Towards Inclusive Parishes: how do Maltese Catholic communities sustain the spiritual journey of disabled persons?

Franco Buttigieg

A dissertation submitted in partial fulfilment of the requirements of the Master of Arts in Disability Studies

Department of Disability Studies

Faculty for Social Wellbeing

University of Malta

April 2021

Dedication

Dedicated to
my wife, Nancy, on our
forty-fourth wedding anniversary

Live as if you were to die tomorrow,
learn as if you were to live forever.
Mahatma Gandhi

Acknowledgements

I would like to express my gratitude to my supervisor, Dr Maria Victoria Gauci, for her constant support and encouragement throughout the research process; her enthusiasm for this project shored me up when the going got tough. My heartfelt thanks go, also, to my co-supervisor, Ms Maria Cynthia deBono, whose attention to detail and expertise were key contributors to the quality of the study.

This research study would not have been possible – nor would there have been any reason for conducting it – without the participation of the five protagonists. Therefore, I am sincerely thankful and indebted to these disabled persons for allowing me to share, albeit peripherally, their lived experiences.

I would also like to thank Mr David Bezzina and Ms MaryAnn Vella, my superiors at SPERO, who supported me throughout these three years that I have been reading for my degree. I express my gratitude, also, to the service users at SPERO who have been the raison d'etre of my journey in the Disability Studies field.

I am most thankful and grateful for my wife, Nancy, who for the duration of my studies had to concurrently contend with an empty nest, a pandemic that dramatically changed our lives and a husband that was more prone to spend his time in front of his laptop, surrounded with books and journals, rather than seek her company.

Above all, thanks to God, Who, through the graces showered undeservedly on me, enabled me to present this infinitesimal contribution to the Disability Studies body of knowledge.

Abstract

Diverse studies have brought forth the positive effect that religion and spirituality have on the physical and mental wellbeing of individuals and how disabled persons have come to terms with their impairments on the back of their religious beliefs (Johnstone, Glass & Oliver, 2007; Selway & Ashman, 1998). Numerous narratives have also been published wherein disabled persons talk extensively about their struggles and ongoing relationships with their religion (Coggins, 2017; Hume-Dawson, 2017; Mairs, 1993). Yet locally, no research has been undertaken to study how disabled persons reconcile their religious belief with their daily reality within the parish community. This study is a step in that direction. Malta is a predominantly Catholic country, where the Church has undoubtedly been at the forefront of institutional care for disabled persons. On the other hand, reviewing the themes found in contemporary literature with relation to disability and the Church, it emerges that disabled persons feel that, in general, they been left marginalised by faith communities. Embracing emancipatory disability research principles while adopting an interpretative phenomenological analysis (IPA) methodology (Smith, Flowers & Larkin, 2009), this study set out to answer the question as to whether disabled persons feel that they are welcome within their local parish communities. The data was gathered through in-depth interviews with five individuals who have physical or sensory impairments and who are in the mid-twenties to mid-forties age bracket. Through the interpretation of this data, the goal was to arrive at what it means for the participants to live their faith within their parish community. Three main themes emerged as recurring between all participants: disabled persons are seen as objects of pity, as opposed to full members of the community who have a lot of qualities to offer – they are talked about but not listened to; barriers to accessibility - be they physical, attitudinal or relating to communication - denote a Church that is discordant with Christ's teaching and therefore lacks authenticity; lack of true friendship - perhaps as a result of the fear of the unknown – hinders their true participation within the community. On the other hand, for those participants who were accepted as equal members of the community right from their formative years, the experience has been very enriching, proving to be fruitful even to the community itself.

Keywords: emancipatory research, phenomenology, IPA, lived experience, Catholic Church, faith communities.

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Introduction

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1.1 Preamble

Several studies, besides having concluded that religion and spirituality have a positive effect on the physical and mental wellbeing of individuals, have also shown that disabled persons have found the strength to come to terms with their impairments, even giving meaning to their lives when this was lacking, on the back of their religious beliefs (Johnstone, Glass & Oliver, 2007; Selway & Ashman, 1998). On the other hand, in numerous memoirs, disabled persons talk extensively about their struggles and ongoing relationships with their religion (Coggins, 2017; Hume-Dawson, 2017; Mairs, 1993). Yet, to date, it appears that no research has ever been undertaken locally to study how disabled persons reconcile their religious belief with their daily reality (Bezzina, 2018). This is not surprising at all, since it follows the trend within disability studies in general, a reality that has led the Jewish academic Sarah Imhoff to lament that disability studies has yet to take religion seriously (2017).

1.2 Giving Context

On the occasion of the 2019 International Day of Persons with Disabilities, Pope Francis gave the Church - and the world - a very clear message: “A person with disability, in order to build himself up, needs not only to exist but also to belong to a community” (Zenit, 2019, para. 7). A year later, in 2020, again on the International Day of Persons with Disabilities, the Pope went one, very important and also deeply significant, step further. By stating that:

> The active participation of people with disabilities in the work of catechesis can greatly enrich the life of the whole parish…the presence of persons with

> disabilities among catechists, according to their own gifts and talents, is thus a resource for the community (Castellano Lubov, 2020, para. 23).

Pope Francis makes the point that the community needs disabled persons to be part of it as much as disabled persons need to feel welcome within the community to build themselves up. The point that the Pope wants to drive home is that the challenge facing any faith community goes beyond that of simply including those who have been unjustly left out. As Christians, the Pope is telling us, we must be conscious of the indisputable facts that as human beings all of us are inherently limited in our actions, lack absolute control over our lives and need others to thrive. Therefore, we should automatically include and not exclude, support rather than weigh down and embrace rather than tolerate those whom we consider not to conform to our standards and, as a consequence, usually push to the margins (Bergant, 1994).

The Pope's message is a clarion call for action from the part of the universal Church: our communities have to ensure that disabled persons, given the unique contributions they can offer, do actively participate within the Church's structures, rendering them more complete. It is the primary aim of this study to learn about the experiences of Catholic disabled persons within the faith communities of the Maltese parishes as well as to appraise how open the community is to active participation of disabled persons.

1.2.1 The Maltese Archdiocese – Some Statistics

In Malta, the estimated total number of Catholics as at the end of 2016 stood at 361,372 or 84.4% of the total population (Discern, 2018). Moreover, a census of Sunday Mass attendance carried out in December of 2017 indicates that 36% of the Catholic population - which translates to 111,578 persons - who were obliged to go to Mass on that day, fulfilled their obligation (Discern, 2018). Although this is a significant amount of churchgoers, it shows a steep decline from the 81.9% - equivalent to 198,150 persons, since the Maltese population was much smaller at that time - registered in a similar exercise that was carried out in 1967, a matter of fifty years earlier.

With such a presence within Maltese society, it comes as no surprise that the Catholic Church played a significant role in the early development of the disability sector within these islands (Callus, 2014). The pioneering work of Mgr. Mikiel Azzopardi saw the setting up of the first residential home for disabled persons in 1964, the Dar Tal-Providenza, which has since its inception depended mostly on the charitable contributions of the Maltese people for its survival.

1.3 Scope of Study

My interest in studying the marginalisation of disabled persons within our faith communities came about as a result of the experiences I have been living through in recent years, wearing two of several hats I have donned over the years. Venturing into the disability studies field was, for me, the natural path to follow once I had been working for numerous years as a team leader in a training and activity centre for visually impaired and blind persons. On the other hand, my decades-long involvement in Church commissions and faith communities, especially at the parochial level, got me pondering on the reasons behind the invisibility of disabled persons within these structures. Disability studies literature did not provide me with much material to conjure any hypothesis for this phenomenon, since references to religion were minimal and mostly reserved exclusively to dedicated journals. The main questions which I set out to address in this study, therefore, were: Are our faith communities sustaining disabled persons in their spiritual journey? Are disabled persons feeling welcome in our communities? Do they feel that they belong?

