes; however,
quite a few interviews went well beyond sixty minutes due to the interviewee’s
engagement with the interview questions. It was very evident that all interviewees felt
comfortable throughout the duration of the interview; the researcher asked ongoing
questions such as “So you’re right to begin the interview, now?” and “So we’re at the

99 See Appendix B.
100 See Appendix C.
101 See Appendix A.
midway point here. Are you feeling comfortable with the interview?” Furthermore, it was also very clear (from the depth of responses) that a mutual respect between the researcher and interviewees was established soon after the interview began. The researcher began each interview with the following excerpt:

So [. . .], do you consent for this interview to be recorded? Okay, so, the interview is now commencing with [. . .] from [. . .]. So how would you like to be named throughout the interview? Firstly welcome and thank you for agreeing to partake in this interview and this will form an integral part of my PhD research. The thesis is titled, “A Critical Analysis of a Theology of Disability in the Australian Catholic Church: An Ethnographic Enquiry of Contemporary Inclusionary Practices,” which I'm currently completing at the University of Newcastle here in Australia. My name is Zachariah Duke, Zach for short and I look forward to briefly introducing myself just in a few moments. Before we get started [. . .], perhaps you might like to share a little bit about yourself, a brief personal story if you like?104

4.5.1. INTERVIEWEES

There was a total of twenty-five interviewees and most were very generous with their time. As noted in the preceding section, the recruitment of interviewees, coupled with the conducting of the interviews, occurred over a period of eight months. Unfortunately, the researcher experienced substantial resistance from various agencies, organisations, dioceses and archdioceses during this recruitment phase. There were times when the researcher and the supervisory team simply thought they would not be able to reach the required sample size. When the potential interviewees were asked to provide a reason for their inability to participate, some quoted lack of time, lack of expertise, and not

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102 This is hugely important when conducting qualitative interviews, as noted by Patton, who states: “the quality of the information obtained during an interview is largely dependent on the interviewer.” (Patton, *Qualitative Research*, 341.)

103 The square brackets and ellipses indicate a placeholder where a person’s name or an organisation’s name was to be inserted.

104 Excerpt from Interview Schedule; see Appendix D.

105 See Swinton and Mowat, *Practical Theology*, 204.
wanting to publicly comment with the impending Royal Commission into Institutional Responses to Child Sexual Abuse. Some potential interviewees, however, volunteered more about why they would not participate: “it is extremely busy here in the Diocese and I am afraid we have no time to participate” (Bishop Colin); “Due to lack of time and expertise, I will unable to be of assistance” (Bishop Bradley); “I am sorry for the delay in getting back to you regarding the participation of Bishop Bob in your research project. Bishop Bob is soon to retire and therefore he asked me to let you know that he will not be participating. The Bishop wishes you all the very best for the project” (bishop’s secretary); and “We would like to inform you that this Diocese does not provide disability services and therefore your study is not aligned to our service model” (bishop’s secretary).

Victor Minichiello, Jeanne Madison, Terrence Hays, Mary Courtney, and Winsome St John stress the importance of introducing readers to the demographics of the interviewees before starting to analyse their data.106 To this end, the researcher outlines a few important demographic details below:

- There were sixteen female interviewees, nine male interviewees.
- Twenty interviews were via telephone or Skype, five were face-to-face interviews.
- Thirteen interviewees were recruited from Catholic social care agencies (for example, CatholicCare, Centacare); three interviewees were recruited from the Catholic school system (for example, the Catholic Education Office, the

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Catholic Schools Office); and eight interviewees were recruited from other Catholic agencies and organisations (for example, the Australian Catholic Bishops Conference, parish support units, parish ministry teams, archbishops, bishops, and other clergy).

- The number of interviewees from each state or territory were:
  - Australian Capital Territory: three
  - New South Wales: fifteen
  - Northern Territory: one
  - Queensland: one
  - South Australia: one
  - Tasmania: one
  - Victoria: two
  - Western Australia: one

The researcher believes that, by providing a brief introduction to each interviewee, their insights and contributions over the next two chapters will be better understood.\(^\text{107}\) I will now introduce each of the twenty-five interviewees, using the following headings: name; state/territory of residence; sample cluster; date of interview; mode of interview; and a brief biography. To comply with the agreed ethical parameters guiding this research, the researcher has attempted to keep biographical information on each interviewee as disguised as possible.

Interviewee 1:

Name: Sandra

State/Territory: New South Wales

Sample Cluster: Catholic social care agency

Date of interview: Tuesday, February 19, 2013

Mode of interview: Telephone

Biography: Sandra is employed as senior manager at a Catholic social care agency in New South Wales. Sandra is a trained psychiatric and general nurse who has spent the past twenty-five years working in mainstream health, community health, mental health and homelessness. Prior to this, Sandra worked as a practitioner, policy analyst and lobbyist for not-for-profit organisations. The three words or phrases that sum up her role/organisation are: “rapidly growing, client centred and here for the duration!” (Interviewee 1: Sandra).

Interviewee 2:

Name: Paul

State/Territory: New South Wales

Sample Cluster: Other Catholic agency or organisation

Date of interview: Thursday, April 11, 2013

Mode of interview: In person

Biography: Paul has been an ordained Catholic priest for over twenty years and a Catholic bishop for some of this time. Paul is responsible for a metropolitan diocese within New South Wales. Paul has completed formal studies in theology, philosophy and ethics. Paul has had a considerable amount of engagement with people living with a disability through pastoral ministry. The three words or phrases that sum up his
role/organisation are: “To proclaim Christ, to proclaim Christ’s good news and that it is good news that we’re proclaiming.” (Interviewee 2: Paul).

Interviewee 3:

Name: Tracey

State/Territory: Australian Capital Territory

Sample Cluster: Other Catholic agency or organisation

Date of interview: Friday, April 26, 2013

Mode of interview: Telephone

Biography: Tracey is currently working for the Australian Catholic Church. Tracey is a qualified teacher, who has specialised in special education, and has taught and held various senior executive positions within Catholic schools. Tracey and her husband Greg have four children living with a disability: three sons with Down syndrome and one daughter with cerebral palsy. Tracey has been a volunteer catechist within three different Catholic dioceses across the east coast of Australia spanning over a period of twenty-eight years. Within her capacity with the Australian Catholic Church, Tracey conducts retreats, seminars and workshops for seminarians, clergy and parishioners. Tracey has authored many books and articles on similar themes. The three words or phrases that sum up her role/organisation are: “enthusiastic, affirming and spirit-filled.” (Interviewee 3: Tracey).

Interviewee 4:

Name: Melinda

State/Territory: Northern Territory
Sample Cluster: Other Catholic agency or organisation

Date of interview: Friday, April 26, 2013

Mode of interview: Telephone

Biography: Melinda is of Italian heritage, having arrived in Australia in her young adult years. Since moving from Adelaide, Melinda has lived in Alice Springs for the past sixty years. She was diagnosed with poliomyelitis when she was seven years old. Melinda’s background in disability has been through working for the Northern Territory Health Department, and, in more recent years, managing a not-for-profit advocacy office catering for people living with a disability. Melinda is also involved in her local parish and assists the Australian Catholic Church in varying capacities relating to disability issues. The three words or phrases that sum up her role/organisation are: “committed, [our association] represents a broad range of disability and leadership.” (Interviewee 4: Melinda).

Interviewee 5:

Name: Phillip

State/Territory: New South Wales

Sample Cluster: Other Catholic agency or organisation

Date of interview: Friday, May 17, 2013

Mode of interview: Telephone

Biography: Phillip was ordained as a Catholic priest twelve years ago and is currently parish priest of a large parish within a regional New South Wales diocese. The parish also has a large primary school. Prior to his ordination, Phillip worked as a full-time chaplain in the Australian Defence Forces and held a variety of occupations, ranging
from studying at university to working as a chartered accountant and as a worker on his family property. Phillip has a close friend who lives with a severe disability, which led Phillip to a greater awareness of disability issues in his preparation for ministry. The three words or phrases that sum up his role/organisation are: “spirit, driven and mission.” (Interviewee 5: Phillip).

**Interviewee 6:**

**Name:** Greg  
**State/Territory:** Australian Capital Territory  
**Sample Cluster:** Other Catholic agency or organisation  
**Date of interview:** Tuesday, May 21, 2013  
**Mode of interview:** Telephone  
**Biography:** Prior to meeting his wife and starting a family, Greg had no personal experience of disability at all. He grew up in a family that did not have any people living with a disability and went through school not knowing anyone with a disability either. Greg and his family are heavily involved in their local parish in various ministries. Greg does not have any formal qualifications in disability; however, he has represented and spoken on behalf of the Australian Catholic Church on disability issues. The three words or phrases that sum up his role/organisation are: “experienced, faith-filled and inspirational.” (Interviewee 6: Greg).

**Interviewee 7:**

**Name:** Carmel  
**State/Territory:** Australian Capital Territory
Sample Cluster: Other Catholic agency or organisation

Date of interview: Thursday, June 13, 2013

Mode of interview: Telephone

Biography: Carmel is a higher degree research student researching the spiritual practices and narratives of L’Arche, as well as the spirituality of its founder, Jean Vanier. Carmel has published and presented papers widely on these topics. She is also a member of a large metropolitan L’Arche community, and serves as a representative on its council and Spiritual Life committees. Carmel has completed courses in spiritual leadership and clinical pastoral education. Carmel enjoys writing, reading and simply listening to others. The three words or phrases that sum up her role/organisation are: “mercy, compassion and gospel values.” (Interviewee 7: Carmel).

Interviewee 8:

Name: Brianna

State/Territory: New South Wales

Sample Cluster: Catholic social care agency

Date of interview: Thursday, June 20, 2013

Mode of interview: In person

Biography: Brianna is a migrant from Malta, who arrived in Australia when she was four years old. Brianna has a connection with disability through the birth of her son, Ricky, who has Down syndrome. Ricky was educated through the public school system for primary school and then attended a Catholic high school that caters for people living with a disability, both of which schools are located in the northern suburbs of Sydney. Ricky now works, has a girlfriend and lives a fairly active lifestyle. Brianna has
advocated extensively for disability services and helped establish a transition to work program within a Catholic diocese in New South Wales. Brianna owns her own publishing company. The three words or phrases that sum up her role/organisation are: “understanding, compassion and community.” (Interviewee 8: Brianna).

Interviewee 9:

Name: Lana
State/Territory: New South Wales
Sample Cluster: Catholic social care agency
Date of interview: Thursday, July 18, 2013
Mode of interview: Telephone
Biography: Lana is currently employed as an operations manager within a Catholic social care agency in New South Wales. Her responsibilities include the overall management of the following programs: disability services; clinical support and counselling teams; youth services; and community development. Lana was educated through the Catholic school system and was raised in a family of practising Catholics. However, her desire to serve others has underpinned her motivation to work in the area of social services and has been the trigger to undertake further study and research in this very important area. The three words or phrases that sum up her role/organisation are: “passionate, dedicated and lively.” (Interviewee 9: Lana).

Interviewee 10:

Name: Leonie
State/Territory: South Australia
Sample Cluster: Other Catholic agency or organisation

Date of interview: Thursday, July 18, 2013

Mode of interview: Telephone

Biography: Leonie has been a paraplegic from birth. However, this certainly does not define her as a person. Leonie is an accomplished sportswoman and was recently acknowledged as one of Australia’s greatest paralympians of all time. Leonie is married with two adult children, and now two grandchildren, whom she minds on a regular basis. Leonie is also a volunteer for a physical disability association and is a member of her local parish council. The three words or phrases that sum up her role/organisation are: “inclusive, welcoming and at home.” (Interviewee 10: Leonie).

Interviewee 11:

Name: Lewis

State/Territory: Victoria

Sample Cluster: Catholic school education system

Date of interview: Wednesday, July 24, 2013

Mode of interview: Telephone

Biography: Lewis’ professional background is in teacher education. He has worked in the Catholic school system in a variety of different roles for the past thirty-odd years. Prior to his present role, he was a principal of two Catholic secondary schools, one rural and one suburban. Lewis has been employed in his current role for the past seven years. It involves oversight of religious education across the primary and secondary schools of a small regional Catholic diocese in Victoria. He has extensive academic qualifications, including a doctorate in education. Lewis claims that there is no point in teaching if you
are not willing to demonstrate that you are open to learning. The three words or phrases that sum up his role/organisation are: “hospitality, support and recognition of difference.” (Interviewee 11: Lewis).

Interviewee 12:

Name: Dale

State/Territory: Victoria

Sample Cluster: Catholic social care agency

Date of interview: Wednesday, July 24, 2013

Mode of interview: Telephone

Biography: Dale has been a director of a small Catholic social care agency in rural Victoria for the past twenty years. Prior to this, he was a member of a religious order. During his time in the order, he managed a welfare agency and served as chairperson and a committee member on a number of different national peak bodies. Dale is now married. His wife has worked in disability services for many years, and they share a beautiful relationship with the children of some friends who have autism spectrum. Dale and his wife have adult children. The three words or phrases that sum up his role/organisation are: “responsive, respectful and we’ll give it a go!” (Interviewee 12: Dale).

Interviewee 13:

Name: Janine

State/Territory: New South Wales

Sample Cluster: Other Catholic agency or organisation
Date of interview: Wednesday, July 24, 2013

Mode of interview: Telephone

Biography: Janine started her working life as a trained Catholic school teacher; however, for the past twenty-five years, she has worked in pastoral ministry in a number of parishes and dioceses, with varied roles and responsibilities. These roles have included serving as a pastoral associate within a number of different parishes as well as a pastoral planner with families and children living with a disability. Janine’s current role involves coordinating family life ministries and the areas of supporting “cradle-to-grave” ministry to families across the life cycle and respect life issues. The three words or phrases that sum up her role/organisation are: “pastoral, caring and progressive.” (Interviewee 13: Janine).

Interviewee 14:

Name: Jerome

State/Territory: New South Wales

Sample Cluster: Catholic social care agency

Date of interview: Thursday, July 25, 2013

Mode of interview: In person

Biography: Jerome grew up in northern New South Wales and moved to Sydney when he was thirteen. As soon as he left school, he entered the seminary for a vocation in the priesthood. During this time, he studied in both Australia and Rome. After his ordination, Jerome spent a number of years working in different parishes across the Sydney metropolitan area. After battling a few mental health issues, Jerome eventually left the priesthood and returned to study psychology, while working in a state
government department. During this time, Jerome met his wife and began working for a small Catholic diocesan social care agency as its inaugural executive director. Jerome worked in this position for the remaining twenty years of his working life. Jerome developed a unique friendship with Shaun, a quadriplegic whom he met during his time as a public servant. They are still in contact with one another today. The three words or phrases that sum up his role/organisation are: “community, people and relationships.” (Interviewee 14: Jerome).

Interviewee 15:

Name: Jacqui

State/Territory: New South Wales

Sample Cluster: Catholic social care agency

Date of interview: Tuesday, July 30, 2013

Mode of interview: Telephone

Biography: Jacqui is employed as a service coordinator in ageing and disability services within a Catholic social care organisation in metropolitan Sydney. Under this umbrella, she coordinates respite activities, leisure activities and day activities. Jacqui and her team currently support over one hundred clients across eight different programs, which also include a community visitor scheme for residents in aged care homes. Jacqui has worked in the disability field for over twenty years. Jacqui has completed a number of different degrees, concerning primary teacher education, habilitation, counselling, and disability. Jacqui has held a number of jobs, which have included work for state government departments, the Cerebral Palsy Alliance and ministry within jails for inmates living with a disability. The three words or phrases that sum up her
role/organisation are: “non-discriminatory, respectful and aware of clients and their rights.” (Interviewee 15: Jacqui).

Interviewee 16:

Name: Robert

State/Territory: New South Wales

Sample Cluster: Catholic school education system

Date of interview: Wednesday, July 31, 2013

Mode of interview: Telephone

Biography: Robert is currently employed as director of Catholic schools in a New South Wales diocese. He has occupied this position in an acting and permanent capacity for the past seven years. Immediately prior to this, Robert was an assistant director of schools and an education consultant in the same diocese; and before this, Robert was an education consultant, a principal and teacher in Catholic schools throughout New South Wales. Although Robert does not have any direct contact with a person living with a disability (in terms of his immediate family and friends), he has certainly enrolled many students with disability, ranging from cerebral palsy, to deafness, to Down syndrome. The three words or phrases that sum up his role/organisation are: “open, inclusive and supportive.” (Interviewee 16: Robert).

Interviewee 17:

Name: Karla

State/Territory: New South Wales

Sample Cluster: Other Catholic agency or organisation
**Date of interview:** Wednesday, August 7, 2013

**Mode of interview:** Telephone

**Biography:** Karla has two children who both have a disability: her adult daughter, Rhonda, who has Down syndrome (diagnosed at birth), and her adult son, Steven, who has Asperger’s syndrome (diagnosed at the age of four). Karla’s professional background is in secondary English school teaching. Karla converted to Catholicism in 1998, when she met her husband. Prior to this, she was a Protestant. Weekly Mass attendance is the norm, and as a family, they fulfil various roles in their local parish, including those of special minister of the Eucharist, reader, and altar server; some are also members of the parish council and the parish finance committee. The three words or phrases that sum up her role/organisation are: “too inclusive (to its own detriment), generally warm and welcome.” (Interviewee 17: Karla).

**Interviewee 18:**

**Name:** Margaret

**State/Territory:** New South Wales

**Sample Cluster:** Other Catholic agency or organisation

**Date of interview:** Wednesday, August 7, 2013

**Mode of interview:** Telephone

**Biography:** Margaret is married with two teenage children and works part-time as a disability support worker for a Catholic social care organisation in New South Wales. Margaret commenced her current employment with this agency in January 2013 and continues to teach painting to apprentices at TAFE. Margaret empowers her clients by letting them choose what they would like to do for their excursions, which include

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regular visits to the beach, bushwalking and shopping. Margaret has also completed various short vocational training courses in disability studies. The three words or phrases that sum up her role/organisation are: “caring, wonderful and compassionate.” (Interviewee 18: Margaret).

Interviewee 19:

**Name:** Andrew

**State/Territory:** New South Wales

**Sample Cluster:** Catholic school education system

**Date of interview:** Thursday, August 8, 2013

**Mode of interview:** In person

**Biography:** Andrew is a seasoned Catholic educator, having commenced as a classroom teacher and progressed to a year coordinator, subject coordinator, assistant principal and then principal of a secondary school. Following this, Andrew held a number of roles within a Catholic Education Office in New South Wales, and more recently, he has been employed at a Catholic university in New South Wales. Andrew also has a longstanding relationship with a Catholic community that caters for adults living with a disability. The three words or phrases that sum up his role/organisation are: “not inclusive, systematised and not prepared to welcome.” (Interviewee 19: Andrew).

Interviewee 20

**Name:** Martha

**State/Territory:** New South Wales
Sample Cluster: Other Catholic agency or organisation

Date of interview: Thursday, August 8, 2013

Mode of interview: Telephone

Biography: Martha is a religious sister who coordinates a small community house in Inner West Sydney for a group of men and women who are homeless and are living with a disability, usually mental illness or some form of intellectual disability. The community in which Martha coordinates provides a caring setting where people feel at home and develop the skills and attributes for one to become independent, should one choose to. Martha taught in religious education in Catholic secondary schools for many years and then trained school executives at a Catholic Education Office in New South Wales. Martha has graduate qualifications in psychology, pastoral studies and religious studies. The three words or phrases that sum up her role/organisation are: “unpredictable, sometimes impossible and enjoyable.” (Interviewee 20: Martha).

Interviewee 21:

Name: Katrina

State/Territory: New South Wales

Sample Cluster: Catholic social care agency

Date of interview: Thursday, August 29, 2013

Mode of interview: Telephone

Biography: Katrina has worked in the disability sector for approximately eighteen years, beginning with working in day program settings providing day activities and community access for adults living with disability. Throughout this time, Katrina has developed several therapy activities and music activities for her clients, most of whom
have extreme and challenging behaviours. She is also working towards completing her master’s degree in community management. In her most recent role with a Catholic social care agency in greater Western Sydney, Katrina manages the disability activities and four community houses where people living with a disability live in community with one another. The three words or phrases that sum up her role/organisation are: “support them [clients] to develop spiritually, emotionally and to be connected in their communities.” (Interviewee 21: Katrina).

Interviewee 22:

Name: Patrick

State/Territory: Queensland

Sample Cluster: Other Catholic agency or organisation

Date of interview: Wednesday, September 11, 2013

Mode of interview: Telephone

Biography: Patrick migrated to Australia in 1960 from Holland. Patrick grew up in Brisbane and, after his secondary schooling, he joined the army and completed officer training and served as an army officer throughout Australia, the United States of America, Canada and the United Kingdom. In 1983, Patrick and his wife adopted their daughter, Amy, who is living with Down syndrome. In more recent times, Patrick was ordained a deacon in the Catholic Church. He ministers to remote parish communities in Queensland and likes to travel with his family. Patrick is completing a master of theology, which will, in turn, complement his ministry. The three words or phrases that sum up his role/organisation are: “challenging, it’s instituted by God and different versions of the Church, different models of the Church.” (Interviewee 22: Patrick).
**Interviewee 23:**

**Name:** Camilla

**State/Territory:** New South Wales

**Sample Cluster:** Other Catholic agency or organisation

**Date of interview:** Thursday, September 19, 2013

**Mode of interview:** Telephone

**Biography:** Camilla is a registered nurse who is currently running her own specialised training and consultancy business. She has over thirty years’ experience in training professionals in the nursing, aged care and work health safety sector. Camilla has three sons; her second eldest, Aiden, is living with Down syndrome. Camilla and her family are involved in various ministries within their local parish on the Northern Beaches of Sydney. The three words or phrases that sum up her role/organisation are: “supportive, supportive and supportive.” (Interviewee 23: Camilla).

**Interviewee 24:**

**Name:** Bethany

**State/Territory:** Western Australia

**Sample Cluster:** Other Catholic agency or organisation

**Date of interview:** Thursday, September 19, 2013

**Mode of interview:** Telephone

**Biography:** Bethany coordinates a Catholic deaf community in Western Australia. In the early 1980s, the Catholic Church in Western Australia conducted some research on what the Church was actually offering people who were hearing impaired and their
families. Out of that emerged a concept of a self-help place that would be directed by people for people; it would be facilitated by people themselves as volunteers. Bethany has postgraduate qualifications in special education, theology and addictive behaviours. Bethany has been involved in deaf ministry for several years and is competent in AUSLAN – interpreting at masses and other Church events. The three words or phrases that sum up her role/organisation are: “image of God, Body of Christ and on a journey together.” (Interviewee 24: Bethany).

Interviewee 25:

Name: Veronica

State/Territory: Tasmania

Sample Cluster: Other Catholic agency or organisation

Date of interview: Wednesday, September 25, 2013

Mode of interview: Telephone

Biography: Veronica is the executive officer of a Catholic social justice group that assists people living with a disability with employment support. The group is an Australian disability enterprise that is partly funded by the Commonwealth Government to provide employment and training in a knitting mill for people living with an intellectual disability. They produce knitted fabric and create school and corporate knitwear, which is distributed to all areas of Australia. Veronica has vast experience working in similar social justice agencies. The three words or phrases that sum up her role/organisation are: “we are more than a place of work, caring environment and we provide much needed service within the community.” (Interviewee 25: Veronica).
4.5.2. INSTRUMENTS

The only instruments used throughout the research were a digital voice recorder and an interview schedule. The digital voice recorder was used to record the voices of the interviewer and the interviewee during the interviews. The researcher made every effort to ensure that the recorder was reliable for the duration of each interview. The researcher even changed the batteries after each interview, considering that some of the interviews were lasting longer than sixty minutes. A professional transcription company (Digital Transcripts) was used to transcribe the recorded interviews at a cost that was covered by the researcher’s university. Interviews were guided and framed by an interview schedule that was constructed before the interviews took place.108 An interview schedule can be best defined as “the guide an interviewer uses when conducting a structured interview. It has two components: 1) a set of questions designed to be asked exactly as worded, and 2) instructions to the interviewer about how to proceed through the questions.”109 The interview schedule for the thesis research was comprised of six formal questions; these were the only questions approved in the Human Research Ethics Application110 and, therefore, they were the only questions the researcher was able to ask during the interviewing process. This obviously excluded any general introductory and/or demographic questions, asking about name, occupation, personal background and so on.111 The interview questions were constructed after performing the literature reviews noted in Chapters One and Two above in order to

108 See Appendix D.
110 See Appendix A.
111 Fowler Jr., “Interview Schedule,” 520.
establish which key issues it would be beneficial to investigate.\textsuperscript{112} The researcher formulated the interview questions in consultation with the supervisory team. The six formal interview questions that were approved were:

\textbf{Table 1: Interview Questions}

1. I wonder if you could share with me your understanding of inclusion of people living with a disability in terms of the current Church community?
2. What do you see as the values and objectives of current initiatives?
3. To what extent does policy and public statements concerning inclusion match up with actual practices?
4. From your direct experience, to what degree are resources directed toward proactive inclusionary processes and practices?
5. How would you describe and characterise a more inclusive Church community? What might this involve?
6. What accommodations in terms of architectural layout, access and modifications to liturgy and worship can you think of? What possible changes can you suggest?

\textbf{4.6. DATA ANALYSIS}

Data analysis is often referred to as the most significant part of the qualitative research process.\textsuperscript{113} In this section, the reasons why a traditional manual approach to data

\textsuperscript{112} Kvale, \textit{Interviews}, 20.
analysis was undertaken are outlined; arguments are extended to explain why the use of qualitative data analysis software was not chosen for this research project; the analysis process is outlined; and the terms of reference for the thematic categories are listed.

4.6.1. QUALITATIVE DATA ANALYSIS SOFTWARE

It is well documented that qualitative data analysis software programs, such as NVivo, The Ethnograph, XSite, MaxQDA and ATLAS. ti, provide tangible benefits to the researcher. However, in the case of this thesis, a decision was made between the researcher and the supervisory team to not use a qualitative data analysis software program. The rationale for following a manual/traditional approach was based on the view that the benefits of deep immersion in the data outweighed the otherwise reported benefits of computer-assisted data analysis.

Pamela S. Maykut and Richard E. Moorehouse assert that while they support, in principle, computer-assisted methods of qualitative data analysis, they caution that the more hands-on approach is in practice more reliable and maintains closer connection to the phenomena being explored. Similarly, Michael Agar argues that computer-

assisted data management has significant drawbacks. In particular, they do not allow the “simultaneous visual access to materials that generate ideas.” Moreover, Thomas J. Richards and Lyn Richards concur when they argue that “computers offer no instant solutions to the problems faced by qualitative researchers, because the data they handle are particularly resistant to tidy processing methods and the methods they use are very unlike the techniques computers easily support.” In other words, there is no substitute for a trained researcher consulting the whole transcript to look for nuances such as patterns, themes and categories.

4.6.2. PHASES OF THE ANALYSIS

Thematic analysis was chosen as the method to interpret the data for the thesis. Such analysis has been described by Braun and Clarke as: “a method for identifying, analysing and reporting patterns (themes) within data.” Thematic analysis can be quite a complex method to understand and there are plenty of qualitative researchers who are opposed to it, for various and conflicting reasons. The researcher, upon reviewing the qualitative research literature, decided this was the most appropriate method to use to analyse the data. When talking about “themes emerging” it:

119 Richards and Richards, “Computers,” 211.
122 See Braun and Clarke, “Thematic Analysis,” 79–82.
can be misinterpreted to mean that themes “reside” in the data, and if we just look hard enough they will “emerge” like Venus on the half shell. If themes “reside” anywhere, they reside in our heads from our thinking about our data and creating links as we understand them.¹²⁴

In the context of this research project, the researcher defines a theme or a thematic category as a subject area (see Table 2 below) – controversial, passive, benign or otherwise – that constantly appears and re-appears throughout the interview transcripts during the preliminary analysis. The themes were double checked by the principal supervisor of this project and this formed the reflexive process that the researcher engaged in order to discern appropriate themes. Before the interview data was analysed, the researcher subjected it to a preliminary analysis, and, from this, the researcher developed a broad range of discerned thematic categories. These were used as markers in terms of analysing recurrent themes and patterns in the interview transcripts. The researcher went to the extent of counting the number of occurrences of the thematic categories in each interview transcript, prior to collating these in a table under each question subheading mentioned in the preceding chapter. Ongoing reliability checks were undertaken by way of consultation and verification by the reference group assisting in the supervision of the qualitative analysis.¹²⁵ The following table, Table 1, presents these thematic categories.

### 4.6.3. THEMATIC CATEGORIES: TERMS OF REFERENCE

**Table 2: Thematic Categories: Terms of Reference**

<table>
<thead>
<tr>
<th>NO.</th>
<th>THEMATIC CATEGORY AND DESCRIPTION</th>
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<table>
<thead>
<tr>
<th></th>
<th>Broader concept and demarcation</th>
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<tbody>
<tr>
<td></td>
<td>The interviewee differentiates between physical disability, intellectual disability and mental health.</td>
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<thead>
<tr>
<th></th>
<th>Intellectually disabled are largely unaddressed, incredibly marginalised</th>
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<tbody>
<tr>
<td></td>
<td>The interviewee stresses that people living with an intellectual disability are largely unaddressed, as opposed to people living with a physical disability. This then leads to people living with an intellectual disability being incredibly marginalised. The interviewee mentions that he or she is juggling the needs of people living with a physical disability with a significant sense and awareness of the dire plight of people living with an intellectual disability.</td>
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<tr>
<th></th>
<th>Role of advocacy</th>
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<tbody>
<tr>
<td></td>
<td>The interviewee stresses the worth of advocacy and social activism and highlights the importance of his or her agency, organisation or the Catholic Church in general in being advocates for people living with a disability.</td>
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<thead>
<tr>
<th></th>
<th>Gender issues</th>
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<tr>
<td></td>
<td>The interviewee refers to gender inequity.</td>
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<th></th>
<th>Potential for creative or alternative models of inclusion</th>
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<tr>
<td></td>
<td>The interviewee mentions a creative or alternative model of inclusion, somewhat different from populist, mainstream examples, and different practices of connecting with people living with a disability.</td>
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<tr>
<th></th>
<th>Empowerment</th>
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</table>
|   | The interviewee stresses the importance of empowering people living with a disability. Adams defines empowerment as “the capacity of individuals, groups and/or communities to take control of their circumstances, exercise power and
achieve their own goals.” This can be contrasted with a controlling and institutional approach.

<table>
<thead>
<tr>
<th>7</th>
<th>Person-centred, client/patient focused</th>
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</thead>
<tbody>
<tr>
<td>The interviewee mentions that Catholic services are often seen to be person-centred, client/patient-focused by their very mission and existence.</td>
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<tr>
<th>8</th>
<th>“Bottom up” approach</th>
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<tbody>
<tr>
<td>The interviewee stresses the need for a “bottom up” approach, in that proactive attempts for inclusion and belonging are driven at the grassroots level (e.g. local parishes and dioceses) – a “bottom up” rather than an authoritarian “top down” approach.</td>
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<tr>
<th>9</th>
<th>Rhetoric versus reality</th>
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<tbody>
<tr>
<td>The interviewee recalls rhetoric, superficial catchphrases or euphemisms that are not coupled with tangible, practical examples of inclusion.</td>
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<tr>
<th>10</th>
<th>Aspirational rhetoric</th>
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<tbody>
<tr>
<td>The interviewee’s comments seem to be very aspirational – less focused on real change. The question that remains unanswered here is: How do the processes and practices link or facilitate action and change?</td>
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<tr>
<th>11</th>
<th>Lack of funding and token policy initiatives</th>
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<tr>
<td>The interviewee highlights the lack of funding to implement inclusionary practices and processes.</td>
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<tr>
<th>12</th>
<th>Reality testing</th>
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<tbody>
<tr>
<td>The interviewee generally links with earlier constructs. Sometimes we have</td>
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ideals, but they cannot be made a reality.

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<thead>
<tr>
<th>13</th>
<th><strong>Demonstrated action, but largely only physical accommodations</strong></th>
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<tr>
<td></td>
<td>The interviewee mentions that there have been instances where</td>
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<td>action has occurred, but typically only action that</td>
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<td></td>
<td>accommodates people living in a wheelchair (e.g. by</td>
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<td></td>
<td>providing ramps, greater spacing between pews).</td>
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<tr>
<th>14</th>
<th><strong>Lack of awareness</strong></th>
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<tr>
<td></td>
<td>The interviewee highlights the lack of awareness of what</td>
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<td></td>
<td>disability actually is, which obviously leads to gaps in</td>
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<td></td>
<td>the Church’s attempts to include people living with a</td>
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<td></td>
<td>disability.</td>
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<tr>
<th>15</th>
<th><strong>Tension surrounding jargon and intellectual spin</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee hides behind jargon or technical language</td>
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<td></td>
<td>and/or intellectual spin. This often involves the word</td>
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<td></td>
<td>“inclusion.”</td>
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<tr>
<th>16</th>
<th><strong>Responsibility of the wider Church community</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee acknowledges the importance of participation</td>
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<td>by the entire Church community. The interviewee mentions</td>
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<tr>
<td></td>
<td>that valuing the personhood of people living with a disability must be a Churchwide commitment and then be seen as pivotal and part of every individual parishioner’s responsibility.</td>
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<tr>
<th>17</th>
<th><strong>Positive affirmation – highlighting existent positive examples</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The interviewee provides positive affirmation (positive feedback) about a particular program or initiative, or more broadly speaking, e.g. “I think it’s something that Catholic services per se do incredibly well.”</td>
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</tbody>
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<table>
<thead>
<tr>
<th>18</th>
<th><strong>Demonstrated action</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee recounts a particular instance where demonstrated action towards inclusion was evident within their organisation.</td>
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<tr>
<td>19</td>
<td><strong>Role of personal philosophy and value base</strong></td>
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<td>------------------------------------------------</td>
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<td></td>
<td>The interviewee confesses that they do not have an extensive understanding of Catholic social teaching, particularly Catholic service care principles; however, their ministry is driven by broader personal values. Not all employees are on the same wavelength or the same page – this increases the risk of fragmentation. It is very often the case that care workers are not linked to the Catholic tradition – this could create parallel, divergent practices.</td>
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<tr>
<th>20</th>
<th><strong>Assumption of Catholic stance</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee assumes that his or her organisation’s social justice principles come from “Catholic ethos,” broadly speaking.</td>
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<tr>
<th>21</th>
<th><strong>Room for improvement</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee acknowledges the need for improvement in his or her outreach to people living with a disability.</td>
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<thead>
<tr>
<th>22</th>
<th><strong>Neoliberal management – cost initiatives vs addressing real needs</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee states that his or her organisation is managed in a way that is driven by economic rationales, rather than by genuine attempts to achieve social justice and inclusion. The interviewee acknowledges that his or her organisation’s operational arm must have a business case and fit within the business principles of the overall organisation.</td>
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<table>
<thead>
<tr>
<th>23</th>
<th><strong>Role of volunteers</strong></th>
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</table>
|    | The interviewee stresses the role of volunteers in realising the dream of full inclusion of people living with a disability. Further, the interviewee might also acknowledge “there is a massive untapped resource of volunteers who want to do good” – but how? by what directives and goals? Again, is this “good-
**doism” that is merely “window-dressing, feel-good” rhetoric?**

<table>
<thead>
<tr>
<th>24</th>
<th><strong>Limited recognition of Catholic culture building</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee highlights the limited reality of Catholic culture building, although he or she is working in a Catholic organisation that attempts to “operationalise Catholic ethos throughout [its] programs and staff.” There is a disconnection between espoused Church initiatives, and staff, who operate from differing agendas, philosophies and goals.</td>
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<tr>
<th>25</th>
<th><strong>Community engagement – reaching out</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee mentions the importance of community engagement, reaching out further than the Church community: “one does not need to be of the faith to be able to utilise the teachings and training of the Church.”</td>
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<table>
<thead>
<tr>
<th>26</th>
<th><strong>Personal enrichment</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee boasts about his or her commitment to inclusion of people living with a disability through the Catholicity of his or her organisation: “I have really appreciated the underpinnings of the faith base, in terms of the richness that you can add to how you work with people.”</td>
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<tr>
<th>27</th>
<th><strong>Personal encounter</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee re-tells a personal story or narrative, generally an encounter with an individual living with a disability. Often such personal encounters have a significant personal impact. This encounter might have been challenging or personally confronting.</td>
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<thead>
<tr>
<th>28</th>
<th><strong>Returns to personal encounter</strong></th>
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<tbody>
<tr>
<td></td>
<td>The interviewee returns to the personal encounter he or she had previously introduced. This then results in a sense of the completion of a circle.</td>
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</table>
4.7. DATA PROTECTION, ETHICS AND LIMITATIONS

Research, especially qualitative research in the social sciences, often includes the collecting and interpreting of sensitive data. While the data collected and interpreted throughout the thesis would not necessarily be considered “extremely sensitive” on any threshold assessment, the researcher takes these issues very seriously and has gone to great lengths to ensure that the data is protected, that ethical considerations are adhered to, and that limitations for the research are managed.

4.7.1. DATA PROTECTION

As noted directly above, the researcher understands the importance of protecting data in relation to the thesis, as Michael Bulmer states: “Identities, locations of individuals and places are concealed in published results, data collected are held in anonymized form, and all data kept securely confidential.”127 All interview transcripts and relevant paperwork were securely housed in a locked cabinet accessed only by the principal supervisor/investigator and student researcher. The “working data” was password-protected and encrypted to protect the identity of the interviewees. Pseudonyms were used to protect the identity of the research subjects, both people and places. Material will be stored in the Faculty of Education and Arts offices for a minimum of five years and then securely destroyed.

4.7.2. ETHICAL CONSIDERATIONS

The initial application to the Human Research Ethics Committee (HREC), seeking approval in relation to the protocol, was tendered on June 1, 2012; it received endorsement and was “peer reviewed” by Dr Barry Morris. The project was considered under L2 Low Risk Research Expedited Review by the HREC Panel on July 17, 2012. As from September 3, 2012, the status of the submission was “Conditional Approval” (reference number: H-2012-0220). The application was not subject to the L3 Full Review. The application considered a number of themes, including: clarification on how the researcher would recruit participants; notification on what contingencies were in place if a participant was to become distressed during the interview; and what action would be taken by the researcher to manage this risk; and, an explanation in the Information Statement concerning how the recipient had been identified for participation. On September 5, 2012, the submission was considered under “Expedited Review” by the Chair/Deputy Chair, and the decision on the submission was “Approved” (Reference no.: H-2012-0220).

4.7.3. LIMITATIONS

As articulated in the Preface and Thesis Introduction above, the researcher has a profound personal interest in disability issues and the Australian Catholic Church; and, as we have seen in Chapter Three, little research has been accomplished in this area; hence the importance of this research. Relevant qualitative research theory has enabled the researcher to study people’s narratives about the crucial research questions around
inclusivity of people living with a disability in the Australian Catholic Church. The researcher has modelled this component of the study on previous investigations that are similar to this one, in particular Swinton and Mowat,\textsuperscript{128} and those mentioned in the book series titled \textit{Studies in Ecclesiology and Ethnography}.\textsuperscript{129}

As with all methods of data collection, both qualitative and quantitative, issues of reliability come into question, perhaps more so for qualitative studies. One of the main reasons for this is that quantitative studies rely on “hard data,” for example statistics, calculations, numbers, equations, and so on,\textsuperscript{130} while qualitative research relies on interview transcripts, field notes, reflections and the like. Therefore, there is a greater risk of researchers “bending” their results to suit their hypothesis or outcome in qualitative research.\textsuperscript{131} In the words of O’Leary: “research is an activity that needs to be approached with discipline, rigour, and a level of standardization.”\textsuperscript{132} The fact that qualitative interviews were recorded using a reputable digital voice recorder eliminated an element of interviewer recall bias.\textsuperscript{133} Reliability in terms of conducting the interviews and the processes thereafter was addressed in the design of the research methodology “in ways that are consistent, logical, systematic, well documented, and designed to account for research subjectivities.”\textsuperscript{134} Furthermore, the implementation of

\begin{itemize}
  \item \textsuperscript{128} See Swinton and Mowat, \textit{Practical Theology}.
  \item \textsuperscript{130} Nahid Golafshani, “Understanding Reliability and Validity in Qualitative Research,” \textit{The Qualitative Report} 8, no. 4 (2003): 597.
  \item \textsuperscript{132} O’Leary, \textit{Essential Guide}, 37.
  \item \textsuperscript{133} See Kelly, “Qualitative Interviewing Techniques,” 314.
  \item \textsuperscript{134} O’Leary, \textit{Essential Guide}, 37.
\end{itemize}
cross-checking and reference group oversight through the various levels of analysis added a greater depth of reliability.\textsuperscript{135}

4.8. REFLECTIONS ON THE DESIGN AND ANALYSIS

The research method mentioned above provided a solid foundation as to how the research was conducted. As noted earlier in the thesis,\textsuperscript{136} the qualitative study into contemporary inclusionary practices in the current research will form a series of critical models of engagement to ultimately determine how effective the Australian Catholic Church is working in the area of including people living with a disability. Deborah Selway and Adrian F. Ashman propose a challenge relevant to this research:

It is only through further research in all aspects of religion and health that we can begin to learn of, and understand, the essence of the spiritual lives of persons with a disability; the influence of religious organisations and religious doctrine on the lives of people with a disability, and their families and caregivers; and the potentialities of religious belief and practice in assisting in the health and well-being of people with a disability generally. The challenge remains for researchers to continue to explore this new field of endeavour in search of the spiritual dimensions of disability.\textsuperscript{137}

The research process, especially the role of an individual qualitative researcher, can be an extremely lonely pursuit.\textsuperscript{138} One question that arose continuously in the mind of the researcher was: How can the researcher measure his performance in terms of conducting the interviews? Having studied qualitative research methods at undergraduate and

\textsuperscript{136} See Thesis Introduction, section i.6.
\textsuperscript{138} See O’Leary, Essential Guide, esp. chaps. 1 and 2.
graduate level and participated in a number of qualitative interviewing mentoring sessions with experts in the field, how does one gauge one’s performance? Perhaps the most relevant solution to this perplexing question is the constant need to apply an active and ongoing reflexivity. As was noted by the researcher earlier, given personal commitment to inclusionary practice and pursuing social justice issues, it was imperative to regularly reflect on one’s active efforts to remain detached and unbiased throughout the research process.

It will be argued here that a larger sample size would have provided the researcher with a greater and more diverse range of opinion; however, this was unfortunately not an option due to the scope of the thesis and the consequent time constraints. In any case, the recruitment of potential interviewees took place over a period of eight months and the researcher experienced a lot of resistance from various agencies, organisations, diocese and archdioceses, as mentioned above in section 4.5.1. In most cases, due to geographical difficulties, the researcher did not access the ethnographic context in which the interviewees experiences had occurred. In future studies, the ethnographic context of the interviewees’ work environment might be considered in an effort to strengthen the validity of results. Further, layers of subjective experience may have been overtly or covertly censored, given the possible perceptions of power dynamics and the researcher’s desire to report a positive portrayal.

4.9. CONCLUSION

In this chapter, an appropriate methodology for undertaking the research project was proposed as “Analysing and presenting qualitative data is one of the most confusing
aspects of qualitative research.” A number of important matters relating to qualitative research were considered, including: the literature on researching qualitatively; the research design and the research process; how the data would be collected and analysed; and ethical considerations. Additionally, attention was drawn to issues of reliability and the need for active and ongoing reflexivity on the part of the researcher, including the need for oversight and consultation with a supervisory group specifically in terms of contentious analysis issues as they arose. Most importantly, the research was conducted in accordance with the Human Ethics Policies and Guidelines of The University of Newcastle and the Australian Code for the Responsible Conduct of Research.

In the next chapter, there will be two main objectives. First, we will see the research findings examined on a question-by-question basis to identify recurrent patterns, themes and categories; and second, there will be a critique of the five key categories that emerged from the thematic analysis. The qualitative research component of the thesis yielded very stark results and findings, which will be elaborated.