A complementary question, which followed naturally from these, and which also formed part of the study, was: Is there the need for any changes to be introduced so that disabled persons can participate fully within our communities? When the answer to this question was in the affirmative, I went on to explore with the participants what, in their opinion, needed to be done differently.

1.4 Disability and the Social Model of Disability

Disability is a complex phenomenon (Priestley, 2003), and providing a universally acceptable definition for it is said to be next to impossible (Altman, 2001). Mine, here, therefore, is surely not an attempt to define disability, which anyway is beyond the scope of this study, but a brief articulation of my understanding of disability as the point of departure for this research. I will also briefly discuss the social model of disability, whilst moving on to build my conceptual framework.

My ontological standpoint is that disability is the oppression that persons with impairments experience as a consequence of society’s ill-informed, prejudiced and unfair relation with them (Barnes, 2014). This oppression manifests itself in a myriad of forms but is most evident in the erection of barriers, deprivation of agency and segregation of disabled persons.

This viewpoint is, significantly, the foundation of the social model of disability which affirms that it is the structures of society that in fact disable individuals as opposed to the philosophy of the individual, medicalised model which sees unlucky persons suffering personal tragedies and who are subsequently limited due to their functional losses (Oliver, 1996). Whereas professionals labouring under the medical model seek to rid people of their impairments so that they can fit into society, disability activists make it their mission to have governing bodies implement policies and strategies that work towards eliminating injustices from our midst.

The social model has been criticised for being too politically focused and for conveniently disregarding the reality of the impaired body which begets distinct lived experiences (Williams, 2001). The social model, which, it has to be kept in mind, knows its inception to a group of physically impaired, white, heterosexual men who in the 1970s wanted to bring about change in the way they were being treated, certainly suffers a number of deficiencies (Shakespeare, 2013). What is critical, however, is the distinction between the person's impairment and disablement – society's behaviour towards disabled persons which results in their marginalisation. Joe Camilleri, a disabled pioneer in Maltese disability activism, succinctly describes the social model as that which "strongly insists that it is the social obstacles, such as lack of physical access, lack of access to means of communication and information, and above all the negative attitudes of certain individuals which cause the biggest disadvantages, or disability" (2009, pp. 7-8). It is this understanding of disability that I sought to study in my research, within the context of Catholic faith communities in Maltese parishes.

Having set the social model of disability as part of my overarching approach to this study, it follows that the terminology I subscribe to, and which I will be using throughout, is 'disabled person' - in that the disability is externally imposed and not residing within the individual - as opposed to 'person with disability' which is the mainstream approach (Shakespeare, 2013).

1.4.1 Emancipatory Disability Research

The development of the social model of disability was, in the last two decades of the second millennium, the wind beneath the wings of the disability rights movement. It eventually led to the formulation of the United Nations Convention on the Rights of Persons with Disabilities (UN, CRPD, 2006) in which, for the first time in history, disabled persons, besides being the target group, also had a direct involvement in its drafting, giving life to their slogan ‘Nothing about us Without us’ (Callus & Camilleri Zahra, 2017).

Rallying behind this same call for their involvement, disability activists made it clear that historically they had been “denied the opportunity to even influence the research agenda, let alone take control of the research process” (Zarb, 1992, p.137) and therefore sought to change the social relations of research production by proposing an emancipatory paradigm of disability research. This paradigm shift in disability research would usher in the reversal of the power relationship between the researcher and those researched which would no longer be a reflection of, but on the contrary become the opposite of, the “unequal power relationship which exists between disabled people and non-disabled people in the wider world” (Stone & Priestley, 1996, p.3).

It is the principles of emancipatory research that I sought to follow in this study, in that as a researcher I tried to take upon myself the struggles of disabled persons through putting my knowledge and skills at their disposal (Barnes, 1992). Although in all fairness, I cannot say that the research process was totally in the hands of the participants, I have striven throughout to shed any parasitic connotations (Oliver, 1999) by ensuring that the ultimate end result of the study will eventually translate into practical benefits for disabled persons by helping to remove disabling barriers – the key guiding principle of emancipatory research (Stone & Priestley, 1996).

1.5 The Conceptual Framework

The ontology and epistemology of the two main research paradigms in the social sciences – the quantitative as opposed to the qualitative position – are rooted in different philosophies. On one end of the ontological spectrum, we have the realist or objectivist worldview which holds that society is an entity in itself and exists independently of individuals. At the other extreme lies the nominalist or subjectivist view which holds that there is no single reality but we, as individuals, are all the time interpreting experiences and therefore making up our own world (Neuman, 2014). So, at one end we have total objectivity or determinism while at the other end we find subjectivity and agency. Between these two extreme, diametrically opposed approaches lie various other standpoints, of which the dualist and agnostic traditions have influenced debates within the social sciences (Benton & Craib, 2011).

From the two main ontological standpoints, flow two different epistemologies: the positivist approach to social science research based on direct observations of social phenomena which can then be analysed so as to arrive at laws that govern the relationships between such phenomena, and the interpretative approach which discards the natural scientific approach and focuses on individual experiences and therefore subjectivity in contrast to the objectivity of the realists' approach.

Having taken off from the premise that disability is a social construct and that this research is of the emancipatory genre, in that it seeks to study what is meaningful and relevant to disabled persons and how they experience living their religious beliefs within the community, it follows that my research has to take an interpretative approach (Neuman, 2014).

1.5.1 A Phenomenological Approach

Having analysed the characteristics of the main approaches to qualitative research, I concluded that a phenomenological approach was best suited to address my research topic since, "A phenomenological study describes the meaning of the lived experiences for several individuals about a concept or the phenomenon" (Creswell, 1998, p.51). This ties in very neatly with what I have expounded above: the narratives of the life experiences of the participants of this study will lead me to arrive at the very essence of what it meant for them to live their faith within the community.

Phenomenology is an epistemology that builds on the central concept that human beings are not passive products of society but individuals who have consciousness and who therefore shape society through their actions. It follows, then, that social scientists need to understand the meaning individuals give to their experiences and to their interactions with society in their respective contexts.

Phenomenology, falling under the umbrella of interpretive social science (ISS), "is rooted in an empathetic understanding or *verstehen*, of the everyday lived experience of people in specific historical settings" (Neuman, 2014, p.103). Max Weber – the eminent German sociologist who lived from 1864 to 1920 and considered by some to have laid the foundations of ISS – emphasises that *verstehen* involves understanding what is going on in the individual's mind, while at the same time framing it within the culture in which the person is living (Benton & Craib, 2011).

Edmund Husserl (1859-1938), often referred to as the founding father of phenomenology, studied the very basic aspects of a human experience – how reality is perceived in the 'human consciousness'. A student of his, Martin Heidegger, elaborated further on his master's work applying a hermeneutical approach to his studies – a method classically employed in understanding religious text to uncover several layers of meaning to that particular text. The primary aim of these philosophers was to investigate and arrive at 'the essence of human experience' (Denscombe, 2014, p.95). Once the qualities that define the essence of an experience have been established, they can be applied to study experiences at a general level.

Since my research will be focusing on the experiences of individuals and how they interpret these experiences to mould their reality, it will certainly not be objective while also being far removed from the positivist approach of establishing causal laws or testing of hypothesis (Neuman, 2014).

1.5.2 Interpretative Phenomenological Analysis (IPA)

An approach towards carrying out research that is rooted in phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009), and which I have adopted for conducting this study, is Interpretative Phenomenological Analysis (IPA). I have taken this decision based on the fact that IPA "aims to explore, in detail, participants' personal lived experience and how participants make sense of that personal experience" (Smith, 2004, p. 40). IPA is also referred to as double hermeneutics, in that the researcher seeks to interpret the interpretation by the participants of their experience of a particular phenomenon.