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CHAPTER FIVE: RESEARCH FINDINGS

5.1. INTRODUCTION

The purpose of this chapter is twofold. First, the research findings will be examined on a question-by-question basis to identify any recurrent patterns, themes and categories. In so doing, the researcher will present a text-based analysis for each of the six interview questions, accompanied by a number-based analysis (in table form), noting how many times each of the thematic categories presented during the thematic analysis process. Second, a critique of the five key categories that emerged from the thematic analysis will be provided. The five categories are: (1) Attitudes and perceptions; (2) Inclusion; (3) Empowerment; (4) Rhetoric versus reality; and (5) Demonstrated action. It is interesting to note that the qualitative research component of the thesis yielded very robust results and findings, which will be elaborated upon in this chapter.

5.2. INTERVIEW QUESTION ONE: CURRENT INCLUSION IN THE CHURCH COMMUNITY

The interviewees were asked: I wonder if you could share with me your understanding of inclusion of people living with a disability in terms of the current Church community? When evaluating this question, most interviewees were able to clearly articulate their understanding of inclusion of people living with a disability in terms of the current Church community. There were a few, however, who were not able to state anything, for example: “I don’t have much of an understanding at all from the perspective of a church community” (Interviewee 1: Sandra). Furthermore, there were
thematic categories that were more prominent than others, for example, thematic category 2, “Intellectually disabled are largely unaddressed, incredibly marginalised,” presented twenty-four times, while thematic categories 1, 4, 9 and 28 did not appear at all.

The interviewees signposted a broad spectrum of particularly polarised and divergent opinions, ranging from “I think there is a genuine attempt to be inclusive” (Interviewee 17: Karla), to “It is not totally inclusive. I think there is a lot of work that still needs to be done . . . disability is a difficult area for people to deal with” (Interviewee 8: Brianna), to “inclusion looks very patchy in the Catholic Church today. I think inclusion is not something that the Catholic Church in Australia is particularly good at” (Interviewee 19: Andrew). One interviewee recounted the importance of not only including the person living with a disability, but his or her family, carer and/or support person as well: “my understanding of inclusion is people living with a disability, and that includes the person with the disability, and their family, or carer or support person, is just fully included in the life of the church” (Interviewee 3: Tracey).

The issue of clergy needing to take leadership on this issue was evident quite a significant number of times. Again, much of this seems to relate to a lack of basic knowledge about what disability actually is, and to training clergy about how disability should be perceived in Australia. A few excepts include: “the art of being a good pastor is actually getting to know it’s supporting good things that are happening in your parish and/or your territory, and being interested in them” (Interviewee 14: Jerome); “older priests often have old fashioned ideas that are quite wounding to families of people with
disabilities. So a lot of education is required there” (Interviewee 4: Melinda); and “I think it’s fragmented from diocese to diocese. It’s also dependent, in my opinion that it is very much to do with the parish priest or the priest of a parish and their attitude and their understanding of what disability is” (Interviewee 4: Melinda).

Quite a few interviewees explained the difficulty of promoting inclusion in the wider society (this now briefly takes us away from the “Church community” as outlined in the question) when inclusion is seen to be an unknown commodity, too hard and/or too expensive: “I think society is still fearful of disability, and they still see disability as a cost and a burden, all of those things, rather than seeing them as real people” (Interviewee 3: Tracey); “I think there is a lack of understanding about disability, what is a disability? As a consequence, people are seen not as equitable as others and in need of special pastoral care” (Interviewee 4: Melinda); and “I think it’s not because people deliberately mean to be exclusive or excluded and I don’t think – sometimes they’re so busy and so stretched that they just don’t even see that” (Interviewee 13: Janine).

Table 2 presents the number of times each thematic category emerged in the responses to Question One.

<table>
<thead>
<tr>
<th>Number</th>
<th>Thematic Category</th>
<th>Number of Occurrences</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Broader concept and demarcation</td>
<td>0</td>
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<tr>
<td>2</td>
<td>Intellectually disabled are largely unaddressed; incredibly marginalised</td>
<td>24</td>
</tr>
<tr>
<td>3</td>
<td>Role of advocacy</td>
<td>10</td>
</tr>
<tr>
<td>4</td>
<td>Gender issues</td>
<td>0</td>
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<tr>
<td>5</td>
<td>Potential for creative or alternative models of inclusion</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>Empowerment</td>
<td>12</td>
</tr>
<tr>
<td>7</td>
<td>Person-centred, client/patient focused</td>
<td>5</td>
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<tr>
<td>8</td>
<td>“Bottom up” approach</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>Rhetoric versus reality</td>
<td>0</td>
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<tr>
<td>10</td>
<td>Aspirational rhetoric</td>
<td>1</td>
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<tr>
<td>11</td>
<td>Lack of funding and token policy initiatives</td>
<td>5</td>
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<tr>
<td>12</td>
<td>Reality testing</td>
<td>14</td>
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<td>13</td>
<td>Demonstrated action, but largely only physical accommodations</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>Lack of awareness</td>
<td>11</td>
</tr>
<tr>
<td>15</td>
<td>Tension surrounding jargon and intellectual spin</td>
<td>2</td>
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<tr>
<td>16</td>
<td>Responsibility of the wider Church community</td>
<td>6</td>
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<tr>
<td>17</td>
<td>Positive affirmation – highlighting existent positive examples</td>
<td>3</td>
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<tr>
<td>18</td>
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<td>4</td>
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<tr>
<td>19</td>
<td>Role of personal philosophy and value base</td>
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<td>20</td>
<td>Assumption of Catholic stance</td>
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<td>21</td>
<td>Room for improvement</td>
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<td>22</td>
<td>Neoliberal management – cost initiatives vs addressing</td>
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<td>real needs</td>
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<td>23</td>
<td>Role of volunteers</td>
<td>1</td>
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<tr>
<td>24</td>
<td>Limited recognition of Catholic culture building</td>
<td>3</td>
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<tr>
<td>25</td>
<td>Community engagement – reaching out</td>
<td>3</td>
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<td>26</td>
<td>Personal enrichment</td>
<td>3</td>
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<tr>
<td>27</td>
<td>Personal encounter</td>
<td>1</td>
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<tr>
<td>28</td>
<td>Returns to personal encounter</td>
<td>0</td>
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5.3. INTERVIEW QUESTION TWO: VALUES AND OBJECTIVES OF CURRENT INITIATIVES

The interviewees were asked: *What do you see as the values and objectives of current initiatives?* This question allowed the interviewees to recall current initiatives that they might be coordinating, or at the very least know of, in their particular contexts. Further, the interviewees were asked to comment on the value and objective of these current initiatives. All but three interviewees were able to recall at least one document, program and/or resource and most just focused on one initiative as opposed to numerous. Those who were not able to comment stated: “*Sorry I really don’t know of anything. Nothing much at all, no*” (Interviewee 10: Leonie); “I’m reasonably connected into the [. . .] diocese now and we’ve actually been through a synod process a while back and I must say that I can’t think of any particular program of inclusion in the entire diocese” (Interviewee 22: Patrick); and “as far as particular programs are concerned, we wouldn’t – I’m not aware of particular kind of programs, as such” (Interviewee 11: Lewis).
There were examples of resources being created and made use of in the Church, for example: “What I’m hearing back from the parishes around Australia, is that the kits and resources that I’ve prepared are slowly being used during international days for people with disability” (Interviewee 3: Tracey); “Some years ago, [...] edited a book around the giftedness of people who had intellectual disability. I mean that’s a real positive that that book came about” (Interviewee 7: Carmel); and “I was part of a working group who, with the support of the bishops, produced a booklet called [...] So it’s only a little booklet, it’s an excellent booklet that was re-launched by the bishops a couple of years ago [... and we certainly know of some parishes in Australia that have taken that book on in the pastoral council and done some great things and that’s still current. I think that’s a very good initiative of the bishop’s [sic] conference” (Interviewee 6: Greg).

There were a number of interviewees who highlighted their personal attempts to effect a positive contribution; however, surprisingly, a few stated that this was not reciprocated by people or organisations external to their own context, for example: “I’m trying to promote relationships with people and also encouraging the government to look at social justice, work payments for support workers, because support workers are very lowly paid” (Interviewee 3: Tracey); and “Priests need to be talking more specifically about minority groups. I don’t hear it enough from priests and I think they are the people who should direct their parishioners to do that” (Interviewee 8: Brianna).
The interviewees who classified themselves as “clergy” referred to a number of profound theological concepts, for example: “I think the values are recognising the importance of every human person in line with our biblical and theological understanding of God’s creation” (Interviewee 5: Phillip). We will revisit this example and a few others in the following chapter. The interviewees from the social care cluster, namely Dale and Lana, said that external pressures, such as the National Disability Insurance Scheme,¹ were forcing them to change their approach to disability service provision, for example: “I think that’s going to have a major impact [the NDIS] – it’s one of these epoch periods in welfare and I think some of us will be out of business” (Interviewee 12: Dale); “It [the NDIS] makes us think we need to move away from the traditional sense of being block funded which is just getting the current funding to looking at a real consumer driven market” (Interviewee 9: Lana); and “We’ve just undergone a restructure to better align our service provision to the Disability Services Standards and so that we can have a stronger focus on person-centric care” (Interviewee 9: Lana).

There were a number of innovative examples of current initiatives that the interviewees were coordinating, for instance:² “We have – the last 12 months really we’ve got now a group of people who are actually doing a certificate IV in Bible Studies through the local faith centre here and that’s connected with the University of Johannesburg” (Interviewee 24: Bethany); “we are providing a service in the fact – well all actually of the people that we have here with intellectual disabilities, if they didn’t work at [. . .].

¹ This Australian national policy initiative is having a profound effect towards encouraging the recognition of the rights and needs of people living with a disability. See Preface above.
probably wouldn’t find employment elsewhere. Therefore, we don’t only provide employment for them, but we provide assistance with life skills, and training in life skills, which makes it possible for them to live within the broader community in an independent manner” (Interviewee 25: Veronica); and “We’ve employed a person who has a disability and mental health problems and his role is to be a voice for the clients and represent their views within our agency” (Interviewee 12: Dale).

Continuing on from Question One, one interviewee, Andrew, commented that he would more likely collect inclusion resources from another Christian denomination, and even from another part of the world: “The only thing I’m aware of is that document I Have a Story and the committee that put out a newsletter. In terms of say resources for inclusion I’d actually be much more inclined to go to Protestant sources” (Interviewee 19: Andrew); and “There are great Catholic resources from the US and UK and a Christian vision impaired group in Melbourne. But I’m not aware of anything like that in the Australian Catholic community” (Interviewee 19: Andrew).

Table 3 presents the number of times each thematic category emerged in the responses to Question Two.

**Table 4: Interview Question Two**

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<thead>
<tr>
<th>Number</th>
<th>Thematic Category</th>
<th>Number of Occurrences</th>
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Limited recognition of Catholic culture building

Community engagement – reaching out

Personal enrichment

Personal encounter

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5.4. INTERVIEW QUESTION THREE: POLICY AND PUBLIC STATEMENTS CONCERNING INCLUSION

The interviewees were asked: *To what extent does policy and public statements concerning inclusion match up with actual practices?* Interviewees were invited to share their opinions on whether their organisation’s policy and public statements concerning inclusion match up with actual practices. Interestingly, a number of interviewees were not entirely sure whether their organisation was in the possession of a policy and public statement concerning inclusion of people living with a disability. The researcher assumes that in most cases it is an unwritten one, as opposed to a formal written policy and public statement. Further, the researcher was keen to include this question (and the next) in the interview schedule, as it provides the unique opportunity to “test” whether the words match the action – a good litmus test as it were.

As for Question One, there was a variety of responses; however, a clear majority believed that the actual practices were not matching their policy and public statements. The responses ranged from: the policy and public statements were matching up with actual practices, for example: “I’ve always been included so I can’t really give you any
negatives. I think within my church there’s no problems about any disabled people” (Interviewee 10: Leonie); “I think that whole understanding has started to penetrate in our community in a very real way, that in fact people in the schools would embrace the opportunities to have children with disability in their midst, not only because it includes the child with the disability, but it’s teaching the others about acceptance and inclusion” (Interviewee 11: Lewis); and there were inroads being made in the policy and public statement matching up with actual practices, for example, “I think there’s always room for growth and improvement, but we really try to model ability to live up to what we say we do” (Interviewee 1: Sandra); but finally, there were instances mentioned when policy and public statements were not matching up with actual practices at all, for example, “The directives aren’t clear; I don’t know what they are, I’m just doing things as I see the need for them and as people perhaps draw certain things to my attention” (Interviewee 6: Greg); “In overall things I think probably not. I think there’s still a long way to go” (Interviewee 8: Brianna); “Well I think I’d first say that we’re really good at putting things on paper. I’m talking about the Catholic Church in general and presenting glossy pamphlets. But behind the text, the reality is always very different” (Interviewee 7: Carmel); and “generally speaking, they’re probably miles apart” (Interviewee 6: Greg).

Again, we see the repetition (from Question One and Question Four) of the idea that people living with a physical disability were by and large included, but people living with an intellectual disability were not: “it’s certainly not reached an ideal level but certainly there’s a greater awareness around physical disablement” (Interviewee 2: Paul). There were a number of interviewees (interestingly those in leadership positions)
who enforced the importance of driving grassroots inclusionary practices, that is, the
direction does not always have to come from upper management, so to speak: “It ought
not to be always about the higher authority putting in place some sort of program”
(Interviewee 2: Paul); and “So you need a catalyst. If a community doesn’t have a good
catalyst, it sort of dies in the arse, as it was.” (Interviewee 4: Melinda). One
interviewee, Melinda, mentioned that we can have all the policy and or public
statements that we like, but at the end of the day the Catholic Church in Australia needs
to be including people living with a disability because it is legislated: “I think the parish
councils need to become more aware of their obligation to the people that they are
serving. And to take on these obligations because they are legislated” (Interviewee 4:
Melinda).

Table 4 presents the number of times each thematic category emerged in the responses
to Question Three.

Table 5: Interview Question Three

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<tr>
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5.5. INTERVIEW QUESTION FOUR: RESOURCES DIRECTED TOWARDS INCLUSION

The interviewees were asked: *From your direct experience, to what degree are resources directed toward proactive inclusionary processes and practices?* Interviewees were asked to comment on whether resources within their organisation were directed towards proactive inclusionary processes and practices. From the researcher’s field notes, it became apparent that most interviewees were unclear what “resources” referred to. In this case, the researcher asked interviewees to comment on both human and financial resources.

People living with a physical disability were by and large included; however, people living with an intellectual disability were not as included in their context: “Physically [disabled], not too bad . . . Cognitively [intellectually disabled], poor although I’m aware that there are a number of religious congregations who are doing terrific work with houses for those in need” (Interviewee 2: Paul) and “People who are physically disabled are included by-and-large – it’s the intellectually disabled people who we need to worry about” (Interviewee 18: Margaret).

A few interviewees cited that inclusionary practices were “held up” due to bureaucratic processes: “Before we can even start [on a project], we need to do a budget and a business plan for it, and then we submit that to the Bishops [for consideration]. I do a
“lot of stuff on the cheap” (Interviewee 3: Tracey); and “I think that it is certainly becoming more and more of a focus and it has certainly become much more businesslike. The church is also becoming much more political” (Interviewee 8: Brianna).

A few interviewees mentioned that their respective bishops or the management of their agencies were supportive in terms of allocating ongoing resources (both financial and human resources); however, the allocation would never be enough, given the monumental gap between the rhetoric and the reality. Greg stated: “the bishops, by establishing a Council and by establishing an employment position, clearly it’s important enough for us to provide funding for it. Is it enough funding? Well, it will never be enough” (Interviewee 6: Greg) and “Not much at all – employees aren’t encouraged really to take on people with disabilities in our community because everyone’s driven by the bottom line” (Interviewee 12: Dale). Furthermore, Greg states: “I think financial resources are hard to come by in the church and so therefore many good things in the church don’t get a lot of financial support just because there’s not a lot of money going around” (Interviewee 6: Greg).

There is also the issue of ongoing expenses versus the amount of money organisations and agencies actually receive: “We’ve got quite high overheads and the higher overheads detract from the money that goes into the frontline work” (Interviewee 9: Lana) and “I would say that’s an area of difficulty. There’s intention and there’s desire, and certainly will, but the resources are actually quite stretched and increasingly so. I think schools are doing the best they can” (Interviewee 11: Lewis).
Table 5 presents the number of times each thematic category emerged in the responses to Question Four.

**Table 6: Interview Question Four**

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5.6. INTERVIEW QUESTION FIVE: CHARACTERISTICS OF A MORE INCLUSIVE CHURCH COMMUNITY

The interviewees were asked: How would you describe and characterise a more inclusive Church community? What might this involve? This question was asked to ultimately understand what each interviewee’s ideal picture of an inclusive Church community might look like. All interviewees suggested some kind of change from the status quo to their picture of an ideal inclusive Church community. The changes mentioned by the interviewees ranged from minimal tweaks, for example, “I think we
need more practice in welcoming people. I think that says it all, if we’re welcoming and friendly than [sic] we’ll find out – we’ll let people tell their stories and others will listen” (Interviewee 3: Tracey); to wide, sweeping changes, for example, “we need to educate the priests. Some of our newer priests come from other cultures. They’re not comfortable with disability and they’ve got their own cultural morays [sic] still sticking to them [people living with a disability being] untouchable. So you know it’s not accepted so they’re making – it’s like sweeping people under the mat. So I guess some of that is ignorance. How many priests know Auslan? To be able to do a deaf mass? Not many. Well, they’re missing out on the word of God . . . why should they?” (Interviewee 4: Melinda).

Finally, Lana commented that it is a bit difficult to talk about an “inclusive Church” when the Australian Catholic Church is reported to be one of the largest institutions to be caught up in the Royal Commission into Institutional Responses to Child Sexual Abuse: “I think this is a hard question to answer because I think that at the moment the Catholic Church – there are so many people who are involved in primary, secondary and tertiary forms of fallout or ramifications from all of the child sexual abuse claims that have come out and I think that that has really deterred a lot of people. The trauma that that’s put people through is quite high and I think it’s really difficult to talk about an inclusive church when all of these things are happening” (Interviewee 9: Lana) and “I think that churches aren’t always the most welcoming places. It’s not very inclusive or welcoming just going to Mass. It’s really difficult to even conceptualise what a more inclusive church would look like” (Interviewee 9: Lana).
Table 6 presents the number of times each thematic category emerged in the responses to Question Five.

**Table 7: Interview Question Five**

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5.7. INTERVIEW QUESTION SIX: ACCESSIBILITY AND MODIFICATIONS

The interviewees were asked: *What accommodations in terms of architectural layout, access and modifications to liturgy and worship can you think of? What possible changes can you suggest?* This final question of the interview schedule, in hindsight, was a difficult question to ask mainly for sample cluster one, representing the Catholic social care agencies. This is due to their line of work, which does not involve attending
a Catholic liturgy,\(^3\) as opposed to interviewees from clusters two and three, who would be attending a Catholic liturgy at least once a month as part of their employment duties. Therefore, interviewees from cluster one did not make a substantial comment in relation to this question (although a few interviewees from this cluster mentioned that they have attended a Catholic liturgy in the past for a special occasion, or a funeral and so on). Moreover, if interviewees did not frequent a Catholic liturgy, they were asked to provide comments on the inclusiveness of their workplace and its architecture, as it is an organisation/agency of the Australian Catholic Church.

All interviewees who had previously attended a Catholic liturgy suggested a number of tangible modifications, such as the installation of ramps (instead of stairs), hearing loops, accessible toilets and parking, moveable pews, good lighting, and so on. Some examples or responses include: “Some of the changes that I have made include things like putting in ramps and getting rid of steps. Putting a covered area at the front of the Church for people to gather and completely installing in the hearing loop” (Interviewee 5: Phillip); “Well I think more churches should accommodate wheelchair people within the toilet facilities, because most toilet facilities at churches are not accessible for disabled people” (Interviewee 10: Leonie); “ramps to the sanctuary so that people who are wheelchair bound have easy capacity to move around” (Interviewee 11: Lewis); and “Well the basic things are accessibility, ramps, wide ramps, and wide doorways and disabled assessed toilets, hearing loops, spacing between pews and provision of materials with Braille or large print for the hymnals, leaflets, etc.” (Interviewee 20: Martha).

\(^3\) Employees and volunteers from Catholic social care agencies do not need to profess the Catholic faith: they simply need to adhere to Catholic values and practices. This also applies to Catholic schoolteachers.
One interviewee, Paul, mentioned that architectural modifications were necessary in some instances, but what mattered most was modifying what he termed the architecture of the person, suggesting that the attitudes and perceptions of people living without a disability towards people living with a disability needed to change. He stated: “yes, we do what we can about architectural things, terrific, but far, far more fundamental is doing something about the architecture of the person not the architecture of the buildings” (Interviewee 2: Paul). Similarly, another interviewee, Janine, revealed that all programs offered by the Australian Catholic Church need to also be accessible and inclusive, that is, it does not just relate to architecture and liturgy: “I think in anything to do with accessibility that you keep it at the forefront of your mind whether – and that’s the same with even like I said, the sacramental program” (Interviewee 13: Janine). Sacramental programs need to be accessible and inclusive for children and adults who might not have the cognitive capacity to be taken through a twelve-week program, for instance.

It is apparent that Catholic schools have employed personnel to modify religious education resources for their students living with an intellectual disability, for example: “We have in our RE department work being done over time particularly for students with autism in developing resources for them in relation to their faith development and their involvement in liturgy, etc.” (Interviewee 16: Robert). It seems from the perspective of this particular interviewee, that he and his colleagues take this point very seriously: “We are utilising some kits in relation to sacramental programs for students with disabilities, we would be encouraging our parishes to take into account the nature
of a disability when a child is presenting for the sacrament. We’re very conscious of the need to support our people with special needs and I could say that we’re rather proud of what we do, not in a patting yourself on the back perspective but we are constantly checking and double checking that we’re doing as much as we possibly can” (Interviewee 16: Robert). Representatives from sample cluster two attested that for inclusion of people living with a disability in the Catholic school environment to occur, the entire community, including parents and guardians, needs to support this mission. Karla stated: “Maybe there needs to be dialogue that happens on the part of parents as well, so that they [priests] can have an appreciation of how to interact with the person” (Interviewee 17: Karla).

A couple of interviewees cited deeper theological concerns with the Catholic liturgy and worship, particularly with the new translation of the Roman Missal and its unsuitability for people living with a disability and for people in general. Bethany stated: “I believe the liturgy needs to mean something to people and I know that there’s a tendency to go too far one way in terms of, you know, bringing worship down to the common level – and I’m not saying that but I just think that there needs to be an ability to worship in a way that is going to be meaningful to people, at the same time inviting people to recognise that worshipping is not like going to a football match, it’s remembering the powerfullness and the awe of God and so it needs to be fitting for both but I’m not sure that – I’m not sure that the translations, for example, in the mass really – you know, whether that does that” (Interviewee 24: Bethany). Further, the same interviewee referred to the life of Jesus the Christ and the fact that his ministry has provided believers with a prime example of how to live an inclusive life: “I mean, if we look at
the way Jesus worked that’s the way he worked. He met people where they were at, he
told stories where people were at and then lifted them from there to a deeper
understanding of what he was trying to get across and to me I think a lot of the time the
ego of the person may get in the way of really seeing what needs to happen or what
could happen” (Interviewee 24: Bethany).

There were a few interviewees who recounted personal narratives of how the
architecture, liturgy and worship of the Catholic Church happened to be a negative
experience. For example, Melinda stated: “I think the future has to see access to the
sanctuary because the way they’re built, with the steps and all of those things, it makes
it a little difficult. We have lots of readers here. Some with disability. I used to be one
but I don’t like sitting down the bottom and being a – what shall we say? A showpiece
because you’re not in the right place and then someone’s got to bring you a
microphone, blah-blah-blah and you become a bit of a show. But to be up there, to be
able to do it up there [reading in the sanctuary], where everybody else goes. That’s the
whole point of it. You’re equal if that’s where everybody is going to read, then that’s
where everybody should be” (Interviewee 4: Melinda).

It is interesting to note that Paul returned to the notion that people living with a physical
disability were included and treated as so; however, people living with an intellectual
disability were not included. He said, for example: “people with physical disablements,
are by and large . . . treated as people. The profoundly cognitively impaired, however,
are not” (Interviewee 2: Paul). On the contrary, Karla believed that people living with a
physical disability were not being included: “certainly our church needs to be
accessible to people who are in wheelchairs, or who have some sort of difficulty which impedes their mobility” (Interviewee 17: Karla).

Table 7 presents the number of times each thematic category emerged in the responses to Question Six.

**Table 8: Interview Question Six**

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<td>6</td>
<td>Empowerment</td>
<td>17</td>
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<td>7</td>
<td>Person-centred, client/patient focused</td>
<td>2</td>
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<td>8</td>
<td>“Bottom up” approach</td>
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<td>9</td>
<td>Rhetoric versus reality</td>
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<td>10</td>
<td>Aspirational rhetoric</td>
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<tr>
<td>11</td>
<td>Lack of funding and token policy initiatives</td>
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<td>12</td>
<td>Reality testing</td>
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<td>13</td>
<td>Demonstrated action, but largely only physical accommodations</td>
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<td>14</td>
<td>Lack of awareness</td>
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<td>Tension surrounding jargon and intellectual spin</td>
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<td>16</td>
<td>Responsibility of the wider Church community</td>
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<td>17</td>
<td>Positive affirmation – highlighting existent positive examples</td>
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<td>18</td>
<td>Demonstrated action</td>
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<td>19</td>
<td>Role of personal philosophy and value base</td>
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<td>20</td>
<td>Assumption of Catholic stance</td>
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<td>21</td>
<td>Room for improvement</td>
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<td>22</td>
<td>Neoliberal management – cost initiatives vs addressing real needs</td>
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<tr>
<td>23</td>
<td>Role of volunteers</td>
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<td>Limited recognition of Catholic culture building</td>
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<td>Community engagement – reaching out</td>
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### 5.8. CATEGORY 1: ATTITUDES AND PERCEPTIONS

From the perspective of an in-depth analysis of the qualitative interview data, it is patently clear that inclusion of the disabled is much easier when one’s attitude and perception of people living with a disability reflects a positive outlook.\(^4\) It is very clear, after analysing the qualitative interview data, that the attitudes and perceptions of the

interviewees can be broken into three subcategories: attitudes and perceptions that are positive; attitudes and perceptions that are negative; and attitudes and perceptions where the onus is put back onto the bishop. Interestingly, Rosemary Leonard and June Crawford believe there are two ways of seeing people living with a disability: “attitudes at the societal level and attitudes at the personal level.” This sentiment was also evident in the qualitative interview data.

As alluded to in the Thesis Introduction above, in the early 1980s, the Richmond Report and the Disability Services Act 1986 (Commonwealth Government) were designed to ensure that people with a disability have access to the community, education, training and employment, and are not unfairly excluded or disadvantaged. Attitudes and perceptions have improved dramatically at this time because there was a trend towards enhancing the rights of people living with a disability. As we have established in Chapter Two, society has progressively moved to a concept of the person living with a disability determining what is wanted (as much as possible) – in effect the individual deciding his or her future direction. Herman P. Meininger states: “Inclusion of people with intellectual disabilities in society and in particular in faith communities greatly depends on the capacities of a community to cope with human differences in culture, character, appearance, behavior, and forms of communication.”


5.9. **CATEGORY 2: INCLUSION**

This thematic category flagged instances where the interviewee determined whether, according to their personal perspective or context, the Catholic Church in Australia is inclusive of people living with a disability (or not). Authentic inclusion is the truly conscious practice of welcoming and maintaining any person or group of people into opportunities that exist for any other person or group of people.⁷ People living with a disability – often referred to as “devalued people”⁸ – are not always afforded the same opportunity.⁹ As one can imagine, the responses in relation to this category from the qualitative interviews offered a broad spectrum of opinions, ranging from: “I’m accepted with no problems, and they smile and say hello to me and quite a lot of people within the church, a lot of them know me. I’ve never been into a church where I haven’t been accepted.” (Interviewee 10: Leonie); to “I think there is a genuine attempt to be inclusive” (Interviewee 17: Karla); to “I would think that it is fairly moderate. It is not totally inclusive. I think there is a lot of work that still needs to be done . . . disability is a difficult area for people to deal with” (Interviewee 8: Brianna); to “Inclusion looks very patchy in the Catholic Church today. I think inclusion is not something that the Catholic Church in Australia is particularly good at” (Interviewee 19: Andrew).

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⁹ See Interviewee 1: Sandra.
Authentic inclusion goes beyond merely including people living with a disability into the faith community.\textsuperscript{10} However, authentic inclusion, as it has been argued throughout the thesis, extends much further in placing people living with a disability at the heart of everything it does: to become person-centred places, people must belong, or, as Swinton points out: “To be included, you simply have to be there, but to belong, you need to be missed.”\textsuperscript{11} With the introduction and roll-out of the Australian National Disability Insurance Scheme, person-centred care has become a necessity for all social care providers, as it is a “new way of providing individualized support for eligible people with permanent and significant disability, their families and carers.”\textsuperscript{12}

As we heard from Brianna above, and throughout the qualitative interview data, it is evident that authentic inclusion is a work in progress and is something that needs to be constantly worked at. This was confirmed by Paul, who stated: “there’s significant attempts to break down barriers that lead to people who are impaired being not able to participate in the life of the Church” (Interviewee 2: Paul).

There are a number of creative examples of authentic inclusion noted in the literature, including an account where a group of deaf philosophy students are using qualified sign language interpreters so they can communicate with the teaching staff.\textsuperscript{13} There are other creative examples where faith communities are installing sensory boards to the back of

\textsuperscript{10} Jean Vanier and John Swinton, \textit{Mental Health: The Inclusive Church Resource} (Norwich: Darton, Longman and Todd, 2014), 100.

\textsuperscript{11} John Swinton, “Time, Hospitality and Belonging: A Practical Theology of Disability” (public lecture, The Broken Bay Institute, Pennant Hills, June 24, 2014). See also Vanier and Swinton, \textit{Mental Health}, 100.


certain pews to include children living with autism and other developmental disabilities.\textsuperscript{14}

There is a widespread understanding that \textit{all} human beings need to feel a sense of welcome and feel that they belong somewhere – we have “a desire for ‘home.’”\textsuperscript{15} People living with a disability often however do not feel as if their “home” is the Catholic Church, and we have seen a number of examples of this throughout the thesis. This widespread understanding, furthermore, is one of the main reasons why established clubs, sporting teams and other associations offer the chance for interested parties to become members of their group, because people feel at “home.” There are many examples of different contexts (schools) and disciplines (psychology, education, medicine, commerce, marketing) highlighting the need for authentic inclusion and genuine belonging for their disciplines to flourish.\textsuperscript{16}

Finally, for authentic inclusion and genuine belonging to be achieved, the attitudes and perceptions of people in the wider society need to change, and the terminology around disability must be clarified. We need to find a way of “defining disability beyond the

\textsuperscript{14} See Mike Duggan, \textit{Confidence and Capacity: Parish Communities Knowing and Supporting People with Disability} (Brisbane: Catholic Archdiocese of Brisbane, 2003), 109–20.
\textsuperscript{15} Thomas E. Reynolds, \textit{Vulnerable Communion: A Theology of Disability and Hospitality} (Grand Rapids, MI: Brazos, 2008), 5.
Medical Model”\(^{17}\) and make sure that our processes and practices are person-centred and inclusive of all. Swinton concurs when he states: “One of the problems in the conversation around disability is that we mis-name things. And when we mis-name things, we end up with stigma, alienation and false names.”\(^{18}\)

**5.10. CATEGORY 3: EMPOWERMENT**

As argued in Chapter Two of this thesis,\(^{19}\) the understanding of disability has moved from a largely Medical Model of disability to a Social Model of disability, which stresses the importance of empowering people living with a disability. Robert Adams defines empowerment as “the capacity of individuals, groups and/or communities to take control of their circumstances, exercise power and achieve their own goals.”\(^{20}\) Further, Rino J. Patti believes that empowerment “encompasses self-determination, self-direction, self-efficacy, mastery and individual competence,”\(^{21}\) while Julian Rappaport states that empowerment “enhances the possibilities for people to control their lives.”\(^{22}\) From these definitions, it is argued that to be empowered or to have empowerment is to exude “power” and to have personal control over one’s life and/or to be given that “power” by others. It is evident from the literature review in Chapter Three that it is the wealthy, the influential, the physically strong and the “able-bodied” who exhibit

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\(^{17}\) Reynolds, *Vulnerable Communion*, 5.

\(^{18}\) Swinton, “Time, Hospitality.”

\(^{19}\) See especially Chapter Three, section 3.4.


empowerment on a frequent basis. It is a given that all people are bound by civic and societal laws and other restrictions, but, in a general sense, the groups of people listed above are perceived to have free rein over how they conduct their lives; they are autonomous and largely independent of others’ involvement. Moreover, the groups of people above self-determine aspects and outcomes of their lives. Contrast this with people who are devalued, disadvantaged and discriminated against, especially people living with a disability who often have ongoing and pervasive support needs. We have seen examples from the interviewees about how some of their life-defining and life-changing decisions had been made for them, sometimes without due regard or respect for what was wanted and/or needed.23

Why, then, are some people living with a disability not empowered to make their own decisions? After all, there are entrenched human rights and other pieces of legislation, both globally and nationally, such as the Universal Declaration of Human Rights 1948 (United Nations) and the Australian Human Rights Commission Act 1986 (Commonwealth Government), as well as specific disability legislation, for example, the Declaration of the Rights of Disabled People 1975 (United Nations) and the Australian Commonwealth Government’s endorsed Disability Discrimination Act 1992 (Commonwealth Government), which promotes the need to empower all individuals, including people living with a disability.24 And yet people living with a disability are in

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23 See Interviewee 8: Brianna, and Interviewee 17: Karla. The researcher knows of people living with a disability where decisions have been made on their behalf in terms of with whom and where they live, how their finances are used, with whom they may associate, and what daily activities they may undertake. Also included with such major decisions are those that most people would take for granted as routine and without room for compromise, for instance, what clothing to wear, what food to eat and when to eat it, whether or not to watch television or participate in something else, and who will be one’s friend.

24 According to the website of the Office of the United Nations High Commissioner for Human Rights, there are four core values of human rights law that are of particular importance in the context of disability. They are:
many ways still ostracised and discriminated against for a multitude of reasons. One of these, at least in part, is because they are not empowered by others (including entities such as social care agencies and many of their workers), whether consciously or subconsciously, to take control of their lives and to make decisions and choices independently. Some social care workers consider themselves dominant, with their own perceived overwhelming power to act as they do on a regular basis with little or no concern for the person living with a disability.25

5.11. CATEGORY 4: RHETORIC VERSUS REALITY

As stated in the Thesis Abstract and at various other points in the thesis, this inquiry seeks to investigate the relationship between this rhetoric and actual substantive efforts towards inclusion of people living with a disability. Action rather than mere rhetoric is important for creating communities of belonging, and this category sheds light on this theme.

As explored in section 5.4 above, there were a number of examples where interviewees thought strongly that their rhetoric matched the actual practice, for example Lana stated:

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(1) the dignity of each individual, who is deemed to be of inestimable value because of his/her inherent self-worth, and not because s/he is economically or otherwise “useful”; 
(2) the concept of autonomy or self-determination, which is based on the presumption of a capacity for self-directed action and behavior, and requires that the person be placed at the center of all decisions affecting him/her; 
(3) the inherent equality of all regardless of difference; and 
(4) the ethic of solidarity, which requires society to sustain the freedom of the person with appropriate social supports.


is great because it just means that we can guide staff to work towards those and it works” (Interviewee 9: Lana) and goes on to say: “I think we’re moving towards a stronger sense of social inclusion. I think as an agency we’ve done person-centred planning quite well across different programs” (Interviewee 9: Lana). While some interviewees were unsure as to whether their organisation’s statements on disability matched the practice, for example Janine indicated: “Well from the diocese I don’t know, I think one [public statement] we did have was to do with inclusion of people with a disability in the reception of sacraments. Again, that’s hit and miss.” (Interviewee 13: Janine). At the other end of the spectrum, we had interviewees who did not believe their organisation’s statements on disability matched the practice (or were unsure whether any statements on disability existed), for example we hear from Phillip: “I’m not sure what policies or directives have been given from either my Bishop or the Australian Catholic Bishops’ Conference or any other group.” (Interviewee 5: Phillip).

The researcher recently experienced an excellent example of a Catholic parish matching the rhetoric and reality. St. John Neumann Parish in Lilburn, Georgia, USA, documents on their website that: “We, the members of St. John Neumann Parish, are a welcoming community of diverse Christians.”26 Another webpage mentions that:

Our mission is to enhance the Parish of St. John Neumann by accommodating, servicing, and welcoming with open arms, all members of our community with special needs, their families and their caregivers. We foster by example, an acceptance of all of God’s children; in the same way that Christ showed his love for us.27

St. John Neumann Parish in Lilburn, were the 2014 winners of the prestigious Loyola Press “Opening Doors” Award. The press release noted that:

St. John Neumann Parish has gone above and beyond to make their sacred space accessible to all who worship there. The sacred space maintains its beauty and purpose while being accessible to all and allows for persons with physical disabilities to worship and minister at their parish. It is not a separate space or program; it is an organic part of the church and the community.28

5.12. CATEGORY 5: DEMONSTRATED ACTION

There were a number of significant examples where demonstrated action of inclusionary processes and practices applied. It goes without saying that ramps and handrails should be a necessity in any building, and they should be required in any new buildings (or at least easy access should be required).29 Ramps and handrails benefit not only people with physical disability, but also families with babies in prams, the elderly, and many others. Hearing loops, Braille and large-print books are also becoming increasingly common in universities, public libraries and government departments. What about appropriate seating for those who may be obese, such as people living with Prader-Willi syndrome?30 Similarly, what is available for people who display challenging behaviours, such as yelling or inappropriate noises, or those people on the autism spectrum who will have difficulty processing information and making sense of a given

environment or situation? The point is there are many different people with many different needs, and for those who cannot verbalise themselves, it must then be for others, including the bishop, to make decisions to benefit them. A greater commitment to person-centredness in relation to people living with a disability is important. Those in positions of power must take responsibility to do the right thing. This standpoint is supported by Peter C. Brinckerhoff, who states: “involvement at all levels of influence in the way the system and services operate [is vital].”  

The qualitative interview data brought to light a number of examples of demonstrated action. Phillip stated: “There are people who are aware, sensitive, caring, wanting to respond, and certainly in the places where I’ve been there have been a variety of people with a lot of disabilities who have been part of my Sunday worship” (Interviewee 5: Phillip).

On reflection, the researcher needed to ask all interviewees to elaborate on particular points about the lack of participation of people living with a disability in Mass; however, this could have been difficult as some of the interviewees are not Catholic – they simply work in a Catholic-based agency.

5.13. CONCLUSION

In this chapter, the research findings have been examined on a question-by-question basis in an attempt to identify any recurrent patterns, themes and categories in the

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responses. From this, the researcher provided a critique of the five key categories that emerged from the thematic analysis, namely (1) Attitudes and perceptions; (2) Inclusion; (3) Empowerment; (4) Rhetoric versus reality; and (5) Demonstrated action. In the next chapter, discrete elements of the data will be interrogated and considered in the context of the literature and interlinked with documentary evidence published by the Catholic Church and relevant agencies and organisations.
CHAPTER SIX: MAKING MEANING OF THE RESEARCH FINDINGS

6.1. INTRODUCTION

The purpose of this chapter is to interrogate discrete elements of the qualitative data, to consider the data in the context of the literature and to interlink the data with documentary evidence published by the Catholic Church and relevant agencies and organisations.

6.2. WHAT ARE THE IMPLICATIONS OF THIS RESEARCH FOR A THEOLOGY OF DISABILITY

The researcher had always intended that this research project make a practical and tangible contribution to a theology of disability. There are several implications of this research for a theology of disability, and the researcher has decided to present these implications under three separate subheadings: (1) a new way of thinking; (2) a new way of seeing; and (3) a new way of acting.

6.2.1. A NEW WAY OF THINKING

People living with a disability are part of the Church. People living with a disability are part of the Body of Christ. James D. G. Dunn understands the Body of Christ to be: “an

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1 The researcher acknowledges that these subheadings were originally used by Denis Edwards during a retreat the researcher attended in December 2014. Interestingly, a similar headline was used by Debra Vermeer whilst reporting on John Swinton’s public lecture at The Broken Bay Institute in June 2014. (See Debra Vermeer, “The Theology of Disability – A New Way of Listening, Seeing and Belonging,” Catholic Communications, June 27, 2014, accessed April 8, 2015, https://www.sydneycatholic.org/news/latest_news/2014/2014627_1055.shtml.)
indispensable corporeality; an active membership – each having its different function as part of the body; a practice of mutual support in both giving and receiving without correspondence on any one member or function.”

The famous novelist, poet and theologian, C. S. Lewis, once stated that “to love is to be vulnerable.” John Swinton states that “disability in all its forms is simply another way of being human” and to be vulnerable is the essence of what it is to be human. Swinton goes further to state that society is lacking vulnerability. Iain McGilchrist affirms this when he attests that “society thinks humans are invulnerable.” The qualitative research presented in this study has demonstrated a significant gap between rhetoric and reality. One of the key themes of the practical theologians surveyed is that Christian rhetoric must transform praxis through solidarity and concern for the common good. Therefore, there is a need for a new way of thinking which prioritises this kind of “standing with” these vulnerable people.

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7 Swinton, “Spirituality and Disability.” See also Swinton, “Body of Christ Has Down Syndrome.” I infer here that all human beings are vulnerable, not just people living with a disability.
8 Swinton, “Spirituality and Disability.”
10 See especially Chapter Five, section 5.4 and section 5.11.
6.2.2. A NEW WAY OF SEEING

We continue to see people living with a disability treated as though they were inferior to others.\textsuperscript{12} We have established that the term “disability” is socially constructed,\textsuperscript{13} and therefore requires us to look at disability differently.\textsuperscript{14} Wayne Morris suggests the question that should be on every church’s lips is: “What can the church do to be more inclusive of disabled people?”\textsuperscript{15} or, better still, what can I do to make the church more inclusive of disabled people? When we begin to think differently we begin to see reality differently, and the data gathered has helped with that process. This then leads to a new way of acting which we will survey below.

6.2.3. A NEW WAY OF ACTING

One of the aims of this research project, as outlined in the Thesis Introduction above,\textsuperscript{16} has been to develop practical strategies and actions that might assist the Australian Catholic Church (and other faith communities, for that matter) to foster faith communities of genuine inclusion, belonging, friendship and ownership. As M. Miles notes: “There are no cookbook answers here,”\textsuperscript{17} but these practical strategies and


\textsuperscript{15} Morris, “Church as Sign,” 47.

\textsuperscript{16} See Thesis Introduction, esp. sections i.3–i.7.

actions will at least provide a sound starting point to enact change. The possibilities for enacting change are “enormous,” according to Erik W. Carter, who states: “The potential for congregations to communicate grace, extend relationships, and share in the lives of people with a disability and their families in their community is enormous, but these rich and deep reservoirs of support remain largely untapped.” These strategies have been garnered from the qualitative interviews and literature surveyed throughout the thesis. While the researcher has attempted to acknowledge original sources in the section below, it must be noted that a number of these strategies have been extensively reported and published elsewhere. The researcher offers the following practical and tangible strategies:

- Avoid linking disability with sin, punishment, an “inescapable consequence,” or describing it “as a curse and as a result of disobedience, unbelief, and ignorance.”
- Avoid thinking that disability is brought on by the Devil.
- Celebrate the gift of disability more than once per year. Avoid instances where the gift of disability is celebrated only once a year by a faith community – normally on occasions such as the United Nations International Day of Persons with Disability. This can become quite tokenistic if not done properly. Make the gift of disability a reality in every faith community all year round. As Vanier

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22 Yong, “Disability Enabling Theology.”
states: “If we really welcome each new person as a gift of God, as His messenger, we would be more loving and more open.”