Typically, an IPA study gathers data regarding a phenomenon, through semi-structured interviews or focus groups involving a small number of participants, which is then analysed in depth. The analysis is pitched at two levels: first in finding out what it is like for the participants to experience the phenomenon and secondly, through interpretative analysis, to arrive at what this lived experience means for them (Larkin, Watts & Clifton, 2006).

In chapter 3, I elaborate on the theoretical underpinnings of IPA and describe how I used such methodology so as to arrive at meaningful insights into my research questions.

1.6 A Religious Spirituality

If, giving a definition to the term disability has been said to be next to impossible to achieve, describing spirituality briefly and neatly is no less daunting, given its diverse range of theologies, experiences, perspectives, and theories (Gaventa, 2018). Before concluding this introductory chapter, I would like, however, to put into its proper perspective the term ‘spiritual journey’ which forms part of the title I adopted for this study.

The meaning which I intend for the term lies in the very roots of the word spirituality, which originated in Christianity and which was used to emphasise a way of life that strives to be guided and influenced by God as opposed to a self-seeking way of life were self-satisfaction and comfort are the hallmarks of success (Sheldrake, 2012). Christian spirituality builds upon the premise that human beings yearn for meaning in their life as they seek their fulfilment in God. Moreover, the biblical roots of Christian spirituality propose a communal presence in the world through the community of believers which translates into the love and service of society at large. As Christians, we believe that God created us to enter into a deep and meaningful relationship with Him and with one another: the spiritual journey is the path we are moving along in furthering these relationships.

This study, therefore, is looking into the religious spirituality of Maltese, Catholic disabled persons. It is worth emphasising this point since the term spirituality, once detached from any form of religious belief will be rendered more vague and difficult to define (Sheldrake, 2012). Once this happens, the terms religion and spirituality take on ambiguous meanings and get used interchangeably.

1.7 The Coronavirus Pandemic

The coronavirus disease 2019 (COVID-19) pandemic that has swept across the world over the past one and a half years has brought about wide-ranging implications to all sectors of society, but disabled persons are being inordinately affected by the resulting restrictions in movement and gatherings as well as due to the curtailing of services that need direct physical contact (Armitage & Nellums, 2020). Taking, for example, the case of blind persons, it is very difficult for them to adhere to the social distancing directive and follow good hygiene practices since most of them are guided by taking a sighted person's arm while using their sense of touch to navigate open spaces through Braille signage, handrails, door handles and public transport rails. When assessing the situation stemming from the COVID-19 pandemic, it can be said that the already existing social inequalities have been further compounded (Goggin & Ellis, 2020).

Archbishop Ivan Jurkovic, the Permanent Observer of the Holy See to the United Nations in Geneva speaking at the sixth Interfaith Dialogue last February, made the point that the pandemic, besides having the obvious, visible and tangible effects, is also bringing forth finer interior crises which are having a deep psychological, emotional and spiritual impact on everyone (Vatican News, 2021). The Christian response calls for a heightened awareness of the needs of others which should translate into tangible efforts to build fraternity while seeking justice in society.

The pandemic, inevitably, also had its effects on the way this research study had to be conducted. As I will be elaborating in chapter 3, the Methodology section, the way participants were approached as well as the build-up to and the actual data collection processes, in the majority of cases, had to be modified to conform with the restrictions that were in place for the duration of the research.

1.8 Conclusion

In this chapter, I have outlined the scope and significance of this research, explained why I chose this area of study and put it into context. I have also discussed the conceptual framework that underpinned my approach. In the next chapter, I present a review of existing literature, bringing to the fore the main issues on the subject matter. In chapter 3, I discuss the methodology followed throughout my research while in chapter 4 the participants of this study take centre-stage as I discuss their experiences. In chapter 5 I draw the main conclusions that emerge from the study, concede the limitations and offer some recommendations before giving my final thoughts on the project.

Chapter 2

Literature Review

Chapter 2 Literature Review

The past thirty-odd years have seen a surge of creative writings by disabled persons calling on communities of faith to transform themselves and move away from theologies and pastoral practices that have resulted in disabled persons being sidelined and marginalised by the Church (Creamer, 2006). I start off this chapter by assessing the manner in which the Church has interpreted disability and how this has impinged on disabled persons' participation within its congregations and communities. Then, given that Scriptures are the main source of Christian theology (McGrath, 2011), I will focus on the principal texts within the Bible that are most frequently quoted when discussing disability. Following this, I will then touch upon a number of different theological models proposed by disabled activists, or by authors who have close family relatives who are disabled. In the final section, I will evaluate the literature available that indicates how the Church in Malta is seeking to address the lack of inclusion of disabled persons within our parish communities.

2.1 The Church and Disability

Whilst it is an undeniable fact that the Church has been a pioneer in supporting disabled persons, it is an entirely different situation when it comes to the manner in how it has defined and viewed disability across the ages (Waldock & Forrester-Jones, 2020). Indeed, historically, the Church has been at best unhelpful and at worst even harmful in the manner in which it has related to disabled persons (Creamer, 2006). Disability activist and prolific writer Nancy Eiesland, who was herself disabled and a professor at a seminary in the United States, writes how "the persistent thread within the Christian tradition has been that disability denotes an unusual relationship with God and that the person with disabilities is either divinely blessed or damned" (1994, p.70) which, in fact, is a grossly distorted representation of the ordinary lives, as well as the lived experiences, of disabled persons. For the most part, disability has been shunned in the day to day life of faith communities as well as in the academic study of religion. It appears that through the ages, religious leaders have often felt uncomfortable in considering that disabled persons are first and foremost persons, who should not be defined solely or primarily by their disability (Yong, 2011). Instead, disabled persons have been looked at as either paragons of sin and therefore to be avoided or, at the other end of the spectrum, as symbols of saintliness and hence to be admired. Moving on to another extreme, disabled persons have also often been pictured as personifications of suffering, thus rendering them persons to be pitied (Creamer, 2006). Although matters have started changing over the last decades, most disabled persons are still far from being welcomed within communities of faith. The biggest barrier appears to be the attitude of the community members whose leaders still use a language that is very often offensive to them and which has led to what Brett Webb-Mitchell has called “the betrayal of people with disabilities” (1994, p. 1) by such communities. Eiesland (1994) calls this betrayal the carnal sins which the Church has committed by failing to be the witness of God’s love to the fragile body. These carnal sins – which can be categorised under the following three main themes – have turned out to be the major stumbling blocks disabled persons have encountered in seeking their inclusion within the Christian community.

2.1.1 Disability as Punishment of Sin

The Church has projected the idea that disability cannot be part of God’s design for our world and therefore disabled persons must be the workings of the evil present in the created order which God seeks to heal and redeem (Spurrier, 2019). As a consequence, even though many a time unintentionally, a causal relationship between sin and impairment has been established: evil-doing demands a punishment on the individual and even, possibly, on the family as well. If we, for example, take the case of Malta, the conflation between sin and disability is very strong. This is primarily due to the fact that the Church has had, until recently, a very strong presence at all levels of society such that one can go so far as to say that it was the Church that gave Malta “its identity” and constructed “much of its culture, such that the religious defined the social” (Tabone, 1994, p. 294). A manifestation of this misconception can be deciphered in the attitude of employers towards disabled persons forming part of their workforce. In a recent research study which sought to assess the impact that technology is having in enabling mainstream employment of Maltese disabled persons, a visually impaired participant, in emphasising the strong linkages between disability, Maltese culture and religion quoted his employer as having told him that “Sight is a gift from God, and if you have a problem with your eyes, then that is a very serious problem” (Gauci, 2018, p.193).

2.1.2 Disabled Persons as Symbols of Saintliness

Giving meaning to suffering has always been an arduous task for the Church. One way out of this conundrum has been found by presenting disability as a divine blessing in disguise. Disabled persons have been presented as those undergoing a temporary trial which, if lived through in an exemplary manner, will merit heavenly rewards (Spurrier, 2019). Disabled persons, therefore, become inspirational role models of how to suffer and yet overcome all obstacles. Singling out disabled persons as being considered by God as very special (Gauci, 2018), puts them, very awkwardly, between a rock and a hard place: such a theology isolates disabled persons, coercing them to adapt their lives to an unjust state of affairs.