- Include Braille text in publications wherever practicable.
- Issue publications, including parish bulletins and correspondence, in a readable typeface (Arial, Times New Roman, Calibri) and in a large font size (greater than size 14 if possible). This would enable people living with a visual disability to have a greater chance of being able to read the text.
- Make PowerPoint presentations available at all parish gatherings and ensure that a range of pictures and large-font text are used.
- Provide AUSLAN interpreters wherever practicable, especially at larger parish gatherings and/or celebrations.
- Foster a culture where the parish community has friendly greeters at the beginning and end of all parish gatherings to not only greet people living with a disability, but all people who are part of the parish.
- Establish a car pooling system and ensure any person living with a disability can be appropriately transported to and from the parish church or other centre.
- Establish and institute a disability survey – either parish-based or diocesan – to determine the needs of people living with a disability in one’s parish/diocese.

### 6.3. CONCLUSION

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23 Jean Vanier, Community and Growth, 2nd ed. (Mahwah, NJ: Paulist, 1900), 168.
25 Australian Catholic Bishops Conference, I Have a Story, 7.
26 Australian Catholic Bishops Conference, I Have a Story, 7.
27 See Interviewee 5; Phillip.
In this chapter, discrete elements of the qualitative data were interrogated and the data considered in the context of the literature and interlinked with documentary evidence published by the Catholic Church and relevant agencies and organisations. The final words of this chapter go to Cristina Gangemi, who states:

Disability beckons to you the listener, “Come and explore where God exists within me. Recognise the gift I am and the contribution I make to the world, and please love and accept me for who I am not what I can or cannot do!” This is a basic desire for all humanity.  

28 Cristina Gangemi, “A Place to Belong: Stewards in a Human Story” (available from c.gangemi@abdn.ac.uk).
CHAPTER SEVEN: THESIS CONCLUSION

7.1. INTRODUCTION

The purpose of this chapter is to provide an overall synthesis of the qualitative data. In summary, conclusions and recommendations will be extended to highlight existing positive attempts towards social justice for people living with a disability and attention will be given to tabling the gaps and inconsistencies. In particular, barriers and competing discourses of inclusion will be outlined. The researcher will also return to the theological literature to analyse, interpret and critique the findings.

7.2. SUMMARY OF THE FINDINGS

It is well known in light of the literature surveyed throughout the thesis, the interview data and the researcher’s own experience of the Australian Catholic Church that there are many individuals and groups doing excellent things when it comes to including, and creating genuine communities of belonging for, people living with a disability. We constantly see people employed by the Catholic Church, along with its various agencies and organisations, acknowledged publicly and winning prestigious awards for their commitment to the inclusion of people living with a disability. At the time of writing the thesis, Trish Mowbray was employed by the Australian Catholic Bishops Conference as its Disability Projects Officer, and, in 2013, Trish was awarded an Order of Australia Medal, while, in 2014, she was awarded the Australian Capital Territory Local Hero Award for her lifelong commitment to disability advocacy. Similarly, at the time of writing the thesis, Michele Castagna, Chairperson of the Australian Catholic
Disability Council since its inception in 2007, was also awarded an Order of Australia Medal, and, in 2015, he was nominated as the Northern Territory’s state finalist for the Senior Australian of the Year Award.

There are instances where Catholic parishes have been recognised for their contribution to inclusive processes or practices;¹ however, this has generally been driven by “grassroots parishioners”² who are passionate disability advocates. Such parishioners might also have a person living with a disability attending their church and it would obviously be in their best interest to strengthen their parish’s inclusiveness. One of the interviewees, Greg, suggested that inclusion works best when “grassroots parishioners” become involved in the inclusion process within the local parishes: “if we want to make a difference, it’s got to be at the local level not at the national level” (Interviewee 6: Greg). Unfortunately, these exemplars are few and far between and such exemplary attitudes and behaviour as theirs is fragmented from diocese to diocese and from parish to parish. True inclusion and creating communities of genuine belonging require a Churchwide commitment. Catholic parishes should be considered places of comfort and support, as outlined by Belva C. Collins, Melinda Jones Ault and others.³ Likewise, a number of Catholic organisations are doing great things and are being rewarded, for

¹ See Australian Catholic Bishops Conference, We Have a Story: A Collection of Stories from People with Disability, Their Families and Faith Communities Participating Fully in the Life of the Church in Australia (Canberra: Australian Catholic Bishops Conference, 2006).
² The term “grassroots parishioners” refers to people based in local parishes who assist with the decision-making processes of that particular context, e.g. as members of the parish pastoral council.
example, the St Vincent de Paul Society and L’Arche (although L’Arche is not strictly Catholic nowadays).

Although there are glimpses of affirmative inclusionary practices within the Australian Catholic Church towards people living with a disability, both garnered from the literature and the qualitative interviews, it can be concluded that the Australian Catholic Church is not doing enough to ensure that the positive regard for all is put into practice. Interestingly, this is a sentiment that is echoed by Erik W. Carter when he states: “Despite many encouraging signs of progress, [...] there is still much work to do. Most congregations continue to struggle with how to meaningfully support people with disability in various aspects of congregational life.”

As was surveyed in Chapter Two of this thesis, attitudes towards people living with a disability have improved over the years and there has been a trend to enhance the recognition of the rights of people living with a disability. As argued above in section 2.2, many of the factors governing normalisation were a precursor for the next stage of development, that is, the emergence of the concept of self-determination, or of “planning by” (as opposed to “planning for” or “planning with”) programs, which aim to allow the person with a disability to determine what is wanted. Carter states that: “efforts to initiate broad changes across entire communities sometimes remain narrow, uneven, or stagnant.”

Moreover, as it has been argued throughout the thesis, it is neither the opinion of the researcher nor observation in practice that people go out to purposefully exclude or discriminate against people living with a disability within the Australian Catholic Church. This is a sentiment that is echoed by Deborah Creamer, who states: “I do not believe that most Christians intend to do harm to people with disabilities.”\textsuperscript{6} As determined from this research project, the problem arises when people working within the Australian Catholic Church\textsuperscript{7} are not armed with the appropriate tools to be able to begin thinking about including people living with a disability, let alone trying to include them.

The Australian Catholic Church and indeed, the universal Catholic Church, has the capacity to become a leader in including, and creating genuine places of belonging for, people living with a disability. Although there are demonstrated and reported movements towards this reality, as shown throughout the qualitative data and the literature surveyed, a significant attitude shift and culture change needs to occur for people living with a disability to be seen “not simply [as] included but [so that they] are made to feel they belong in our communities, in our lives and in our hearts.”\textsuperscript{8}

The researcher argues that the pontificate of Pope Francis could provide the ultimate catalyst and platform for this rhetoric to become a reality. Pope Francis’ second encyclical, \textit{Laudato Si’} (literally “Be praised”, or “Praise be to you”), was released in June 2015 and offers a number of practical ways people can care for the environment, or

\textsuperscript{7} The researcher uses this term very broadly.
“care for our common home” as Pope Francis puts it. What is more important to this research project is its reference to how individuals should treat vulnerable, poor and marginalised people. Pope Francis’ pontificate has been characterised by simple and humble statements that are becoming “already-legendary.” A few examples from his first encyclical, *Evangelii Gaudium* include: “Evangelisers thus take on the ‘smell of the sheep’ and the sheep are willing to hear their voice,” “an evangeliser must never look like someone who has just come back from a funeral!” and “I want to remind priests that the confessional must not be a torture chamber but rather an encounter with the Lord’s mercy which spurs us on to do our best.” While in his second encyclical, *Laudato Si’* we see observations such as: “the ultimate purpose of other creatures is not to be found in us; rather, all creatures are moving forward, with us and through us, towards a common point of arrival, which is God,” “it [consumerism] is actually making our earth less rich and beautiful, ever more limited and grey” and “Every violation of solidarity and civic friendship harms the environment.”

Francis has been a very popular public figure in mainstream and secular media – so much so, he made the front of the *Rolling Stones* magazine, was voted in the *Times* Top 100 Most Influential People in 2013, and has over five million followers on

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9 Francis (Pope), *Laudato Si’*, 2015, accessed June 27, 2015,  
http://w2.vatican.va/content/francesco/en/encyclicals/documents/papa-francesco_20150524_enciclica-laudato-si.html  
10 Francis (Pope), *Laudato Si’*, especially Chapter Four.  
14 Francis (Pope), *Evangelii Gaudium*, n. 15.  
15 Francis (Pope), *Evangelii Gaudium*, n. 41.  
16 Francis (Pope), *Laudato Si’*, n. 41.  
17 Francis (Pope), *Laudato Si’*, n. 83.  
18 Francis (Pope), *Laudato Si’*, n. 142.  
19 See Mark Binelli, “Pope Francis: The Times Are A-Changin’,” 2014, accessed January 14, 2015,  
Twitter. Furthermore, there have been numerous images that have been published in popular media showing Francis’ deep love and affection for people living with a disability during his papal audiences. Francis also invited Jean Vanier and a handful of core members and assistants from L’Arche to the Vatican in March 2014 to celebrate World Down Syndrome Day and the jubilee of L’Arche International. Likewise, very early in his pontificate an event was organised where “an estimated 600 disabled people met,” and from which have come photos of Francis:

strolling through a sea of wheelchairs, stopping to touch each person, allowing them to touch him back, and making sustained eye contact. The photos illustrate what words cannot adequately express: The pope’s actions say, “I see you. You matter.” Unlike the Vatican security detail and other onlookers in the room, the pope looks absolutely comfortable with the disabled, an attitude of openness around him, an air of authentic welcome. It is something one cannot fake.

In short, the universal Catholic Church has probably the best chance of introducing inclusive practices under the leadership of Pope Francis. His immediate predecessors were considered more conservative, while Francis is considered more progressive, according to contemporary Catholic theologians.

7.3. IMPLICATIONS OF THE FINDINGS OF THE RESEARCH PROJECT

21 Horton, “Pope Francis.”
23 I do not claim here that Pope Francis’ predecessors were not inclusive of people with a disability, but rather, due to Francis’ progressive leadership, we are more likely to see a culture change.
24 Lennan, “Evangelii Gaudium.”
This research has examined the role of the Australian Catholic Church, its leaders and its relevant agencies in advocating for and welcoming people living with a disability into the life of the Church. This research has implications for the Australian Catholic Church and their response to disability issues. This research provides an “examination of the field” which offers a number of different models of how the Australian Catholic Church could foster and support communities the genuinely welcome people living with a disability and to enhance their sense of belonging to such communities. Finally, the research generated in this study provides a substantial basis for further research to take place, which will ultimately continue the healthy conversation, meaningful dialogue and comprehensive debate that this research project has engendered.

7.4. CONCLUSION

In this chapter, an overall synthesis of the qualitative data was provided. Conclusions and recommendations were put forward to highlight existing positive attempts towards social justice for people living with a disability and attention was given to tabling the gaps and inconsistencies. In particular, barriers and competing discourses of inclusion were outlined. The researcher also returned to the theological literature to analyse, interpret and critique the findings.
EPILOGUE

I know what you are thinking: you need a sign. What better one could I give than to make this little one whole and new. I could do it but I will not. I am the Lord and not a conjuror. I gave this mite a gift I denied to all of you: eternal innocence. To you she looks imperfect but to me she is flawless, like the bud that dies opened or the fledgling that falls from the nest to be devoured by the ants … she will not offend me, as all of you have done. She will never destroy or pervert the work of my Father’s hands. She is necessary to you. She will evoke the kindness that keeps you human. Her infirmity will prompt you to gratitude for your own good fortune. More! She’ll remind you every day that I am who I am; that my ways are not your ways and that the smallest dust mote whirled in darkest space does not fall out of my hand. I have chosen you; you have not chosen me. The little one is my sign to you. Treasure her . . .

The researcher came across this reflection by Morris West when one of his students passed it onto him. This quote actually means a great deal to the researcher’s student in that it was sent to him after his daughter was born with Down syndrome. The researcher’s student states:

This poignant reflection was actually sent by my mother shortly after she first stayed with us during the birth of our daughter. Twenty-nine years later, I still love these words! Early on some of our closest Christian friends said that we should pray for healing for our daughter. I thought then and I still do that this was misguided. My daughter has had an enormous impact on our lives just as she is. And yes, she can be quite a clown.

Upon reflecting on the thesis and the researcher’s professional and academic background, it is evidently clear that people living with a disability make a significant contribution to wider society (including faith communities), and as Vanier states:

People with disabilities have taught me so much over these past forty-two years as we have lived and shared together in L’Arche as friends and companions, as

25 Morris West, The Clowns of God (New Milford, CT: Toby, 2003), 68. I wish to acknowledge one of my students who supplied me with this quote and the narrative that goes with it.

26 Anonymous, personal communication to the researcher by email, June 10, 2012.
brothers and sisters, as people brought together by God. In fact, they have not only taught me; they have transformed me and brought me into a new and deeper vision of humanity. They are helping discover who I am, what my deepest needs are, and what it means to be human.  

As the researcher stated in the Dedication: I wish to dedicate this thesis with love and respect to people living with a disability, known and not known to me, in the hope that, one day, your gifts will be unconditionally welcomed and treasured by all [emphasis added]. You have taught me to listen, to be humble, to be patient and to be grateful for what we have each day. This is for you.

BIBLIOGRAPHY

The following resources have been consulted or quoted, or both, during the research and writing of this thesis.

A


Avalos, Hector. Health Care and the Rise of Christianity. Peabody, MA:
Hendrickson, 1999.


B


Basinet, Jean-Claude. “Communal Journeys: A Phenomenological Inquiry into the


Berryman, Renee C. *Children Are Gifts from God, Disabled or Not! A Mother’s Personal Journey of Hope and Inspiration*. Maitland, FL: Xulon, 2009.


C


———. Personal communication with the researcher. June 8, 2015.


Fleming, Dan. Personal communication with the researcher. June 11, 2014.


Fontana, Andrea, and James H. Frey. “Interviewing: The Art of Science.” In


G


———. “A Place to Belong: Stewards in a Human Story.” Available from c.gangemi@abdn.ac.uk.


Gascoigne, Robert. *Freedom and Purpose: An Introduction to Christian Ethics*. 


Hunsinger, Deborah van Deusen. *Theology and Pastoral Counselling: A New*


I


J


K


McIntosh, Lawrence D. *A Style Manual for the Presentation of Papers and Theses in


Mowbray, Trish. Personal communication with the researcher. July 4, 2010.


N


O


O’Connell Killen, Patricia, and John de Beer. *The Art of Theological Reflection*. New


P


**R**


S


———. “Forgetting Whose We Are: Theological Reflections on Personhood,


U


V


——. Followers of Jesus. Toronto, Canada: Griffin House, 1980.


——. In Weakness Strength. Toronto, Canada: Griffin House, 1975


———. “St. Thomas Aquinas on Living as the Image of God, or, the Rational Soul, Perfected in Love.” Paper presented at the 4th Biennial Conference of the European Society for the Study of Theology and Disability, Catholic University of Lille, France, June 2013.

W


———. *Dancing with Disabilities: Opening the Church to All God’s Children*. Eugene, OR: Wipf and Stock, c.1996.


Woodward, James, and Stephen Pattison, eds. The Blackwell Reader in Pastoral and


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APPENDIX A: HUMAN RESEARCH ETHICS COMMITTEE
APPROVAL TO CONDUCT HUMAN RESEARCH CERTIFICATE

HUMAN RESEARCH ETHICS COMMITTEE

APPROVAL TO CONDUCT HUMAN RESEARCH

To Chief Investigator or Project Supervisor: Doctor Alexander Beveridge
Co- Investigators / Research Students: Doctor Tim Stanley
Mr Zacharias Duke

Re Protocol: A critical analysis of a theology of disability in the Australian Roman Catholic Church: An ethnographic inquiry of contemporary inclusionary practices

Date: 10-Apr-2013
Reference No: H-2012-0220

Thank you for your recent application to the University of Newcastle Human Research Ethics Committee (HREC) for approval of the protocol identified above.

Details of previous approvals for Initial, Renewal and Variation applications are available upon request.

A Certificate of Approval is enclosed.

THE CERTIFICATE AND THIS ADVICE ARE TO BE RETAINED. THEY ARE IMPORTANT DOCUMENTS

• Note any comments related to the approval.
• Where the HREC is the lead or primary HREC, if the research requires the use of an Information Statement, ensure the Reference No. is inserted into the complaints paragraph in the approval documents prior to distribution to potential participants.
• Where the research is the project of a higher degree candidate, it is the responsibility of the project supervisor to ensure that the candidate receives the approval advice.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol as detailed below:

PLEASE NOTE: In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, you will apply to the External HREC for approval in the first instance and then Register that approval with the University’s HREC.

• Monitoring of Progress

28 The quality/readability of the text in the certificate is poor given the file was changed from .pdf format to .jpeg format for it to be inserted into this document.
Other than above, the University is obliged to monitor the progress of research projects involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. The Certificate of Approval identifies the period for which approval is granted and your progress report schedule. A progress report is required on an annual basis; you will be advised when a report is due.

- Reporting of Adverse Events

1. It is the responsibility of the person first named on the Certificate to report adverse events.

2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.

3. Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Certificate to the (HREC) by way of the Adverse Event Report form within 72 hours of the occurrence of the event or the investigator receiving advice of the event.

4. Serious adverse events are defined as:
   - Causing death, life threatening or serious disability,
   - Causing or prolonging hospitalisation,
   - Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure,
   - Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma,
   - Any other event which might affect the continued ethical acceptability of the project.

5. Reports of adverse events must include:
   - Patient's study identification number;
   - Date of birth;
   - Date of entry into the study;
   - Treatment arm (if applicable);
   - Date of event;
   - Details of event;
   - The investigator's opinion as to whether the event is related to the research procedure; and
   - Action taken in response to the event.

6. Adverse events which do not fall within the definition of serious, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

- Variations to approved protocol

If you wish to change, or deviate from, the approved protocol, you will need to submit an Application for Variation to Approved Human Research. Variations may include, but are not limited to, changes or additions to investigator, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. Variations must be approved by the (HREC) before they are implemented except when registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your registration.

Linkage of ethics approval to a new Grant
HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

With best wishes for a successful project.

Professor Alyson Holbrook
Chair, Human Research Ethics Committee

For communications and enquiries:
Human Research Ethics Administration

Research Services
Research Integrity Unit
The Chancellery
The University of Newcastle
Callaghan NSW 2308
T +61 2 4921 1969
F +61 2 4921 1764
HumanEthics@newcastle.edu.au


Linked University of Newcastle administered funding:

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HUMAN RESEARCH ETHICS COMMITTEE
Certificate of Approval

Applicant: (first name in application)  
Co-investigators / Research Students:  
Protocol:  

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Note: Approval is granted subject to the requirements set out in the accompanying document Approval to Conduct Human Research, and any additional comments or conditions noted below.

Details of Approval

| HREC Approval No: H-2012-0220 | Date of Initial Approval: 04-Sep-2012 |

Approval

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.

Progress reports due: Annually.

If the approval of an External HREC has been "noted", the reporting period is as determined by that HREC.

Approval Details

Initial Application  
17-Oct-2012

Approved

The Committee ratified the approval granted by the Deputy Chair on 4 September 2012 under the provisions for expedited review.

Variation

20-Mar-2013

Variation to:

1. Seek organisational consent directly from Bishops, rather than via the Executive Directors/Senior Managers of Catholic Welfare Agencies

2. Increase the proposed number of participants from 20 to 53

Organisational Participant Information Statement, version 1 dated 26.2.2013

Approved
The Committee ratified the approval granted by the Deputy Chair on 5 March 2013 under the provisions for expedited review.

**Variation**

21-Nov-2012

Variation to amend the Participant Information Statement to reflect the student researcher's change of study from a Masters to a PhD program

- Participant Information Statement, version dated 22.10.2012

Approved

The Committee ratified the approval granted by the Chair on 24 October 2012 under the provisions for expedited review.

**Authorised Certificate held in Research Services**

Professor Allyson Holbrook
Chair, Human Research Ethics Committee
APPENDIX B: SAMPLE INFORMATION STATEMENT

FACULTY OF EDUCATION AND ARTS

Dr Alexander Beveridge
School of Humanities and Social Sciences
Faculty of Education and Arts
The University of Newcastle
University Drive, Callaghan NSW 2308
Phone + 61 2 4921 6772
Facsimile + 61 2 4921 6995
Email Alex.Beveridge@newcastle.edu.au

[Date]

Information Statement for the Research Project:
“A CRITICAL ANALYSIS OF A THEOLOGY OF DISABILITY IN THE
AUSTRALIAN ROMAN CATHOLIC CHURCH: A QUALITATIVE STUDY
INTO CONTEMPORARY INCLUSIONARY PRACTICES.”
Document number 1; Document version 1.0; dated February 2013

Names of investigators: Dr Alex Beveridge (Principal Supervisor)
Emeritus Professor Terry Lovat (Co-Supervisor)
Mr Zachariah P. Duke (Student Researcher)

Dear [. . .],

We would like to invite you, and any eligible staff from the [. . .] to participate in the research project identified above, which is being conducted by Mr Zachariah Patrick Duke from the Discipline of Theology and Religious Studies, at The University of Newcastle (Australia).

This research is an essential part of Zachariah’s Ph.D. candidature at The University of Newcastle, supervised by Dr Alex Beveridge and Emeritus Professor Terry Lovat.

Why is the research being done?

The purpose of this research is to critically investigate whether the Australian Catholic Church is making a genuine, practical contribution to the area of disability.

Who can participate in this research study?
We would like to invite you, [. . .], to participate and/or nominate suitable staff within your geographical jurisdiction who may be interested in participating. The researcher is focussed on the following key areas:

1. Catholic social welfare agency (e.g. CatholicCare, Centacare, etc.).
2. Catholic Schools Office / Catholic Education Office.
3. Catholic Parishes, Parish Support Unit, Parish Ministry Team.
Alternatively, if you would not be available to participate, any of your staff who are aged over 18 years, and who work as a social educator or manager are also eligible to participate.

**What would you (or your staff) be asked to do?**

Interested participants will be invited to participate in a recorded interview with the student researcher. The interview will last forty-five to sixty minutes in duration (depending on how much information is supplied), at a mutually agreed upon time and location. With the participant’s permission, the interview will be audio recorded. There may be instances where follow up emails and telephone calls may be required to clarify information; however, these will be short in length. The interviewer will ask a number of questions pertaining to disability, as well as your own personal experiences. During the project, participants can review and/or edit the transcript of the interview upon request.

**What are the risks/benefits of participating?**

Although not expected, there is the possibility of participant’s becoming distressed with the topic of this research project. In the unlikely event that any participants should become distressed during the course of the interview, please feel free to contact Lifeline Australia on 13 11 14 or beyondblue on 1300 224 636. Participants can cease the interview at any time.

We cannot promise you any tangible benefits from participating in this research. However, please be re-assured that your input is valuable and will assist in contributing to a growing body of knowledge considering the affect religion and spirituality has on people living with a disability.

**How will the information collected be used?**

Data collected will be used as part of a thesis submitted by Zachariah in complete fulfilment of the requirements for the degree of Ph.D. at The University of Newcastle (Australia). Beyond the submission of the thesis (circa June 2015), please be advised that data cannot be withdrawn. Participants can request a summary of the results of the research be e-mailing Zachariah after the interviews have been completed.

**How will your privacy be protected?**

All data will be securely housed in a locked cabinet in a secure data storage area accessed only by the principal supervisor/investigator and student researcher. All
working data will be password protected and will have codes encrypted to protect identity of participants. Material will be stored for a minimum of five years and then destroyed. Individual participants will not be identified by name at any stage throughout the data analysis and synthesis.

What choice do you have and what should you do to participate?

Please thoroughly read this Information Statement and be sure you understand its contents before you consent to participate.

Your participation in this project is completely voluntary. Please be assured that your identity will be kept strictly confidential and only those individuals or groups who give their written informed consent will be included in the project.

If you do decide to participate, you are permitted to withdraw from the project at any stage without providing a reason and have the option of withdrawing any date which identifies you or your organisation.

If you decide to participate, it would be greatly appreciated if you could sign and return the attached consent form (document number: 2) by reply email within fourteen days. Alternatively, if you are unable to participate but know of staff members within your agency who may be interested in participating, we would ask you to please provide them with the enclosed ‘Information Sheet’ for their consideration.

Further information

Should you have any questions about the research, please contact the principal supervisor/investigator, Dr Alex Beveridge via telephone (+ 61 2 4921 6772) or email (Alex.Beveridge@newcastle.edu.au), or the student researcher, Zachariah Duke via email (Zachariah.Duke@uon.edu.au).

This project has been approved by the University’s Human Research Ethics Committee (Approval Number: H-2012-0220). In the event of lodging a formal complaint or concern about this research project or how it has been conducted, please contact:

Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan, NSW 2308, Australia

I look forward to hearing from you and thank you once again for taking the time to read this proposal.

Yours sincerely,

Dr Alexander Beveridge
Principal Supervisor/Investigator

Mr Zachariah Duke
Student Researcher
APPENDIX C: SAMPLE CONSENT FORM

FACULTY OF EDUCATION AND ARTS

Dr. Alexander Beveridge
School of Humanities and Social Sciences
Faculty of Education and Arts
The University of Newcastle
University Drive, Callaghan NSW 2308
Phone + 61 2 4921 6772
Facsimile + 61 2 4921 6995
Email Alex.Beveridge@newcastle.edu.au

[Date]

Consent Form for the Research Project:
“A CRITICAL ANALYSIS OF A THEOLOGY OF DISABILITY IN THE AUSTRALIAN ROMAN CATHOLIC CHURCH: A QUALITATIVE STUDY INTO CONTEMPORARY INCLUSIONARY PRACTICES.”
Document number 4; Document version 1.0; dated September 2012

Names of investigators:  Dr. Alex Beveridge (Principal Supervisor)
                        Emeritus Professor Terry Lovat (Co-Supervisor)
                        Mr Zachariah P. Duke (Student Researcher)

I agree to participate in the above research project and I give my consent freely.

I understand this research project will be conducted in strict accordance with the Information Sheet a copy of which I have retained.

I understand I have the capacity to withdraw all participation at any stage throughout the course of this research project and do not have to give an explanation why I have tendered my withdrawal.

I consent to being interviewed.

I consent to having the interview recorded.
I understand the interview will last between forty-five (45) and sixty (60) minutes.

I understand the possibility of participating in a follow up conservation either by email or phone.

I understand that my personal information will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

I understand that I can review and edit the transcript of any interview in which I participate.

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APPENDIX D: SAMPLE INTERVIEW SCHEDULE

Interview Schedule

“A CRITICAL ANALYSIS OF A THEOLOGY OF DISABILITY IN THE AUSTRALIAN ROMAN CATHOLIC CHURCH: A QUALITATIVE STUDY INTO CONTEMPORARY INCLUSIONARY PRACTICES.”

Names of investigators: Dr Alex Beveridge (Primary Supervisor)
Emeritus Professor Terry Lovat (Secondary Supervisor)
Mr Zachariah Duke (Student Researcher)

Do you consent for this interview to be recorded?

Yes OK. I’ve just pressed ‘record’ on my digital voice recorder.
No No problems. This interview will not be recorded.

Interview commencing with [. . .].

How would you like to be named throughout the interview?

Firstly, welcome and thank you, [. . .], for agreeing to partake in an interview, which will form an integral part of my PhD research, titled “A critical analysis of a theology of disability in the Australian Catholic Church: a qualitative study into contemporary inclusionary practices,” which I am currently completing at the University of Newcastle (Australia). My name is Zachariah Duke and I look forward to briefly introducing myself in a few moments.

[. . .], you might like to introduce yourself?

Thank you for painting a brief personal story.

May I now take a few moments to introduce myself?

My name is Zachariah Duke, Zach for short, I reside in the northern suburbs of Sydney. I am a confirmed PhD candidate in the discipline area of philosophy, religion and
theology at The University of Newcastle, supervised by Dr Alex Beveridge and Emeritus Professor Terry Lovat. My areas of research include: theological voices of marginalised and vulnerable people; disability theology; perspectives on ecclesiology and ethnography; and the impact of service care in religious organisations. I am active member of a number of different academic and professional associations, including the Association for Practical Theology in Oceania, Carers NSW, Deaf Australia, Down Syndrome NSW, Fragile X Syndrome NSW and Physical Disability Australia, among many others. Do you have any questions for me?

Would it be OK if I ask you a few general demographic questions now?

- How long have you been employed with [. . .]?
- What is your background in disability?
- What is the core mission of the [. . .]?
- Is the [. . .] driven by strategic directions? If so, what are they?
- If you were to sum up [. . .] in three words, what would they be?
- What triggers your interest in disability and church ministry?

Before we begin with the more formal component of this interview, I might take a few moments to outline some important background information. Would this be OK?

- This project has been approved by the University’s Human Research Ethics Committee (Approval Number: H-2012-0220).
- It is also important to note here, that I do not enter into the space of the interview as an expert in the field. For me, the emphasis is based around adopting a co-constructionists approach, where both the interviewer and the interviewee are participating in a mutually enriching dialogue with one another around the subject.
- Data collected from this recorded interview, will be used as part of a thesis submitted by me in complete fulfilment of the requirements for the degree of PhD at The University of Newcastle (Australia).
- You won’t be at all identified throughout the data analysis and synthesis; however, it may be necessary to refer to you using a pseudonym. Beyond the submission of the thesis (circa June 2015), please be advised that data cannot be withdrawn.
- Participants can request a summary of the findings of the research by e-mailing me directly. A summary will then be provided to you at the conclusion of the research.
Now, [ . . . ], is it OK if we continue to the more formal aspects of the interview?

**Interview Questions**

1. I wonder if you could share with me your understanding of inclusion of people living with an intellectual disability in terms of the current Church community.

2. What do you see as the values and objectives of current initiatives?

3. To what extent does policy and public statements concerning inclusion match-up with actual practices?

   *Are you feeling comfortable with the interview so far, [ . . . ]?*

4. From your direct experience, to what degree are resources directed toward proactive inclusionary processes and practices?

5. How would you describe and characterise a more inclusive Church community? What might this involve?

6. What accommodations in terms of architectural layout, access and modifications to liturgy and worship can you think of? What possible changes can you suggest?

   *Is there anything else you would like to add, [ . . . ]?*

   *Is there anything else I should have asked you?*

Thank you, [ . . . ], for participating in this interview.

Your contribution is truly appreciated.
APPENDIX E: SAMPLE INTERVIEW TRANSCRIPT FROM A PSEUDONYMISED INTERVIEWEE – SAMPLE CLUSTER 1: CATHOLIC SOCIAL CARE AGENCY

Full transcript of interview with Interviewee 9: Lana, telephone interview with the researcher, Thursday July 18, 2015

Facilitator: So Lana do you consent for this interview to be recorded?

Interviewee: Yes, I do.

Facilitator: Okay great, so I've just pressed record here. Yes. Okay so interview now commencing with Lana from [. . .]. So how would you like to be named throughout the interview?

Interviewee: [. . .] fine.

Facilitator: Firstly welcome and thank you for agreeing to partake in this interview and this will form an integral part of my PhD research. The thesis is titled, "A Critical Analysis of a Theology Disability in the Australian Catholic Church: An Ethnographic Enquiry of Contemporary Inclusionary Practices" which I'm currently completing at the University of Newcastle here in Australia. My name is Zachariah Duke, Zach for short and I look forward to briefly introducing myself just in a few moments.

Before we get started [. . .], perhaps you might like to share a little bit about yourself, a brief personal story if you like?

Interviewee: What would you like to know?

Facilitator: Well the interview itself will start off with a few demographic questions in terms of where you're working, how long etcetera and then there's six formal interview questions but perhaps a little bit about your work at [. . .].

Interviewee: Okay, my role is pretty broad in that it covers a variety of different program areas so I've got overall management of our disability services program, our clinical support and counselling team, our youth services, programs and our community development arm. That forms half of all of the programs in the Hunter. So it's quite broad but it's very interesting.

Facilitator: That's great, thanks for just introducing yourself there.
Interviewee: No worries.

Facilitator: I might take just a few moments to introduce myself because I think it's very important to trust the person that you're speaking to. So, my name's Zach as I mentioned before. I reside in the northern suburbs of Sydney in a leafy suburb called Beecroft. I'm a confirmed PhD candidate in the discipline area of Philosophy, Religion and Theology at the University of Newcastle. I'm being supervised by Dr Alex Beveridge and Professor Terry Lovat.

My areas of research and expertise mainly lie in the practical and pastoral strands of theology, in particular, theological voices of marginalised and vulnerable people, the theology of disability, perspective on ecclesiology and ethnography and the impact of service care in religious organisations.

I'm an active member in a number of different academic and professional associations including the Association for Practical Theology in Oceania, Carers New South Wales, Death Australia, Down Syndrome New South Wales, Fragile X Syndrome New South Wales and Physical Disability Australia among many others. Do you have any questions of me?

Interviewee: No. Not at all. It all sounds very interesting.

Facilitator: Okay, so I might just ask you a few demographic questions now. Some of what you've just mentioned before may cover some of this. So, how long have you been employed at [...]?

Interviewee: Three years.

Facilitator: Did you want to comment briefly about your background in disability or disability services programs?

Interviewee: Well, prior to starting in this current role and as [...] level which has been for the past I think nine months, I had less to do with disability services in a formal sense in that the programs that I was managing and working within were all around youth services and at home care specific. So while there might have been some people accessing the service with disability in those program areas, they weren't accessing a designated disability service.

Facilitator: What would you say the core mission of [...] is in terms of the overarching organisation?

Interviewee: Well, we do have our Mission, Vision and Value statement which I'm not sure if you've had a look at or would want a copy of. I'm not sure if that would be useful at all.
Facilitator: If you could forward me a copy that would be great.

Interviewee: I can email that. Do you want me to talk on that or are you happy to email that to you.

Facilitator: That's fine if I just get it I can have a look through it.

Interviewee: Sure. Well, I'll send you a link that outlines our Mission, Vision and Values so that's everything that underpins our work and that we really do draw back on to the extent that it's in our Performance Development Reviews and it is in all of our essential criteria where we talk about it at interview stage and it is in our bi-yearly PDLs so it gives staff a chance to demonstrate how they align themselves and how their work ethics and work performance aligns to our Mission, Vision and Values. I'm going to send that to you right now as we talk.

Facilitator: Fantastic. The next question was actually touching on whether [. . .] is actually driven by any strategic directions and you've mentioned that that link will draw me to that attention.

Interviewee: Yes, but we also have a strategic plan that has a greater emphasis on disability services in it. I wonder if – it should be here for me to forward that to you too if that would be helpful...

Facilitator: That's great.

Interviewee: ...but I can tell you that we do have a strategic plan that we're half way through and that in there, I'm just trying to see where it's at – I should be able to send that to you but in our strategic plan it does talk about a stronger or better service provision in the area of disability services. I can send that to you too.

Facilitator: Fantastic. I'm getting spoiled here. Now this question comes up – there it comes through now. Yes.

Interviewee: That's the mission. I'll try and find the other one.

Facilitator: Great this question comes I suppose a little bit from left field, if you were to sum up [. . .] in three words, what might they be?

Interviewee: I would say, passionate, dedicated and lively. It's a bit similar to passionate but we've got people who are passionate but we've also got lively in that we've got people with a lot of energy. I think it's an area where you've got to have a lot of energy to be able to sustain yourself in social services.
Facilitator: Okay and just the last question in the demographics set here, is there any particular triggers that I suppose catalyst your interest in this particular area of disability? Here you might comment perhaps on a personal encounter or perhaps a family member may...

Interviewee: No, I think for me in a wider sense because I went through the Catholic school system and I was brought up to be – in a family of practicing Catholics, our family has got a strong work ethic but also a strong desire for service to others and I suppose that's kind of underpinned my wanting to work in social services not just disability services but also that's driven my desire to study at a higher level as well.

Facilitator: In terms of, and if you're happy to comment on this, what are your qualifications?

Interviewee: So, I've got an undergraduate in Social Science. Another undergraduate in Psychology and I'm about a unit off finishing a Masters in Counselling.

Facilitator: Fanatastic. Okay, so Lana before we begin the more formal component of this interview I might just take a few moments to outline some important background information. Would this be okay?

Interviewee: Sure. Of course.

Facilitator: So first of all this project has been approved by the University of Newcastle's Human Research Ethics Committee. Secondly it is important for me to note here that I certainly do not enter the space of this interview as an expert in the field. For me, the emphasis is based around adopting a co-constructionalist approach where the interviewer, myself and the interviewee, yourself, are participating in a mutually enriching dialogue with one another around the topic area.

Data collected from this recorded interview will be used as part of my thesis submitted in complete fulfilment for the requirements of the Degree PhD at the University of Newcastle. You won't be identified at all throughout the data analysis and/or synthesis however it may be necessary to refer to you and your organisation using a pseudonym which is basically a fake name if you like.

Beyond the submission of this thesis, please be advised that data obviously can't be withdrawn. So, once it's gone to the examiners, obviously it's locked in so to speak.

Interviewee: No worries.
Facilitator: Participants can request a summary of the findings of this research by emailing me directly or saying yes on the recorded interview now. A summary will then be provided to you at the conclusion of the research.

Interviewee: Okay.

Facilitator: Now we might move into the more formal aspect of the interview. As I mentioned before the interview itself comprises of six questions and obviously in terms of the richness of the data and drawing on your wisdom and experience, the more you're able to provide, will certainly make the study more rich.

Interviewee: Of course.

Facilitator: Interview Question One: I wonder if you could share with me your understanding of inclusion of people living with a disability in terms of the current church community and by the way feel free to ask me to repeat the question or elaborate, ask me to elaborate on it.

Interviewee: No worries. I suppose this is an area that I'm trying to work in at the moment so my answers will be based on my thoughts and perception of what happens based as a manager in [...] So my thoughts at the moment are – with our own disability services we've got a few people within our group homes for example who don't have any other external connections. So, one of my bit pushes on is to develop a program of volunteers using parishioners.

So I guess what I would like to see in the very near future is that we're able to approach the parishioners in our diocese and say, "Here the people in the community who would need some fresh connections and some support without – social connections and support and I suppose people being driven by their sense of Catholicism or social justice and the right to respect and dignity and just the right to be part of society and be included in society.

For them to undertake that volunteer role as a separate to it being an opportunity to evangelize I suppose for want of a better word. So, my drive at the moment is to source those parishioners and I suppose based on some of my prelim contacts and work, my concern is that we won't have a widely available pool.

So while at a higher level there is talk about parishioners wanting to be involved and people who are linked to a parish and a church may have a thought that they should assist I suppose in community inclusion for
people, my prelim research may show that we don't have as many people interested as I would like.

Facilitator: Okay, isn't that quite funny because it's sort of the same experience I'm feeling with recruiting interview participants actually.

Interviewee: Ah, interesting.

Facilitator: When I send out the information statements I get quite a lot of initial responses, oh Zach this is a great study. We haven't seen anything like this done anywhere in Australia so this is very timely. We'd be happy to be involved but when you chase them up to, as my supervisor says, to try and seal the deal, people then start using all different reasons why they can't participate or don't have the time to participate.

Interviewee: I know myself it took me a little while to actually get myself to allocate some time so I do apologise for that.

Facilitator: I understand and appreciate all those sort of things. People move on and change positions and time's always of the essence, even with me but it's just very interesting that you mention that.

Interviewee: Yes, and so this could just be my really early days perception because we haven't put out a formal request for volunteers yet and I may be inundated and I hope that I am but that's probably my concern.

So I know that we've got a lot of people within our disability services who would really benefit from some external contact because people in the group homes, they live with people with a disability and they go to a day program with people with a disability and they come home to be with people with a disability and that's fine but it's not social inclusion so I would really hope that we have people who will hopefully – and I don't want to put a judgement call on people saying something like people practicing what they preach but it would be great to be able to get some people to assist in that.

I hope that answers that question.

Facilitator: Yes. Great. Okay, Question Number Two – what do you see as the values and objectives of current initiatives. So, here I want you to comment on something that perhaps a program or a booklet that you've implemented and just comment on the success or perhaps not success of that particular project or initiative.

Interviewee: So, in what context?
Facilitator: So just in the context of your day to day role I suppose. So if there's a program that you have implemented or perhaps someone else in [...] that you know has implemented.

Interviewee: Specific to disability services?

Facilitator: Yes.

Interviewee: I could talk about – no of course, that would be – why else would we be talking? We've just undergone a restructure so that we can better align our service provision to the Disability Services Standards. So, I've been instrumental in doing that and also so that we can have a stronger focus on person-centric care but also so we can be really – we may say that we do a good job but I want us to be able to measure that and measure it against something.

So, I want us to be able to prove, not just anecdotal evidence. I want some qualitative data so we're moving towards that now. We've implemented a restructure which wasn't without it's challenges but that's done now and actually today at 4:00, staff are coming in for a workshop around NDIS Disability Care changes and how they should respond to those.

I suppose the afternoon's about inviting them to be innovative and flexible in their work practices to try and change that mindset from – yes, while people are always going to think this is a job I'd like all staff to consider that people in the group homes – that's their home and we want to make it I guess as enriching as we can.

Facilitator: That's fantastic yes. Because I am aware that the Hunter area is one of the pilot areas for the...

Interviewee: It is, yes.

Facilitator: Okay. Has that affected your operations at all in any way?

Interviewee: Not yet. So, I shouldn't say that actually. It's effected our operations in that it's made us look at our operations closer which we were always going to do but this kind of has hastened that which is great. I suppose it makes us think we need to move away from the traditional sense of being block funded which is just getting the current funding to looking at a real consumer driven market. I think that's fantastic because I think that promotes accountability and keeps us on our toes in a good way.
Okay, Question Number Three: To what extent does policy and public statements concerning inclusion, match up with actual practices in your organisation of [...]?

I think we're moving towards a stronger sense of social inclusion. That is what you asked isn't it?

Yes.

So while there is a lot of talk around disability care and NDIS really promoting that choice and control and person-centred care and planning, I think as an agency we've done person-centred quite well across different programs. We would call it strength based and individual case planning but there's a similar kind of underpinning that we've been working towards for some time so I think that's great. That's positive for us to know that we were on the right track all along.

It just needs a bit more training for staff at all levels which is fine and which is want we're doing but I suppose there's a difference in a lot of the talk around choice and control, I don't think that has been present to as high a capacity as it can be and realistically that's down to budget restraints and it's also down to effective management of house and things like that. A group home for example is quite rigid in its guidelines but that's because you've got five people in one home.

To me, that's not enough anymore so my role is about talking about choice and control and getting staff to that way of thinking that people can have more flexibility so we just have to be a bit more creative in what we're talking about. I suppose having these different public rhetoric or policies and procedures coming out is great because it just means that we can guide staff to work towards those.

That's the half way mark. Are you feeling comfortable with the interview so far?

Yes. All good.

We'll soldier on. Question number Four – it's a great segue that you mentioned budgetary constrains because this one touches on this a little bit. So Question Number Four: From your direct experience, to what degree are resources, both financial and human resources, directed toward proactive inclusionary processes and practices?

I would say this is probably our biggest area of contention. We've got quite high overheads and the higher overheads detract from the money
that goes into the frontline work. I understand that overheads are necessary but as long as they increase that's more money that's going away from frontline service provision so while we have great HR and finance kind of policy and procedure in place, there are some fixed things in the budget that I can't argue against. So that makes it difficult to then be able to just give the best type of care that we can give. That kind of is what it is at the moment unfortunately.

Facilitator:  Okay, Question Number Five: How would you describe and characterise a more inclusive church community? What might this involve?

Interviewee:  I think this is a hard question to answer because I think that at the moment the Catholic Church – there are so many people who are involved in primary, secondary and tertiary forms of fallout or ramifications from all of the child sexual abuse claims that have come out and I think that that has really deterred a lot of people. The trauma that that's put people through is quite high and I think it's really difficult to talk about an inclusive church when all of these things are happening.