2.1.3 Persons to be Pitied

The Church has a long history of preaching the need for charitable acts from the faithful, leading by example. The charitable works of the Church can be witnessed in all sectors of society, be it in the education of the young, in caring for sick or disabled persons as well as in looking after the elderly and the poor. This has led to charitable practices that keep segregated the donors from those being helped, thus exacerbating the exclusion of the marginalised from the community.

Moreover, what most irks disability activists in all this is the fact that the kindness shown by the faithful in donating toward such causes is, in fact, a front to their sense of pity towards disabled persons. Donating out of a sense of pity reinforces the power imbalance between the donor and the person being pitied – and that is dangerous for disabled persons since it undermines all discourse leading to social justice (Belser & Morrison, 2011).

2.1.4 Narratives of Disabled Persons

One of the major contributors to this sense of betrayal of disabled persons by the Church is its decades-long reluctance to lend an ear to the voice of disabled persons, to engage with their narratives to understand them together with their needs – this when disabled persons have been showing an eagerness to share their story, to feel accepted and to getting engaged spiritually (Gaventa, 2018).

Rodney Hume-Dawson who is a professor in the Education Department at the California State Polytechnic University as well as a disability activist, contracted poliomyelitis when he was eighteen months old. Describing himself as an ardent Christian, Hume-Dawson, recounts how, when still young, he kept being invited to attend healing services and being left emotionally traumatised when, after being paraded in front of the congregations present at these sessions, he eventually never got healed (2017). The end result of all these failed healing sessions was that he eventually got regarded as lacking in faith. It also reinforced the notion that his disability was a curse, a just retribution of something wrong either he or his parents had committed.

Megan L. Coggins, who at the age of eighteen was diagnosed with a schizoaffective disorder of the bipolar type as well as with panic disorder, talks of similar reactions from members of her church community (2017). Having been actively involved within the community, she saw herself becoming more and more isolated as her relationship with the community deteriorated with the only help offered being that of healing services being set up to cast away the demons possessing her mind. Given that no evil spirits inhabited her mind, the only effect of all these healing services was to push her to attempt suicide as she failed to find any valid reasons which motivated her to keep on living.

2.2 Disability and The Bible

In his authoritative book *A History of Disability*, Henri-Jacques Stiker makes the point that it is fundamentally factual that in the Old Testament "disabilities as a whole were judged impurities, disqualifying their bearers from active participation in the cult" (1997, p. 24). This stems primarily from what is found in the book of Leviticus, the third book of the Bible which forms part of the Pentateuch, the five books which for Jews lay down the 'The Law'. Leviticus details the legislation for the ritual of the Israelite religion and specifically prohibits anyone who "has an infirmity such as blindness or lameness…is disfigured or deformed…is a hunchback or a dwarf" (Lev 21, 18) from approaching the altar with offerings for the sacrifice as the priest, although it was admissible for such persons to partake in the sharing of the food. This is but one example from at least 46 occasions to be found in the Bible in which disability is shown in a negative light, especially when taken in the modern context (Selway & Ashman, 1998).

Another passage that is considered to have been very influential in stigmatising disability as being a just punishment for sins committed (Yong, 2011) is taken from Deuteronomy. This is the fifth and final book of the Pentateuch wherein one finds the Jewish code of civil and religious laws, which very explicitly declares that: “If you do not diligently observe all the words of this law that are written in this book…then the Lord will overwhelm both you and your offspring with severe and lasting afflictions and grievous and lasting maladies” (vv. 58-60). Here lie the roots of the misplaced belief that disability is caused by sin, which is, in fact, one of “the two most common assumptions in popular theology that marginalize people with disabilities” (Wynn, 2007, p.61), the other being that a strong enough faith heals impairments.

2.2.1 Providing Context – The Graeco-Roman World

When reading such Biblical texts, one has to keep in mind that these were written over 2500 years ago (Lukefahr, 1998) and therefore due consideration has to be given to the context of how disability was depicted in the wider Graeco-Roman (332BC -395 AD) world. This is fundamental since correct understanding of the Biblical text necessitates that due attention “be paid to the customary and characteristic styles of feeling, speaking and narrating which prevailed at the time of the sacred writer, and to the patterns men employed at that period in their everyday dealings with one another” (Dei Verbum, para. 12).

During the Graeco-Roman period, the so-called science, sometimes also referred to as the art, of physiognomy – that is arriving at interpreting a person’s moral character through the observation of physical appearance - was widely practised (Evans, 1969).

Evans, in fact, has researched thousands of examples of the use of physiognomy across all forms of literature of that era, wherein authors, in detailing the physical descriptions of particular persons inferred their character traits as well. In such a world, where perfection is the benchmark, any form of impairment translates to inferiority at both the physical and spiritual level. Also important to note is the fact that research of documents of this era show that although the practice of physiognomy owes its origins to Greek culture, it was widespread throughout Mesopotamia and, therefore, it is to be expected that ancient Israel shared and partook in these cultures (Hartstock, 2007). When examining the text from Leviticus under this light, it becomes more understandable that disabled persons were not allowed into the priesthood since this would have sent the message that it was acceptable for priests to be spiritually weak and fragile, when in fact they had to lead primarily by example.

2.2.2 Interpreting the Bible

Although the Bible is composed of 73 books, split into two main sections – the Old and the New Testaments - and authored by numerous sacred writers spanning a centuries-wide period, we, Catholics, believe that God is the true inspirer and author of both Testaments (Lukefahr, 1998). Like every other literary work, Scripture needs to be interpreted. When interpreting the narratives to be found in the Bible, however, the following two facts have to be borne in mind: first of all, “serious attention must be given to the content and unity of the whole of Scripture if the meaning of the sacred texts is to be correctly worked out” (Dei Verbum, para. 12) and secondly that “the books of the Old Testament with all their parts…acquire and show forth their full meaning in the New Testament” (Dei Verbum, para. 16). Therefore, any attempt at interpretation must always take into consideration the whole content and unity of Scripture in that no particular episode can be considered in isolation and without taking into account the broader picture. Furthermore, one has to keep in mind that the full meaning of Scripture is to be found in the New Testament and specifically in the four Gospels which take preeminence over the other books since they contain the teachings of Christ himself. It is to some salient passages from the New Testament that I now turn my attention to.

2.2.3 The New Testament

When discussing disability, one of the most commonly cited passages, as well as one of the longest narratives of the New Testament that involves a disabled person (Yong, 2011), is that found in the Gospel of St. John. The Evangelist opens chapter nine of his Gospel by describing how as Jesus went on his way, he encountered a man who had been born blind. As Jesus and his disciples approach the blind beggar, the first thing that the disciples ask Jesus is whether the reason for this person being born blind was that he himself had sinned or because his parents had done so (John, 9:2). This questioning, on the part of the disciples, was to be expected since in the Graeco-Roman world "disability had deep religious significance… the link between disability and sin was common" (Webster, 2008, p.28). The answer is categorical: "Neither this man nor his parents sinned" (John, 9:3): Jesus clearly and unequivocally rejects the causal connection between sin and disability (Yong, 2011; Eiesland, 1994).

Although in this instance we have a categorical answer to a direct question, other passages found in the Gospels are not so clear-cut and are therefore subject to interpretation. In chapter five of his Gospel, for example, Luke recounts how one day Jesus was teaching in a jam-packed residence when some men had to lower a disabled person from an opening they prized open in the roof as this was the only way possible to arrive next to Jesus. The

Evangelist recounts that Jesus, upon “seeing their faith he said, ‘My friend, your sins are forgiven you’” (Lk 5:20). This declaration, coming from Jesus, has been interpreted as a confirmation that the disabled person was a sinner who lacked faith, while it is the non-disabled stretcher-bearers, who through their faith, acted as catalysts for the healing of the disabled person.