I think that churches aren't always the most welcoming places for people to go to when we look at just the groups of young people or people accessing our services, they're more likely to be involved in an evangelistic type of – I shouldn't say New Age Church but more of a C30 I think it's called or churches where someone picks them up at home, they take them to church, they invite them to lunch afterwards and then they drop them back home as opposed to...

Facilitator:  Charismatic Pentecostal.

Interviewee:  Charismatic, thank you. So I haven't been to Mass for some time and I know when I walk in people look at you just like the look of well you haven't been here... they sit in judgement that goes along, gets into Catholic Mass. It's not very inclusive or welcoming just going to Mass. This is just my take on it. I think while all that's happening it's really difficult to even conceptualise what a more inclusive church would look like.

Facilitator:  That's a fair statement and one in which I think I've done about 8 interviews now so no-one's ever quite put it in that light but that's totally understandable.

Okay, Question Number Six and I suppose this sort of leads on from Question Number Five so you may not have a lot to comment on but I'll ask it anyway. So, what accommodations in terms of architectural layout, access and modifications to liturgy in worship can you think of? What
possible changes can you suggest? So you mention there, by the very architecture of the church it can be exclusive in terms of someone in a wheelchair but perhaps there's something else that you'd like to comment on?

Interviewee: I think that I come back to an example that someone gave me the other day. I actually put forward a request to get some support for a gentleman who was an active member of his parish who has an intellectual disability whose mother died recently in x amount of months. When the priest said our prayers are with such and such, no-one – he didn't say and our prayers are still with the gentleman who is still attending Mass every Sunday. So no-one reached out to him in that parish. This is a man who has been attending the same church for years and years. He's 60 years old and when his Mum died the parish didn't form any kind of support around him so he was left to – one person in the parish had a connection with me and this gentleman had siblings and things but just think this is a person who attends. I don't know if I'm answering the question correctly but I'm probably answering the last one a bit more but here's a man who attends regularly and didn't get support from the parish so I don't know. We can talk about changing the architecture and things but I think there's something a bit more ingrained.

Facilitator: Yes. That's what I argue too is quite a lot of churches that I've gone to don't have ramp access but I mean the parish community can do that on a Sunday afternoon with a few beers and a barbeque but...

Interviewee: That's right. It's an easy fix.

Facilitator: What is more ingrained is what you've mentioned, the attitude of people within the congregation. There's that real sense of us and them or I and the other and I think that's the issue that comes in pole position for me in terms of changing to become, bridging that gap between people being ostracised and being fully inclusive.

Interviewee: I agree.

Facilitator: I myself I've got quite serious issues with the actual word inclusion because in the very first instance the church should be inclusive.

Interviewee: That's right.

Facilitator: There's shouldn't be a reality of inclusion so the word really should be belonging, true or genuine belonging.
Interviewee: My husband is an Anglican and we're more likely to go to – I'm now more likely to go to an Anglican service than I am to Catholic Mass and it's – the Anglican service – when you walk in there, people say hello to you. They sit down, want to have a chat and people are just – there's a genuine warmth there. We hadn't been for a while and the minister sent us an email just saying "Hope everything's well. Come back whenever you feel happy to." So she put it out there. It's just something that I had never experienced in my previous 20, well I'm 30 now, 29 years of going to Mass. So I can see that difference.

Facilitator: Okay, so that brings an end to the formal component. Is there anything else I should have asked you Lana?

Interviewee: No, I don't think so. I hope that was helpful.

Facilitator: No, certainly it was. Is there anything else you would like to add?

Interviewee: No, I think that's pretty much it.

Facilitator: Okay, so just in conclusion here. I'd like to obviously thank you for participating in this interview. Your contribution is truly appreciated and as I mentioned, quite a few things that you've said is quite new in terms of the other interviews that I've done so that's going to certainly give me some stuff to work with. So that's great.

Interviewee: Hopefully not too out of line anyway.

Facilitator: No that's great. Okay then Lana, that's all so thanks again for your time.

Interviewee: No dramas. Good luck with the rest of it.

Facilitator: Great.

Interviewee: Thanks Zach.

Facilitator: See you now. Bye.

Interviewee: Bye bye.

End of transcript
Facilitator: So Robert do you consent for this interview to be recorded?

Interviewee: I do, yes.

Facilitator: Okay great. Okay so interview commencing with Robert from [. . .]. How would you like to be named throughout the interview?

Interviewee: [. . .] is fine.

Facilitator: Sorry, thanks for clarifying that. So firstly welcome and thank you, Robert, for agreeing to partake in this interview which will form an integral part of my PhD research. The title of my thesis is: A Critical Analysis of a Theology of Disability in the Australian Catholic Church; an Ethnographic Enquiry of Contemporary Inclusionary Practices which I’m currently completing at the University of Newcastle here in Australia. My name is Zachariah Duke, Zach for short, and I look forward to briefly introducing myself in a few moments.

Perhaps Robert before we get started you might like to just share a little bit about yourself, just in basic background in generic terms, so how long you’ve been employed at [. . .] there and what your role is all about and all those sort of things?

Interviewee: Yes Zach well I’m the director of schools, I’ve been in this position in an acting capacity and permanent capacity for six years, just on six years, one year acting. Prior to that I was assistant director of schools and a consultant here. Prior to that I’d worked in the [. . .] diocese as an education consultant, and a principal and teacher. Originally started teaching in the [. . .] in [. . .] back in 1973. I’m originally from the [. . .] area so educated in both primary and high school in the Catholic system in the diocese of [. . .] as it was then, [. . .].

Facilitator: Great. Okay so thanks for just introducing yourself there, I might just take a few moments to introduce myself because I think it’s important that we both know each other just for the context of the interview. So as I mentioned my name is Zach, I reside in the northern suburbs of Sydney...
in a suburb called Beecroft. I’m a confirmed PhD candidate in the disciplinary of philosophy, religion and theology at the University of Newcastle. I’m currently being supervised by Dr Alex Beveridge and Professor Terry Lovat. My areas of research and expertise mainly lie in the practical and pastoral strands of theology, in particular theological voices of marginalised and vulnerable people, the theology of disability of course, perspectives on ecclesiology and ethnography, and the impact of service care in religious organisations. I’m also an active member of a number of different academic and professional associations including the European Society for the Study of Theology and disability, the Association for Practical Theology on Oceania, Deaf Australia, Down Syndrome New South Wales, Fragile X Syndrome New South Wales and Physical Disability Australia among many others.

Before we get started Robert do you have any questions of me?

Interviewee: No.

Facilitator: Okay great, so the interview itself Robert forms two parts, so the first section now we’ll just touch on a few sort of generic demographic questions, in some ways sort of extending on the personal narrative that you’ve just previously painted. Then we’ll then shift into the more formal component of the interview which comprises of six brief questions. So we’ll get started with the generic demographic questions now, so the first question is how long have you been employed at the [. . .], so you mentioned six years so that’s great...

Interviewee: Well in the capacity as director, I’ve been in the [. . .] here now for 16 years in various roles.

Facilitator: Yeah sure, and Robert do you have any background in disability at all in terms of perhaps knowing someone, in terms of a personal encounter with disability...?

Interviewee: Yeah, mainly as a teacher and as a principal, I don’t have any – there’s no one in my immediate family with a disability. But I have certainly as a principal enrolled students with disabilities ranging from cerebral palsy, to deafness – not a lot in those days, that’s going back into the early 80s, early to mid-80s. We wouldn’t have had a lot of students with a disability in our school and I was aware probably around that time that the public education office in the diocese of [. . .] I suppose had some difficulty with enrolling students with a significant disability such as down syndrome child in the school. So we didn’t have any downs kids in our school but as I say we had some kids with varying degrees, one
severe cerebral palsy and a number of kids who were deaf. They were supported by itinerant support and also by the employment of teacher aides and that type of thing.

Facilitator: Sure, fantastic. Okay now obviously the [...] I suppose would be driven by any strategic directions. Would any of them sort of capture disability at all, or inclusion, or...

Interviewee: Most definitely there would be a commitment to – there’s a very strong commitment in this diocese to the inclusion of students with disabilities in our mainstream schools. That has been certainly strongly supported in the time I’ve been here and our previous bishop, Bishop Michael Malone, was a very strong advocate for the inclusion of students with disabilities, and are very encouraging of the directors of the schools over that time to support that inclusion financially.

Facilitator: Okay fantastic. Okay and this is the last sort of question in this opening phase, and I suppose Robert it comes from a bit of left field, so if you were to sum up the Catholic Schools Office within the [...] in three words what might they be? And I’ve asked all the interview participants this and it’s just been interesting to sort of get their responses.

Interviewee: You mean from a perspective of disability?

Facilitator: Well no just in sort of general terms because I just want to see whether inclusion is captured perhaps in this.

Interviewee: Yes, three words, I would say open, inclusive and supportive.

Facilitator: Fantastic.

Interviewee: Now I mean by open we are open to all children irrespective of their background, their family circumstances, their financial abilities to meet whatever financial requirements we have of them, disabilities academic performance, etcetera. We’re open to everybody, probably that’s our main word I would use anyway.

Facilitator: Yeah fantastic. Okay Robert before we begin with the more formal component of this interview I might just take a few moments to outline some important background information. This project has been approved by the university’s Human Research Ethics Committee and the approval number has been provided to you in the documentation. It is important for me to note here that I certainly do not enter the space of this interview as an expert in the field, for me the emphasis is based around adopting a co-constructionalist approach where both the interviewer and the
Interviewee are participating in a mutually enriching dialogue with one another around the subject of disability inclusion. Data collected from this interview will be used as part of the thesis submitted by me in complete fulfilment of the requirements for the PhD at the University of Newcastle. You won’t be identified at all throughout the data analysis however it may be necessary to refer to you and your organisation, which is a Catholic Schools Office of [...], by using a pseudonym, which is basically a fake name if you like.

Beyond the submission of the thesis please be advised that data obviously can’t be withdrawn. So once it’s sent to the examiners I suppose to put it colloquially it’s locked in, but up until that time should you feel not comfortable to be part of the study all you need to do is just let me know and all the data from this interview will be destroyed. Participants can request a summary of the findings of this research by e-mailing me directly or saying yes on the recorded interview now, and then at the conclusion of the research a summary will be provided to you. Okay so Robert we might just move to the more formal component of the interview, and as I mentioned there’s six questions and the only six questions I can ask you. Obviously the more you’re able to get across will certainly enrich the study more so, and likewise if you perhaps don’t understand the question you can certainly ask me to restate it, or provide extra explanation. Okay so we’re right to go?

Interviewee: Yes.

Facilitator: Question number one; I wonder if you could share with me your understanding of inclusion of people living with a disability in terms of the current school church community? So how does inclusion look like in the school and the church today?

Interviewee: Well I think probably my interpretation of that would be that in a school context a student is accepted fully in the life of the school, it’s as involved in the life of that school as is possible for them, and I see many outstanding examples of that across our schools where not only are they part of the fabric of the school but they are given I suppose special opportunities to ensure that their self-concept is developed in relation to them being a valued part of the school community. Similarly I’d expect ion our parishes that people with a disability are welcomed and are engaged in the life of the parish, again as much as they can be depending on the nature of their disability. I do see some examples of that but probably not a lot, I can’t say, just in my own parish I don’t see a lot of that but I certainly have seen some. I have certainly seen in some cases
young people with severe disabilities coming to mass with their parents and they have always been exceedingly welcomed.

Facilitator: Fantastic, okay so thanks for that. Question number two; what do you see as the values and objectives of current initiatives? So here it gives you the ability to perhaps mention a particular program that you’ve piloted in terms of enhancing inclusion of children living with a disability, or perhaps talk about something – any other linkages in terms of initiatives that the schools office there are running.

Interviewee: Yeah well I think there are a number of things that this diocese does which may or may not happen in other diocese. One of them – and this again comes back to the relationship between the bishop, the parents of children with disabilities, the Catholic Schools Office and the schools, is we have an annual special needs mass celebrated by the bishop, and it’s been celebrated without break by a bishop – in fact I don’t think there’s been a time where the bishop hasn’t celebrated that mass, so that’s how important that is. So in the overall diocese and approach to people with disabilities it’s a beautiful liturgy which is prepared by one of our schools in the local parish church. The attendance of parents, students with disabilities, former students with disabilities, staff members from the vast majority of our schools, CSO staff, particularly those that work in the area of disability, it’s a huge celebration. It’s kind of reaffirming the diocese position which is echoed by the Catholic Schools Office and the schools, that people with disabilities are an absolutely important part of our community, our church community.

That is, as I say, undertaken every year. One of the other things that we’ve done recently is conscious of the fact that students with autism in particular, and particularly those with severe levels of autism, are involved in our schools through the Aspect organisation. They’re involved in our primary schools through satellite classes at the Aspect school, which we have four of those. But we’ve been very conscious of a number of Catholic families enrolled and those who have right from the word go when their child was entering kindergarten said what will we be able to do when our child gets to high school and our answer was very limited. Now we have this year established a special autistic class in one of our high schools and it’s going exceedingly well, and it looks as though we’ll have at least two classes next year with the likelihood of a further class that’s being established in some of our other high schools. So that’s part of our commitment to, again, ensure that Catholic education is available to every child no matter what their circumstances.
In the past every child with high levels of autism – access to a Catholic secondary education was most unlikely, now it’s becoming a very important part of what we do.

Facilitator: Yeah sure, okay that’s great. Okay question number three; to what extent does policy and public statements concerning inclusion match up with actual practices? So here you may like to comment on a particular policy document that the Catholic Schools Office has or perhaps I suppose even further out – a document that the diocese of [...] has.

Interviewee: Yeah I can’t specifically refer to one that the diocese has but that’s just through probably lack of knowledge, just a lack of recall. Certainly in our documentation, our strategic plans, in our annual plans, in our whole philosophy I suppose of how we run the system. We hear frequent statements about the inclusion of students with disabilities and that is very strongly advocated. How does the policy match with the reality? I would say very strongly, and again I’d say that probably in the last 16 years – and I give great credit to a subcommittee of our Federation of Parents and Friends Association which was called the Special Needs Working Party. So parents, not necessarily ones with children with disabilities, but they are involved in it, it was set up by very concerned parents about the opportunity for children to be enrolled in our schools. The Special Needs Working Party has been a great advocate for families with children with special needs, and I think you would find – because it’s been a couple of years the average number of students per school across the state in relation to disabilities – at one stage the legislative council of New South Wales did an inquiry into that and I think the average was around 4.6%, we’re currently sitting on around 5.2% of our enrolment as students with disabilities.

So I think the reality matches it, we attract some money from the Commonwealth government in relation to students with disabilities but we put in our own resources way above that in providing very strong support for those children in our care. So I think what we espouse in our documents is very much matched by the reality of what happens in our schools.

Facilitator: Great thanks for that Robert. So we’re at the midway point here, are you feeling comfortable with the interview?

Interviewee: Yes.

Facilitator: Okay so we’ll soldier on. I suppose in some ways question three certainly leads into question four, so some of what you’ve just mentioned
you’ll probably be repeating here but we’ll ask it anyway. So question number four, from your direct experience to what degree are resources – so resources both human and financial – directed toward proactive inclusionary processes and practices within your schools?

Interviewee: Yes I can certainly respond to that. We had a review of our provision of special needs a few years back now – I’m trying to think what year, probably around 2005, maybe 2006 or 2007 – yeah probably 2006 I’d say it would be. As a result of that we have dramatically grown the level of support we provide in our schools, we provide a – in our high schools we provide a full time learning support needs – we refer to a learning support coordinator who is class free, so that person is there to coordinate the support of the students with disabilities and other learning needs, but principally disabilities. We have learning support teachers in every one of our primary schools and again in some of our high schools, so depending on what the need is. We have specialised support here in the office who work with those people and the principals to ensure that there is a great deal of support. The actual budgetary nature of that has been increasing each year to the tune of between about $800,000 to $1m a year because of the – and we seem to be very successful in our work with students with special needs, and seem to be very pastoral to the extent of our enrolment growth in that area has been quite dramatic.

Facilitator: That’s fantastic. Okay then question number five; how would you describe and characterise a more inclusive school church community, what might this involve?

Interviewee: What might it involve?

Facilitator: What might this involve?

Interviewee: Yeah okay. I suppose looking at it from the school perspective it would be one where the students and parents of those students feel that they really belong, where the children are seen as a vital part of the school community. I can think of many examples of that, one is we have one of our senior colleges, 11 and 12 school, where they have set up a – all of our high schools have set up or are in the process of establishing a special needs unit. In some cases it’s maybe given certain names, in one of our senior colleges it’s called the MacKillop Centre, it’s given a prominent place in the school, it’s an area where children with disabilities are able to gather. They have some of their lessons there if they’re doing life skill courses, that’s where they undertake those. But that centre is also used for students who are part of the school’s debating team, so your higher academic kids, that’s where they go and meet, they have their practices
there. So it’s not seen as just a standalone place for the kids with disabilities, it’s seen as a centre for a number of different groups to come and gather, and to undertake some work. But it’s very much their safe space but it’s a safe space that they share with some of the brightest and most able kids in the school.

It is a real flagship in the school and the students with disabilities are then given prominent roles whenever there’s an official function on at the school, so they’re often the meeters and greeters of people such as the bishop and myself, and other dignitaries that might be invited to it. Their self-worth, their self-confidence, all of those grow quite significantly through programs like that. One of our primary schools has just been nominated by two parents for a major national award and they’ve been – for the way they support students of special needs in their school, and they’ve just been named as one of the three finalists in that national award which will be determined in Canberra in the coming weeks. So in our schools there is that great sense of dignity provided for these students and their families. For some of the families it’s been a struggle at times, people might not have seen eye to eye with ever process in each school and as they’ve progressed through schools things can improve or things might get worse because they move from primary to high school or whatever. But overall it has been a very positive encounter and I’m more aware of the very positive ones than necessarily the ones that haven’t worked. But I often get feedback about just how well these students are accepted into our schools.

When it comes to the parish level again there’s a flow on effect. I think again these young people, the ones that I do see in parish life, are very acknowledged and supported. My parish priest is very supportive of people with disabilities. So I wouldn’t suggest that every family that has a child with a disability in our school is regularly involved in our parish, just as I could say the same for every able minded student. The numbers are fairly low but certainly the sense of welcome and recognition of them as a vital part of our community.

Facilitator: Sure, thanks very much Robert. Question number six, and the final question; what accommodations in terms of architectural layout, access and modifications to liturgy and worship can you think of, what possible changes can you suggest?

Interviewee: Can I suggest, does it need to happen within our system you mean, if possible?

Facilitator: Yes.
Interviewee: Well we’re very conscious of that, all schools have great access built into them, particularly our newer constructions but even – we’ve done a full audit of all of our schools across the diocese for a range of reasons in relation to what maintenance might need to occur, what future plans might be needed, etcetera. But a vital part of all of that is how do we provide for students with special needs. As I mentioned all of our secondary schools either have are in the process of establishing special needs centres within them and architecturally what I like about them is that they’re given a really prominent place in the school, and with high quality furniture. It supports programs for the kids so kitchens and that type of thing are put in them. So for accessibility all of our schools – any of our primary schools that have two stories, most of them would have lifts in them for sure. There would be – we’re currently planning a new school and the plans for that incorporate a very strong emphasis on ease of access for students with disabilities. So yeah we take that matter very seriously and – yeah, I’m not sure if that’s answering the question but...

Facilitator: No that’s great.

Interviewee: Probably in relation to the architecture I’d say it is absolutely important for us in creating an environment in our school for all students – that it’s a welcoming aesthetically pleasing environmentally sustainable structure. But I would emphasise that it’s probably even more important when it comes to the facilities that may be utilised or accessed by students with disabilities. As far as the liturgy and things go whenever we celebrate in our diocese from a school perspective there are two or three components of that. There is the special needs mass which I’ve already mentioned that is a very prominent part played in that mass by students with disabilities. When it comes to our Catholic Schools Week celebrations we involve particularly the students from our special school, we have a hearing impaired school, they’re involved in that, they often form a signing choir as part of that liturgy. We have in our RE department work being done over time particularly for students with autism in developing resources for them in relation to their faith development and their involvement in liturgy, etcetera.

We are utilising some kits from places like Loyola press in relation to sacramental programs for students with disabilities, we would be encouraging our parishes to take into account the nature of a disability when a child is presenting for the sacrament. So they would be certainly the things that we are doing and would be encouraging our schools and parishes to do.
Facilitator: Fantastic, what a great way to end. Okay Robert is there anything else you would like to add?

Interviewee: No Zach, again the only thing I’d say is we’re very conscious of the need to support our people with special needs and I could say that we’re rather proud of what we do, not in a patting yourself on the back perspective but we are constantly checking and double checking that we’re doing as much as we possibly can. So just finally I wish you well with your study and with your thesis, and I have great respect for people who take on the journey of studying for a PhD. I haven’t done it myself but I admire people who get as close as you obviously are and I wish you well with the final presentation.

Facilitator: Thanks very much. Okay Robert we might just finish up there so thanks very much for participating in this interview, your contributions certainly are very much appreciated, and yeah I’ll keep in touch either through our BBI connections or perhaps when I get in touch when I forward you the summary of the research.

Interviewee: Very good, okay.

Facilitator: Okay Robert, thanks very much for your time.

Interviewee: Okay all the best.

Facilitator: Bye.

*End of transcript*
Full transcript of interview with Interviewee 5: Phillip, telephone interview with the researcher, Wednesday July 31, 2013

Interviewee:  Good afternoon, [. . .] speaking.
Facilitator:  Phillip, it’s Zachariah Duke calling. How are you going?
Interviewee: I’m going very well thanks.
Facilitator: That’s great.
Interviewee: I can call you Zach? You’ve been signing your emails that.
Facilitator: Zach’s fine, yes.
Interviewee: Zach’s fine, yes. Well I’m pleased we finally caught up. That’s good.
Facilitator: Yes, yes, sorry about the delay with the emails.
Interviewee: No, no, no, that’s all right. When you say, “I’m available here, here and here”, there’s almost too many options, you know what I mean?
Facilitator: Yes, yes.
Interviewee: Anyway, that’s the way things go. So how’s your research project going?
Facilitator: It’s going very well. I’m at the stage now where I’ve constructed the first four chapters of the thesis and I’m just now conducting ethnographic interviews, so to be honest, I’ve had quite a difficulty finding people who have been willing to participate. I need a sample size of about 20 and I’m at about halfway.
Interviewee: Oh, okay.
Facilitator: So just plugging along [laughs].
Interviewee: Okay, well hopefully people will put up their hand.
Facilitator: Yes, yes. So now’s a convenient time to meet?
Interviewee: Absolutely, yes.
Facilitator: Okay, great. So we might just start with the interview.