One of the numerous healing episodes to be found in the Gospel of John recounts how Jesus, when he happened to be in Jerusalem, one Sabbath day, cured a disabled person by the pool of Bethzatha. The man, who had been impaired for thirty eight years, we are told, picked up his sleeping mat and walked away, mingling into the large crowd who were angry that Jesus was healing on a Sabbath. Eventually, Jesus and this person meet again at the Temple and Jesus has this advice for him: “Now you are well again, be sure not to sin any more, or something worse may happen to you” (Jn 5:14). This passage has often been quoted as proof that in the Bible disability is depicted as the divine retribution for sin.

Disability activists believe that healing episodes such as these and others found in the New Testament have been wrongly interpreted by preachers to give the impression that disabled persons would rather that they live without their disability (Belser & Morrison, 2011). While conceding that disability has made disabled people’s lives more difficult, they cannot, on the other hand, ignore the fact that it has also enriched their lives in other ways. The clergy have given the impression that disability is nothing but a tragedy rendering life not worth living: it is only once disability is healed that real life can begin. This has led the disability movement to come out with a gospel of their own which can succinctly be expressed as “I don’t want personal healing; I want social transformation” (Belser & Morrison, 2011, p.159).

2.2.4 The Gospel of Luke

In chapter fourteen of his Gospel, Luke, relates a parable in which the host of a great banquet finds himself without any guests sitting at his table since, when the time comes for the feast to commence, all of them come up with different excuses so as not to take up the invitation (Lk 14:16-20). Since everything had been prepared, the host seeks to find alternative guests to sit at table with him and therefore directs his servants to “Go out quickly into the streets and alleys of the town and bring in here the poor, the crippled, the blind and the lame”(Lk 14:21). The parable ends with an admonition to those who were invited but never accepted the invitation: they will never have a taste of the banquet. This is a significant theological point: God had extended the invitation - it was certainly not God’s choice to exclude them - but they excluded themselves from the banquet (Webb-Mitchell, 1993).

Jesus recounted this parable while he himself was one of the guests at the table of a leading Pharisee. Jesus had been watching the other guests who had been invited and how each one of them sought to pick a place of honour. Noting all this, and obviously aware of the traditions followed by the well-off at banquets and the following symposia, Jesus had two pieces of advice to offer: first of all, He suggested to the guests to go for the back seats rather than the front ones as they might be humiliated by being asked to leave the prominent place they would have chosen for somebody else deemed more distinguished than them, and secondly – which is much more pertinent – he recommended to the host not to invite his friends, relatives or rich neighbours to his table but the poor, the crippled, the lame and the blind.

In order to fully appreciate the manner in which Jesus was seeking to completely subvert the predominant way that society treated the marginalised, thus moving them from the fringes of the community and right into the centre, some context is in order. The Gospel of Luke, which was written around the year 85 AD in Greek and described as a literary masterpiece, had as its target audience the early converts to Christianity who were not Jews (Lukefahr, 1998). Biblical scholars have argued that Luke's Gospel relies heavily on Graeco-Roman banqueting and symposium imagery in delivering its message (Smith, 1987). For the purpose of this discussion, three of these banqueting practices are of interest and to be looked into. Salient among these practices was the seating arrangements, since guests, while at table, would be engaged in discussing real or hypothetical events. Being seated next to other guests who were considered to be of a lower rank would reflect badly on the individual (Gosbell, 2015). Another important feature of the banquet is that it served as a platform for philosophical discussions and thirdly, the fact that the invitees never featured the marginalised. As a matter of fact, disabled persons, if present at all at such banquets, would either be there as entertainers or as persons to be ridiculed and made fun of (Smith, 1987).

Luke subverts all this by showing Jesus exhorting his followers to first of all shun the places of honour and, most importantly, to ensure that the invitees at their table are not those of the same or higher status level as themselves, but the most marginalised. Indeed it is not only this chapter but, as I shall argue, Luke's gospel as a whole, which can be defined as being a subversive narrative.

Luke opens the narrative of the public ministry of Jesus at Nazareth, the village where he grew up. Jesus, we are told, went into the synagogue on the Sabbath day and, quoting from the Old Testament, told the gathering that his mission was to "bring the good news to the poor, to proclaim liberty to captives and to the blind new sight" (Luke, 4:18).

The stage is set here: the blind, representative of persons with impairments, are being drawn from the periphery and placed as the central figures of the narrative.

In their excellent book *Narrative Prosthesis*, Mitchell and Snyder contend that narrative - and much more so, disability narrative - has a cyclical pattern wherein “the deficiency inaugurates the need for a story but is quickly forgotten once the difference is established” (2000, p.56). They argue that since disability cannot be accommodated in the realms of the normal, two options are available to the storyteller: either lose the character on the way or otherwise penalize the nonconformity. However, far from being used as a prosthetic, disability is, on the contrary, the leitmotiv in the narrative of Luke’s New Testament writings: embedded in Jesus’s mission statement at the beginning of the narrative and given centre-stage throughout the text especially through the narratives of the banquet feasts, which reveal the inclusive characteristic of the kingdom of God (Webb-Mitchell, 1993).

Mitchell and Snyder also drive home the point that one should “bring a variety of interpretative strategies to bear on literary works and not dismiss literature as hopelessly mired in stereotypical imagery” (Huff, 2002, p. 202). It is with this mindset that one has to read Luke’s New Testament narratives, which in fact, subvert the prevalent discourse surrounding disability since the early Christian milieu.

2.3 Moving away from a Disabling Theology

Nancy Eiesland recounts how it often occurred to her that while participating in sacred Liturgy, when it came to receiving Holy Communion and the congregation files up to the altar, she was always asked to remain in her place and was then served once everyone else had returned to their place. Eiesland used a wheelchair or crutches and she acknowledges that the ushers asking her to refrain from joining the community were well intentioned. However, in actual fact, what was happening was that a communal moment uniting the congregation in one body and the highlight of the Liturgy was being rendered a solitary moment of degradation. Moments like this made her, and disabled persons alike, feel as if they are simply “trespassers in an able-bodied dominion” within a Church which has been “physically inaccessible and socially inhospitable” (2005, p.584). The Eucharistic exclusion is, for Eiesland, symptomatic of a disabling theology that has prevented the inclusion of disabled persons and rendered them objects of pity and paternalism while denying them a voice and a real presence in the Church.

Eiesland’s sentiment is echoed in the daily experiences of disabled persons who feel excluded, even though unintentionally, from the Church structures, cultures and theologies which appear to have been construed with only the non-disabled faithful in mind (Jacobs, 2019). Eiesland, in fact, proposes a completely new and innovative way of how to envisage God that also encompasses experiences of disability. Hers is a liberatory theology that audaciously presents the image of the Disabled God, spelled out in her book bearing the same title (1994).

Eiesland has, as the cornerstone of her theology, the resurrected Christ who appeared to his apostles and reveals himself through his wounded hands and feet:

> They were still talking about all this when he himself stood among them. In a state of alarm and fright, they taught they were seeing a ghost. But he said “Why are you so agitated, and why are these doubts rising in your hearts? Look at my hands and feet; yes, it is I indeed. Touch me and see for yourselves; a ghost has no flesh and bones as you can see I have” (Lk 24: 36-39).

In this powerful passage, the resurrected Christ confirmed his promise that God will be with us “embodied as we are, incorporating the fullness of human contingency and ordinary life into God” (Eisland, 1994, p.100). This Disabled God has, in fact, been part of the hidden tradition of the Church since it has not been common practice to project a God whose divinity, through the wounded hands, feet and side, bears the marks of physical impairment (Creamer, 2006).

The Disabled God puts to rest the long-held belief of the causal relationship between sin and disability: Christ did not sin, yet became disabled. More than this, Christ’s invitation to his followers to touch his wounds - that is his disability - is a sure sign that hollow utterances of pity and empathy are not good enough. All the stereotyping and negative attitudes need to give way to affirmative action (Creamer, 2006). In presenting Jesus as the disabled God, Eiesland seeks to call the Church into “the theological task of rethinking Christian symbols, metaphors, rituals and doctrines so as to make them accessible to people with disabilities and remove their able-bodied bias” (1994, p. 104).

2.3.1 A Theology of Access

Eiesland’s voice is not a lone one in proposing alternative framings for disability theology, brought forth through the experiences of disability. Jennie Weiss Block is a Roman Catholic American Dominican laywoman, practical theologian and disability advocate who although not disabled herself, had a brother, now deceased, who was born with multiple impairments. She has authored the book *Copious Hosting: A Theology of Access for People with Disabilities*, which is widely considered to be a seminal text in the development of a theology of disability (Creamer, 2006). In her text, Block presents her vision, based on an inclusive theology of access, which ultimately would see disabled persons not only partaking in worship, but also in being leaders of their parish congregations (O'Connor, 2008).

Rooted in her belief that disabled people are oppressed by society, her theology of access strives to immobilise Christian communities to challenge oppressive structures – both within as well as outside of the Church - so as to ensure full access, and hence inclusion, for disabled persons (Creamer, 2006). For Block, the accessible God has revealed himself in the Bible through Christ's inclusion of all people in his ministry regardless of their nationality, gender, background or physical attributes (Block, 2002). She contends that it is now up to the people who matter to realise that the Church has been theologically wrong in excluding disabled persons from within its structures and therefore must seek to remedy the situation. A theology of access presents to us a God who is with us not in those ways we would like them to materialise, but in a manner that summons us to an embracing hospitality, conscious of our vulnerability (Hickman, 2018).

2.3.2 A Theology of Interdependence

The cause of disabled persons for their full access and inclusion in the life of the Church has certainly not been given a helping hand by the poor homiletic discourse employed by the clergy (Black, 1996). Kathy Black, who identifies herself as a person with a hidden physical disability, is a Methodist professor of homiletics who has for most of her adult life been involved in Deaf ministry. She strongly holds that the manner in which homileticians have interpreted and preached the Biblical texts, has often been oppressive to disabled persons resulting in their exclusion and alienation. The theology and language used in sermons have had the exact opposite effect to that intended on the disabled persons' community.

In her excellent book *A Healing Homiletic*, Black proposes a theology of interdependence. She pitches her argument on society's near obsession with independence: being dependent on someone else is anathema in today's culture (Creamer, 2006). Black, however, advances an interdependent view of life which acknowledges that in reality, no one is fully independent since "we are all interconnected and interdependent upon one another so that what we do affects the lives of others and the earth itself" (1996, p.34). This perspective resonates with Canadian philosopher and disabled activist Susan Wendell's call to society: we need to shift our focus from the skewed ideal of independence to a more realistic goal of attaching value to relations of dependency and interdependency (1996).

Black puts forth, therefore, the image of the interdependent God so that the Church becomes the place where people can be accepted as the children of God created in His image and where dependency is recognised and interdependency given a value (1996). It is, in fact, through the powerful image of the resurrection that "God can transform our lives through the healing touch of an interdependent community of faith" (p. 43).

Eiesland, Block and Black are all calling for a shift from a theology that stigmatises disabled persons, depicting them as the consequences of evil-doing. On the contrary, disabled persons can identify themselves with God, safe in the knowledge that they are also created in the image of God, while seeking recognition and acceptance within the Church communities as well as society in general (Miller, 2020).

2.3.3 Disability as God's Will

Joni Eareckson Tada takes a very contrasting theological approach to living her disability when she expresses the view that disability is God's intended will for certain individuals (2010). It was in 1967, when Eareckson Tada, then seventeen years old, was injured while diving at Chesapeake Bay in Virginia. That accident left her a quadriplegic, but, despite the suffering she goes through daily, she has since authored several books and has also set up her own ministry by the name of Joni and Friends. She firmly believes that God works in His own particular ways, ways which we cannot comprehend at times, but which eventually will bring out his intended results (Miller, 2020). It is through fully embracing God's will for her that she eventually found the joy, peace and contentment that had previously eluded her. It is her conviction that in her case, "the best position, the best place and the timeliest circumstance in which God can be glorified the most…happens to be a wheelchair" (2010, p.52-53).

Stephanie Hubach, an American author and a research fellow in disability ministries at the Covenant Theological Seminary as well as the mother of a child who has Down syndrome, has convergent theological views to those of Tada. Having affirmed that nature's brokenness is the result of humanity's fall, disability becomes a normal part of life in an abnormal world with "God being in the business of taking whatever is broken and difficult in our lives and redeeming it for His glory" (Faith Inclusion Network, 2015).

2.3.4 Who is the God we Worship?

In acknowledging that disabled persons have been given the cold shoulder in the development of Christian theology and practice, Scottish theologian John Swinton – chair in Divinity and Religious studies at the University of Aberdeen – posits that the debate surrounding disability theology has to take off from the answer to the fundamental question "Who is the God we Worship?"(2010, p.276). Answering this question is key, since we all make sense of the world through our bodies and minds, and this is no exception even when talking theology. Therefore, the image of God that we make up will influence deeply how we understand what it means to be human which then determines how we relate to disabled persons. Now, the fact that the most influential theologians have been non-disabled men who, in developing images of God, could not do so in any other way except through a non-disabled hermeneutic, has led to misrepresentations of disability that spawned exclusion and oppression. To compound matters further, the Church, in her theology "has often been overly influenced by the values and assumptions that emerge from dominant cultures…cultures that reflect the assumptions of modernity" (2010, p.277).

To answer the question posed, Swinton introduces the theological dimension of the apophatic tradition, which, he claims, has hardly been touched upon in discussions surrounding disability theology. Apophatic theology, which is an approach to theology to be found eminently within the monastic tradition of the Eastern Orthodox church, stresses that God can never be known in terms of human categories (McGrath, 2011). The basic premise is that God is unknowable and therefore it is best for us to talk about what God is not: in fact, this theology is also referred to as negative theology. For Swinton this is interesting since no category of humans can claim that only they are created in the image of God: God is not disabled and neither is God non-disabled. Swinton introduces this concept of apophaticism to instil a sense of humility in our discussions, in a bid to dissuade us from projecting our own images onto God and other human beings.

Since we can only gain knowledge of God through that which is revealed to us, what we know for sure is that "God is Love" (Jn 1, 4:8) because this has been revealed to us through Jesus Christ. Therefore it is the quality of our relationship with Christ that will determine the manner in which we encounter God. Keeping in mind that Christ's relationships on earth were with the marginalised and the rejects of society, our relationship with God must translate into solidarity with the oppressed. The Church, then, as the mystical body of Christ, must become the place where “discrimination and prejudice are abandoned and uncompromising love is embraced” (Swinton, 2010, p.306).

2.4 The Pope’s Latest Encyclical

This uncompromising love, true Christian love, is at the heart of the latest encyclical of Pope Francis, *Fratelli Tutti*, a love that goes beyond physical or moral appearances and that builds bridges instead of walls, thus eliminating isolation and making everybody feel at home (Reese, 2020). Pope Francis is resolute about the centrality of love in the life of the Christian: “The spiritual stature of a person’s life is measured by love” (2020, para. 92). Having set love as the litmus test for the Christian, he then goes on to denounce racism, sexism, xenophobia and ableism (Ford, 2020).