Interviewee: Yes.

Facilitator: So [. . .], do you consent for this interview to be recorded?

Interviewee: Absolutely.

Facilitator: Okay, I’ll just turn on the digital voice recorder here. Okay, we’re off and running. So interview commencing with Father [. . .], parish priest of [. . .], in the diocese of [. . .],

Interviewee: Correct.

Facilitator: How would you like to be named throughout the interview?

Interviewee: Just – well Phillip will do but if you need to put Father Phillip in front, Father in front, that’s fine.

Facilitator: Okay, great.

Interviewee: I’m happy for you to call me Phillip.

Facilitator: Okay, so Phillip it is. So firstly, welcome and thank you Phillip for agreeing to partake in the interview…

Interviewee: No worries.

Facilitator: Which will form an integral part of my PhD research and the thesis is titled, as you probably read…

Interviewee: Yes.

Facilitator: A Critical Analysis of a Theology of Disability in the Australian Roman Catholic Church…

Interviewee: Yes.

Facilitator: And Ethnographic Enquiry of Contemporary Inclusionary Practices.

Interviewee: Yes.

Facilitator: I’m currently completing this at the University of Newcastle here in Australia.

Interviewee: Yes.

Facilitator: As mentioned, my name is Zachariah Duke, Zach for short…

Interviewee: Yes.
Facilitator: And I look forward to briefly introducing myself in a few moments.

Interviewee: Okay.

Facilitator: Phillip, perhaps you might like to start by sharing a little bit about yourself? And with that, you can interpret that in any way…

Interviewee: Okay. Well look, I am the parish priest here at [. . .] and I’ve been here for a little over two years. As a priest in the Catholic Church I have before that, for 12 years, did a full-time chaplaincy in the Royal Australian Navy and then prior to that I did four years as an assistant priest in one of the other main centres in the diocese of [. . .].

Prior to that, seven years training to become a priest, and then prior to that I had a variety of occupations and activities ranging from studying at university and working as both a chartered accountant and as a worker on my family property, which is located to the east of [. . .], and accounts for why I am in this part of the world.

So I come from a big family and I had my 12 years of military service and I was keen to get back to where my family was because the Navy took me away from my home location. It didn’t help to bring me back here. And therefore I have emerged in as the parish priest into the, not only the spiritual leadership, but the managerial aspects of being the parish priest and having a big primary school as my responsibility as well.

Facilitator: Oh, great. So is there a primary school attached to the parish there?

Interviewee: Correct, yes.

Facilitator: Okay.

Interviewee: I’m – in [. . .] Street you’re close to the Cathedral. That’s the first and main church of the city, Catholic church, and I’m the second oldest church and I’m probably about 10 minutes’ drive away from there, heading south towards [. . .].

Facilitator: Right, okay, yes.

Interviewee: But on the western side. I’m on the western side of town, whereas [. . .], which is another parish, is on the eastern side.

Facilitator: Yes, okay. Yes, I think I’ve got a good idea of where you are.

Interviewee: Yes.
Facilitator: Okay, so thanks for introducing yourself and painting a brief personal story. I might take a few moments to introduce myself now.

Interviewee: Yes.

Facilitator: So Zach for short. I reside in the northern suburbs of Sydney in a leafy suburb called Beecroft. I am a confirmed PhD candidate in the discipline area of philosophy, religion and theology, as I said, at the University of Newcastle. My research and expertise mainly lie in the practical and pastoral strands of theology and in particular theological voices of marginalised and vulnerable people, the theology of disability, faith in human development, notably in relation to individuals and groups, living with a disability, perspectives on ecclesiology and ethnography and the impact of service care in religious organisations.

I'm an active member in a number of different academic and professional associations including The Association for Practical Theology in Oceania, Carers New South Wales, Death Australia, Down’s Syndrome New South Wales, Fragile X Syndrome New South Wales and Physical Disability Australia, among many others.

Do you have any questions of me?

Interviewee: Not really.

Interviewee: Yes, yes.

Facilitator: So is it okay if you – sorry, is it okay if I asked you a few general demographic questions?

Interviewee: Yes, yes, no worries. Yes.

Facilitator: So okay, how long have you been involved in the Catholic Church? How many years have you been ordained?

Interviewee: Well look, I’m a cradle Catholic.

Facilitator: Yes.

Interviewee: And I’m 54 years old, so I think you have to say I’ve been involved with the Church for 54 years.

Facilitator: Okay.

Interviewee: I’ve only been a priest since 1994.

Facilitator: Right.
Interviewee: And I suppose my deeper level of involvement and, dare I say, understanding, happened – began in 1998 when I began my seminary training and I began to immerse myself into the Church in that particular way. But I’ve always been a practicing Catholic. I went to Catholic schools, universities, etc, etc.

Facilitator: Okay, great. And may I ask which seminary?

Interviewee: I went to [. . ] in [. . ].

Facilitator: Oh, yes.

Interviewee: It’s moved now. George, as we affectionately refer to him as, moved it from Clayton where it was near Monash University, and there was a relationship happening between that University and that theological college, and he moved it into Carlton where he could keep a better eye on what was going on.

Facilitator: Oh, right.

Interviewee: And as you might be aware, I don’t know.

Facilitator: Yes. Okay, great. So Phillip, do you have any background in disability at all? Or are you just fascinated by the research topic, or…?

Interviewee: Not really. I think probably - I have a very good friend who’s quite disabled, so that has led me to some just general life experiences in relation to her and some of the challenges she has had that’s made me, perhaps, slightly more aware of issues. But I would probably say – I think particularly when you get into ministry, that is preparation for ministry and ministry itself, you run into people with quite significant disabilities and people are looking to you as the priest, or the trainee priest, for support in one way or another.

And I certainly think that whilst people recruited to the Australian Defence Force are meant to be perfect, if you understand what I’m saying, like if anyone has a defect of any sort they’re not allowed in the door. Although once if people are in the Defence Force and something happens to them, like an IUD blows their leg off, those people have been very sensitively given the opportunity to remain in the Defence Force. But I think the Defence Force is certainly an area where from – I became very aware of Occupational Health and Safety issues, which I think leads into concern for people with disabilities.

Facilitator: Certainly.
Interviewee: It sort of – it’s a funny thing, but it does. But I think it does create some awareness and, you know, whatever.

Facilitator: Yes. Sure. Phillip, what would you say would be the core mission of the [. . .]? I mean, that can be commenting from your local parish or diocese, or…?

Interviewee: Yes, yes. I would say that the core mission is to make the person of Jesus Christ known and loved and to share that knowledge and that love, and that will – that’s probably a succinct thing that would cover a whole lot of different activities.

Facilitator: Sure, yes. And if you were to sum up the Catholic Church in three words, what might they be?

Interviewee: If I were to sum it up? In three words, okay. All right, I’ll call it, Spirit Driven Mission.

Facilitator: Okay, lovely. And Phillip, you mentioned before a personal encounter with someone that’s close to you and that’s been one of your triggers or, I suppose, awareness in disability.…

Interviewee: Yes.

Facilitator: Are you able to comment about that encounter in terms of disability and Church ministry? Has it made you change? Or it might be the case where you just say it’s just made you more aware?

Interviewee: I think my personality type means that I am sensitive and aware of people with needs, whatever those needs might be, and it may not be a physical disability. It just might be someone with the need, whatever that need is. But it certainly - it’s certainly made me want to be – want to create more inclusive situations for people so that people feel included rather than excluded.

Facilitator: Okay, fantastic. Great. Before we begin with the more formal component of this interview I might just take a few moments to outline some important background information.

Interviewee: Yes.

Facilitator: So this project has been approved by the University of Newcastle’s Human Research Ethics Committee.

Interviewee: Yes.
Facilitator: And it’s important for me to note here that I certainly do not enter the space of this interview as an expert in the field.

Interviewee: Yes.

Facilitator: So for me the emphasis is based around adopting a co-constructionalist approach where both the interviewer, me, and the interview, yourself, are participating in a mutually enriching dialogue around the subject.

Interviewee: Yes.

Facilitator: Data collected from this interview will be used as part of my thesis, submitted in complete fulfilment for the requirements for the Degree PhD. You won’t at all be identified throughout the data analysis and synthesis, however, it may be…

Interviewee: That’s good.

Facilitator: Yes, however it may be necessary to refer to you using a pseudonym.

Interviewee: Okay, yes.

Facilitator: Beyond the submission of the thesis, please be advised that data cannot obviously be withdrawn.

Interviewee: All right, yes.

Facilitator: Participants can request a summary of findings of the research by emailing me directly, or saying yes on the interview now.

Interviewee: I would be interested, yes.

Facilitator: Okay, great. So that’s noted. No problem. Okay, so now Phillip, is it okay if…?

Interviewee: If you do all that hard work it’s nice to think that someone wants to read it.

Facilitator: Well exactly, that’s – I think that’s what practical theology is all about, or how I like to refer to it as practice in theology. So I certainly hope that the thesis is one that doesn’t get dusty on a bookshelf but rather a resource, a tangible resource that even parishes – because I believe that an inclusive ministry is driven at the grassroots levels – so hopefully it can be a resource that people can use.

Interviewee: Yes.
Facilitator: So Phillip, the interview forms the part of six formal interview questions, okay?

Interviewee: Yes.

Facilitator: So, these are the same questions that I’m asking all the interviewees.

Interviewee: Yes.

Facilitator: So obviously whatever you wish to comment on, whatever you feel comfortable with. Obviously the more you comment on, the more enriching the study will be.

Interviewee: Yes.

Facilitator: Okay, so Question One: I wonder if you could share with me your understanding of inclusion of people living with a disability in terms of the current Church community. So it looks. How does inclusion of people with a disability look in the Church today?

Interviewee: I think that – I think that while there have been many thoughtful adaptions to many aspects – I suppose I’m not focussing a little bit on church architecture and buildings – there’s been thoughtful adaptions to allow people with disabilities to be involved and feel included and what have you. Many of the old buildings are not very user friendly and some of them haven’t been altered and there may well be people who don’t participate at all because they just don’t feel that they can enter or be included or be part of things. I think there’s probably, across the board, an awakening awareness. I would have to say that probably not everybody’s aware of it, but it’s not like it’s a desolate field either. There are people who are aware, sensitive, caring, wanting to make a difference, wanting to change, wanting to respond, and certainly in the places that I’ve been there have been a variety of people with a whole lot of disabilities who have been part of my Sunday worship.

I know that in the school there have been, also in recent times, modifications and changes and efforts made to give people who are on the edge the opportunity of being part of the bigger community for the benefit of that individual despite the difficulties of doing that. So I think we’ve moved off first base, we’re probably not where we could be, and I think the other issue is that with an ageing population there are certain issues that are only coming forward now that weren’t issues maybe 20 years ago. So there are emerging issues that are coming out that people
have to wake up to. But I think there’s – I think we’re going in the right
direction but we’re not quite completely there where everybody would
feel included and what have you.

Facilitator: Okay great. So Question Two: What do you see as the values and
objectives of current initiatives? So perhaps you might wish to comment
on something that the diocese is piloting or perhaps something that
you’ve been told by the […] perhaps, or any other programs that you
might be aware of?

Interviewee: Just go back on that. Just ask me the question right from the beginning
again.

Facilitator: Yes, I’ll reword the question. What do you see as the values and
objectives of current initiatives?

Interviewee: Okay. I think the values are recognising the importance of every human
person in line with our biblical and theological understanding of God’s
creation.

Facilitator: Yes, imago dei, yes.

Interviewee: Yes. And to instead of taking the view that these people get shuffled
over there into a corner somewhere, that we make every effort, as
challenging as that might be. There might be limited resources and so
on, for everything. But you might like in a perfect situation that people
are aware of that and aware of the importance for those people to be – for
everybody to have the opportunity to be part of something. So that’s
what I see is the basic, underpinning raison d’être.

Facilitator: Great, yes. Question Three: To what extent does policy and public
statements concerning inclusion match up with actual practices? So we
have, perhaps, strategic directions or synod statements that say that your
parishes must be inclusive, but how does this actually match up with
actual practices? So are we walking the talk, so to speak?

Interviewee: Look I think – I think it’s probably a sign of where everything is up to
that I’m not sure what policies or directives have been given from either
my Bishop or the Australian Catholic Bishops Conference or any other
group.

I’m led to believe that a committee did run around and look at schools, I
think. They might have looked at churches as well and tried to identify
things that needed to be done. But then you then get back to well, the
cost of this or that. But although I’m fairly certain that happened, I don’t
know for example, what the comments were on the parish that I’m involved here. And certainly while I’ve been here I’ve made a number of – and I’ve only been here two and a bit years – I’ve made a number of significant changes which nobody knew of it before.

So look, it’s – so probably the standards are not clear. I don’t know what they are. The directives are not clear; I don’t know what they are. I’m just doing things as I see the need for them and as people perhaps draw certain things to my attention.

Facilitator: Great. And I might just ask you to comment on some of those things that you’ve done, just in Question Six.

Interviewee: Okay, yes.

Facilitator: So that might be a good segue into that one.

Interviewee: Yes.

Facilitator: Okay, so are you feeling comfortable with the interview so far?

Interviewee: Yes, yes, absolutely. Yes.

Facilitator: Okay. So we might continue on. Question Four: From your direct experience, to what degree are resources, either human resources or financial resources, directed toward proactive inclusionary processes and practices?

Interviewee: Look I think there’s an increasing amount of resources being projected towards a whole lot of areas, from aged care all the way through down to schools and everything in between. I think probably the National Disability Insurance Scheme, that was sort of lauded in the last couple of days, is probably a sort of out-there indicator of where the rest of everything’s up to. Do you know what I mean? I think that…

Facilitator: Right.

Interviewee: …suddenly this is an important issue that people need to get on board with. It costs a lot of money and the Government, of course, have got their answer for that but everybody has to look at their resources and just make the allocations. If you truly believe in some of these things then you’ve just got to do it.

Facilitator: Yes.
Interviewee: So yes – so it’s probably moving in the right direction but it probably hasn’t been – lack of funds has probably been an excuse not to do things in the past, I would suggest.

Facilitator: Yes, yes. That’s certainly the sort of sense I’m getting from the interviews so far, yes. Okay, so Question Five: How would you might describe and characterise a more inclusive Church community? What might this involve?

Interviewee: I think a more inclusive Church community would be a community where the community reached out. So whatever that community is, they are reaching out to people, and people who are looking at that community would feel drawn to it and included. So that’s both in physical ways - ramps and all the amenities which it might need, the physical things - as well as the human inclusiveness and welcome and care that people might want to feel that they’d like to be part of that over there. Which then feeds into people reaching out again, to other – because often people are standing, sitting, watching and they’re waiting for a whole lot of reasons for people to reach out to them and that can be a transformative thing for those people.

Facilitator: Sure. Great. Some fantastic insights there. Thank you. Question Six, and the last question: What accommodations in terms of architectural layout, access and modifications to liturgy and worship can you think of? What possible changes can you suggest? Or, in your case, what changes have you actually implemented?

Interviewee: Okay. Some of the changes that I have made, things like putting in ramps and getting rid of steps. Even little steps for older people are quite dangerous. Putting a covered area at the front of the church for people to gather, which wasn’t there before. Completely putting the hearing loop – if you understand what that is?

Facilitator: Yes, I certainly do. Yes.

Interviewee: It was only under part of the church when I arrived, like between pew three and pew five and from two people in and two people in on the other side. So it’s now the whole of the church so that people can hear.

Facilitator: Great. And do you get that maintained on a regular basis?

Interviewee: Well it’s only been in – it’s probably been in 18 months so I wasn’t aware it had to be maintained. I get feedback from people who say they can’t hear or they can hear, and sometimes people switch the jolly flick –
turn the switch off and I’m thinking it’s all working and it’s not because I
do’t have a hearing aid so I don’t know whether it’s working or not.

Facilitator: Yes.

Interviewee: But – so the answer is, I don’t have it maintained but it is new and I
wasn’t aware that I had to and the guy who put it in, who is a local, didn’t
tell me that. But you’ve made me aware of something and I’ll check that
out.

Facilitator: Yes.

Interviewee: It’s a wooden-floored church so they crawled in underneath and put it on
underneath. In terms of the Sunday liturgies, we have the entire liturgy
on a data projector, and that’s very helpful for people.

Facilitator: Certainly is, yes.

Interviewee: Particularly new Australians; not only them, but particularly them. And I
certainly have been a magnet for some of the new Australians, the
refugees that have been settled here, because they don’t have to flip
around on cards or try and understand me. All the words are up there and
they can join in.

I think my toilets aren’t good enough. It’s something I’ve got to do. The
cost is a major issue with that one. And lighting, signage, trying to get
the Passionist Family Group established here, which it wasn’t. Having
monthly morning teas, having like a cocktail party or drinks and nibblies-
type things for the brand new parents at the beginning of the year. To –
I’m just trying to think what else.

One thing that is – I intend to have welcomers that stand at the church
and say hello to people when they arrive.

Facilitator: Oh, that’s nice, yes.

Interviewee: That’s a plan but it hasn’t happened yet. I think having people involved
in ministries around the place makes them feel included. And I think –
you’re just constantly looking at things, trying to – taking suggestions
and looking at things to see whether it could be done better or differently
or whatever. So I think that’s probably all I can think of just at the
moment.

Facilitator: Okay, fantastic. [. . .], just one more thing sorry, when you were going
through your pastoral formation, seminary training, where you exposed
to any sort of – you know, a person would come in and speak about disability and how we would minister to them?

Interviewee: I don’t think so. No, no. No we didn’t. But what we did do was the Seminary actually hosted – the buildings were very flat and there was an organisation, I don’t know what’s happened to it. I haven’t heard of it in years. It was called - I mean you wouldn’t call it that now, but this was back in the 80s or early 90s - and it was called Handicapped Encounter Christ. Okay?

I’ve got no idea whether it’s still going or not, but they used to come and use our facilities for a little – like a little cursillo retreat, a three days thing, and they got seminarians to assist with that by just – we all had to be – we were allocated. So there was one seminarian per person. They were quite disabled some of them; cerebral palsy, etc, whatever. And I was involved in – not running it; that was done externally – but I was one of the carers. I was given somebody to look after.

Facilitator: Yes, okay.

Interviewee: Yes, so it was sort of a – yes. It was an accidental encounter would be the way I’d call it.

Facilitator: Okay, great. So is there anything else you’d like to add, Phillip?

Interviewee: No, I don’t think so, except that I think the area of disability is huge. And I probably see that more in the school than I do in the parish because parents want the best for their children, so that people with disabilities are arriving at our doorstep and then we have to deal with them. Whereas if it’s just waiting to see them at church, sometimes they’ve already withdrawn because it’s up to them and they don’t want to be part of it, if you know what I mean. So I’d probably see it more in the school than in the parish, but there’s just a huge area of needs. So it’s not a little pimple over in the corner.

Facilitator: Yes, certainly.

Interviewee: And it’s disability in every conceivable sense of the word.

Facilitator: Yes, sure. Is there anything else I should have asked you, Phillip?

Interviewee: I don’t think so. I think – I mean, I’m in the lucky position to have done a few things and just – it’s a very important thing for me and I suppose that might be why I responded to your invitation.

Facilitator: Okay then.
Interviewee: Okay, well I look forward to hearing – getting your summary, or brief, or whatever it is.

Facilitator: Yes, sure, sure.

Interviewee: You’re going to send that electronically, will you?

Facilitator: I will, yes. So it might not be for some time. I’ll wait until….

Interviewee: No, no, no. No, you’ve got to wait for your 20 people.

Facilitator: It’ll certainly come your way. So just concluding: Thanks very much Phillip for participating in this interview.

Interviewee: No worries Zach. I’m very pleased to help and I appreciate that on the learning continuum you need people doing what you’re doing.

Facilitator: Certainly.

Interviewee: If I can be of assistance to that without having to do it myself, I’m very happy.

Facilitator: [Laughs] Great. Okay, so your contribution is truly appreciated.

Interviewee: All right. Thanks Zach.

Facilitator: Okay then. Bye

Interviewee: Okay. Bye.

Facilitator: Bye.

End of transcript
BIOGRAPHY

Zachariah Duke

Zachariah (Zach) Duke is a confirmed doctoral student in the discipline area of philosophy, religion and theology at The University of Newcastle, Australia. Prior to this, Zach completed a bachelor of theology (majoring in Christian practice and Christian thought) at Australian Catholic University. Zach was invited back to the Australian Catholic University to complete his honours year and wrote a smaller research thesis titled “Speaking Out! The Catholic Church in Australia and Its Intervention in the Question of Refugees and Asylum Seekers” under the supervision of Professor Robert Gascoigne. In 2013, Zach completed a graduate certificate in disability studies at Flinders University, Australia, and in 2014, he completed a graduate certificate in tertiary teaching at Curtin University, Australia.

Zach’s main areas of research are: theological voices of marginalised and vulnerable people; disability theology; the art and processes of theological reflection; perspectives on ecclesiology and ethnography; and the impact of service care in religious organisations. Zach is employed as a lecturer in theology and biblical studies at The Broken Bay Institute, Australia, as well as an affiliate lecturer in the discipline area of philosophy, religion and theology at The University of Newcastle, Australia and an Adjunct Lecturer in the school of education at The University of Wollongong, Australia. He is an active member of several academic and professional associations, including the European Society for the Study of Theology and Disability, the Australian
Catholic Theological Association, the Association for Practical Theology in Oceania, Carers NSW, Deaf Australia, Down Syndrome NSW, Fragile X Syndrome NSW, DeafBlind Association, and Physical Disability Australia, among many others. Zach also volunteers regularly at a Catholic primary school catering for children living with disability and at L’Arche Sydney.