Turning his gaze specifically on disabled persons, the Pope empathises with them, declaring that most of them “feel that they exist without belonging and without participating” (2020, para. 98). He then sets out his vision of how Christian love has to build the necessary bridge:

> Our concern should be not only to care for them but to ensure their active participation in the civil and ecclesial community. That is a demanding and even tiring process, yet one that will gradually contribute to the formation of consciences capable of acknowledging each individual as a unique and unrepeatable person (para. 98).

2.4.1 Closer to Home

At the turn of the last millennium, between 1999 and 2003, the Catholic Church in Malta held a diocesan Synod whose purpose had been described as being a serious effort to unravel what the risen Christ is saying to the contemporary community of believers (Frendo, 2003). During the course of the Synod, it became apparent that the role of disabled persons in the life and work of the local church needed to be studied in more detail. For this purpose, following the formal conclusion of the Synod, a working group was set up to study the work that was taking place, both at a local level, as well as in other countries outside Malta and to give its recommendations as to what else needed to be done so that the Church ensures the inclusivity of disabled persons within all its structures. This working group finalised its work and issued its report entitled *Towards a Church that is Ever more Inclusive* (Archdiocese of Malta) three years later, in 2006.

Although this working group did not include disabled persons in its setup, it consulted widely with disabled persons and their families and emphasised that disabled persons “felt oppressed through the dominance of non-disabled persons” (p. 7) and that therefore it was essential that they partake in all those decisions that would affect their participation in the life of the Church. In fact, as a starting point, it is attested that inclusion “requires consultation, especially on matters affecting the participation of people with disabilities, since no-one can presume to know their needs” (p.10), quoting from a document issued by the Bishops’ conference of Britain and Wales, entitled *Valuing Difference: People with Disabilities in the Life and Mission of the Church,* which had been published in November of 1998. Arguing that disabled persons, like everyone else, have a need and a right to participate in all the activities that make up Catholic life, it also argues that a change in mentality is needed. Only when disabled persons are actively participating in the study of Theology, form part of Parish Pastoral Councils, serve as extraordinary ministers of the Eucharist, are employed within the Church structures and involve themselves in social justice movements, can it be said that inclusion has been achieved. The 50-page document refrains from entering into any theological considerations but offers suggestions as to how accessibility for disabled persons can be improved and inclusion achieved in the life of the parish, catechesis, liturgy and sacraments as well as in Church schools and in the workings of the diocese.

2.4.2 Attitudes towards Disability in Catholic Malta

Unfortunately, by choosing to side skirt studying the root causes of the marginalisation of disabled persons within the Church in Malta, the working group set up by the Synod missed a golden opportunity to kick start a process that, hopefully, would eventually have led to significant changes in the way disabled persons are perceived by their brethren. Admittedly, we have come a long way since children with severe impairments were kept out of sight inside cellars or even treated like animals on a farm (Camilleri & Callus, 2001), with such treatment stemming, at least partially, from the Catholic belief that equated impairment with sin (Camilleri, 1999). In Maltese society, where the Church has been so potent in instilling the attitudes held by the population (Camilleri & Callus, 2001), literal interpretations of Biblical episodes have been instrumental in seminating the belief that disability is brought about by sin, either by the individual or the family (Cardona, 2013).

The Church's teaching has been seen by some as being primarily responsible for framing disability in terms of charity. Notwithstanding the introduction of anti-discrimination legislation, disabled persons still feel that society looks at them as objects of charity and not as equal citizens who have identical rights as non-disabled persons (Cardona, 2013). Through this charitable approach, which is the predominant position taken by the Church, disabled persons have been disempowered, lack agency and set themselves low expectations, content with whatever society's benevolence provides them with (Garland, 2015).

2.4.3 One Church, One Journey

Spurned by the Pope's desire for the renewal of the Universal Church, the local Church revisited the outcome of the Diocesan Synod of 2003 and formulated a process of ecclesial renewal for the years 2020 – 2024 which it laid out in the document *One Church, One Journey* that was launched by the Archbishop, Charles Jude Scicluna, in June 2020 (Archdiocese of Malta, 2020). In his introductory message of the document, the Archbishop calls "all entities of the Church in Malta—parishes, religious congregations, schools, lay movements, families and all others—to be imbued by the spirit of this vision and to journey together as one Church on this process of discernment" (p. 2).

The document spells out the four pastoral attitudes that the Church needs to learn and embrace: a Church that listens – the Word of God, a Church that welcomes – everyone without discrimination, a Church that accompanies – with sensitivity and full respect, a Church that goes forth – to the forgotten peripheries. It then sounds a word of caution, pointing out that we need to be vigilant since the peripheries are not always apparent. Putting hand on heart and admitting that "we often claim to know everything about each other", it then concedes that very often it happens that we "become blinded and indifferent" (p. 44) to those we see around us.

In this document, the local Church declares that it is "wounded through excluding specific groups in the very life of the Church when we fail to accompany them in their struggles, but rather simply marginalise them or appear to cast them out through words that kill through condemnation rather than give life" (p. 56). I did not find any specific reference to disabled persons in this document, but what is proffered in it, when talking about specific groups, appears to reinforce the sentiments expressed by disabled persons in literature. Neither did I find any reference to the 2006 document *Towards a Church that is Ever more Inclusive* which I have talked about earlier and which had set specific targets for inclusivity of disabled persons. It is still to be seen what this process of renewal initiated by a refreshed, hopeful vision of the Church in Malta will eventually translate to in practice for disabled persons.

2.5 Conclusion

In this chapter, I sought to review literature that discusses the impact that religious belief and practice have on disabled persons. Looking mainly from a Catholic perspective, I have discussed the main themes – including, but not exclusively, theological ones – which arise in contemporary literature concerning disability, disabling conditions and the Church. Unfortunately, I could not find any published work which discusses such themes in the context of the local Church.

A last significant factor to mention here with regards to this study is the fact that although Christian theology has four sources, these being Scripture, Tradition, reason and religious experience (McGrath, 2011), literature has shown that the religious experience of disabled persons has not been given its due consideration in the theological debate. It is such experiences, which in fact constitute the body of this study, that I will be discussing and interpreting in Chapter 4. However, before arriving at the experiences of the participants, I will, in the next chapter, present the methodology I followed throughout my research.

Chapter 3

Methodology

Chapter 3 Methodology

Disability research has often been criticised for serving mainly, if not exclusively, the interests of the researchers – who, in the vast majority of cases are non-disabled persons – rather than the interests of the disabled persons who are being researched (Kitchin, 2000). In attempting to redress this anomaly, disability scholars propose that disability research should be conducted along emancipatory guidelines wherein disabled persons are active participants in the research process and with the outcomes of the research eventually proving to be somehow of benefit to the participants (Stone & Priestley, 1996). Central to the emancipatory genre of research is the use of qualitative techniques (Barnes, 1992). In this chapter I will first of all sketch the theoretical underpinnings of the IPA approach and then proceed with describing the IPA process utilised to arrive at my observations and conclusions.

3.1 An Interpretative Approach

Qualitative research, which used to be regarded as not standing up to scholarly rigour, has, over the past three decades, gained acceptance as a legitimate scientific way of carrying out research in numerous disciplines (Brinkmann, 2012). 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" (Denzin & Lincoln, 2011, p. 3). Moreover, although the main aim of qualitative inquiry is to comprehend and interpret human phenomena – that is, the lived experience of humans, the ultimate goal may very well be that of inducing social change (Lichtman, 2014). This ties in neatly with emancipatory disability research guidelines which emphasise that disabled persons involved in research projects should be the end beneficiaries of such research through the positive social change initiated in the wake of the project (Hodge, 2008). A philosophical approach to get to the essence of the lived experience of a particular phenomenon and what it meant for the individuals who have gone through this experience, is phenomenology.

3.1.1 Phenomenology

Phenomenology, which is both a philosophy and an array of research approaches, “examines taken-for-granted human situations as they are experienced in everyday life but which go typically unquestioned” (Finlay, 2012, p.173). Edmund Husserl, who, as I said in my introduction, is the founder of phenomenology as a philosophical movement, held that there is nothing more fundamental than experience and that therefore experience must be the starting point of any investigation (Ashworth, 2015). He established that in studying human experience what is essential is to get to the meanings humans give to that experience: the lived experience can be said to be a system of interrelated meanings which are tied together, forming what he termed the lifeworld.

Heidegger, Merleau-Ponty and Sartre, all three existential phenomenologists, developed further Husserl’s ideas of the lifeworld. Existential phenomenology postulates that although the lived experience of individuals of their situation tends to be quite unique, all lifeworlds nonetheless do share a number of commonalties such as temporality, subjective embodiment, intersubjectivity and personhood (Ashworth, 2006). The term intersubjectivity here refers to the “shared, overlapping and relational nature of our engagement with the world” (Smith, Flowers & Larkin, 2009, p.17). For Heidegger, a person always exists in relation to the world and the concept of intersubjectivity describes this relatedness as well as “our ability to communicate with, and make sense of, each other” (Larkin, Eatough & Osborn, 2011, p. 7).

In carrying out a phenomenological study, the researcher has to investigate how the participant lived, or is living, a particular experience over time, going beyond what is said about the experience and digging deeper to arrive at what is revealed in that which is said (Van Manen, 2007; Finlay, 2012).

3.1.2 Hermeneutics

The researcher, therefore, has to interpret that which is being said about the experience by combining phenomenology to hermeneutics - the theory of interpretation – which postulates that it is through language that we experience the world, besides using it to gain knowledge and understanding (Lichtman, 2014). German philosopher Hans-Georg Gadamer (1900-2002), the leading figure in the 20th-century development of hermeneutics, in his magnum opus *Truth and Method*, argues that hermeneutics is the philosophical theory of knowledge and that all cases of understanding anything necessarily involve interpretation (Schmidt, 2014). This description, in fact, sets out the two main branches within the field of hermeneutics: one which deals with the philosophy of understanding with the other being the area that concerns activities related to interpretation (Tomkins & Eatough, 2018).

Gadamer engaged with and developed themes proposed in the writings of Schleiermacher and Heidegger. For Schleiermacher, interpretation is a form of art, going beyond rigidly following a given set of rules which eventually lead to the meaning of the text (Smith et al. 2009). The goal of any interpretative process must be to understand the author as well as what is written. Schleiermacher actually believed that when undertaking a truly thorough and comprehensive analysis of a text, an interpreter will get to know the author more than he/she knows themselves.

For Heidegger “the interpretation of people’s meaning-making activities is central to phenomenological inquiry” (Smith et al., 2009, p.18). For him, phenomenology and hermeneutics are but two strands of the same chord. One aspect of Heidegger’s work that is very relevant to interpretation when carrying out research, is the potential obstacles that preconceptions may present (Tomkins & Eatough, 2018). Going against what was proposed by his master, Husserl, Heidegger affirms that any interpreter cannot but view any new material through previous experiences and pre-suppositions. More than this, he argues, interpreting new texts will ultimately shed light on one’s preconceptions (Schmidt, 2014).

Common to all these writers of hermeneutic theory is the notion of the hermeneutic circle. The hermeneutic circle reflects a dynamic dimension within the process of interpretation where the part gives meaning to the whole and the whole sheds light on the part, with the part and whole being in constant flux (Smith & Osborn, 2015). Heidegger is applying the concept of hermeneutic circling when suggesting that one should revisit one’s assumptions prior to encountering a text and then once the text has been interpreted: having gathered more information about a phenomenon, pre-assumptions held are to be revised (Tomkins & Eatough, 2018). Schleiermacher, on the other hand, uses the hermeneutic circle to draw a relationship between the particular and the general: how considering a specific thing can lead us to reflect on the whole.

3.1.3 Idiography

Idiography is concerned with the particular, with studying the unique and understanding the detail (Eatough & Smith, 2017) as opposed to the nomothetic approach that seeks to establish general laws of human behaviour (Smith et al., 2009). This does not mean that idiography shies away from generalisations, but rather that it goes through a different route in establishing these generalisations.

3.2 Interpretative Phenomenological Analysis

A qualitative research approach that brings together concepts described above from phenomenology, hermeneutics and idiography is Interpretative Phenomenological Analysis (IPA) which was established some thirty years ago in the field of qualitative psychology (Chenail, 2009). Seeking to help qualitative researchers examine “how people make sense of their major life experiences” (Smith et al., 2009, p.1), IPA has since been used in various disciplines proving to be a rigorous approach producing “a plethora of rich data” (Callary, Rathwell & Young, 2015). IPA draws from the work of the existential phenomenologists mentioned earlier – Heidegger, Schleiermacher and Gadamer, as well as Merleau-Ponty – as it guides the researcher to focus on reflection and systematic analysis of experience (Wagstaff et al, 2014).

After studying the different methodologies available to me to carry out this study, I chose IPA since, in my opinion, it was the best approach to enable me to understand what it means for the participants of this study to be part of a Catholic community of faith in Malta and what they make of this experience (Cameron, 2016). I arrived at this conclusion by considering the following facts:

(a) being a phenomenological approach, the lived experience is the very raison d’etre of IPA and what’s more, it is primarily interested with experiences that are of major importance for an individual, such as, in my case, religious belief (Smith, 2011)

(b) IPA helped me enter in a double hermeneutic, engaging with the experience of the participants to interpret the meanings they give to their experiences as they navigate their lifeworld

(c) since my research involves a small number of participants it was imperative for the methodology to be idiographic, thus enabling me to analyse in detail a small number of experiences but obtaining meaningful data thereof.

3.3 Participants to the Research

Given that IPA is based on an idiographic paradigm, participants to this study had to be selected purposively, paying attention to the homogeneity of the sample which had to be composed of between three and six individuals for whom the area of study was meaningful (Smith et al., 2009; Englander, 2012). The inclusion criteria, therefore, were: adults in the 21 to 50 years age bracket who had a physical or sensory impairment (acquired or from birth) and who considered themselves to be practising Catholics. I set the upper limit to be 50 years to ensure that participants grew up in a post-Vatican Council II era. Vatican Council II (1962 – 1965), which is probably the most significant event that took place in the modern era of the Catholic Church, has been described by Karl Rahner – one of the most influential theologians of the 20th century – as "that event of Church history in which the world Church modestly began to act as such" (1979, p. 726). The *Pastoral Constitution on the Church in the Modern World – Gaudium et Spes*, which is one of the most important documents that came out from that council, has been universally recognised as having fundamentally changed the Church's relationship with the world (McEvoy, 2006). Considering that it is calculated that a Church council's vision is realised two generations after it is held (Gaillardetz & Clifford, 2012), the targeted participants, therefore, should have experienced a strong Catholic formation, benefitting from the fruits of the council.

Keeping within the said age bracket, therefore, strengthened further the group’s homogeneity.

An information letter which included an invitation to participate in the study (Appendices 1a, 1b) was sent to potential participants through the Commission for the Rights of Persons with Disability (CRPD) who acted as my gatekeepers. At this very first stage of the data collection process, the COVID-19 pandemic straightaway curtailed the potential pool of participants. The CRPD informed me that due to the restrictions that were in place, only those registered persons who had access to email could be notified given that only electronic mail was being handled by the commission. This process did not yield enough participants and therefore I resorted to snowballing to reach the required amount of five participants: three males and two females, of whom three are visually impaired and two physically impaired individuals, two were born with the impairment while the other three have an acquired impairment with onset during childhood or early adulthood. I will now give a brief description of these five participants, using pseudonyms to protect their identity.

David is a forty four year old visually impaired gentleman who lives on his own in his recently bought property. He was a member of the Society of Christian Doctrine (SDC) till the age of sixteen, with his impairment setting in during early adulthood. David is a university graduate and holds a full time employment. Although he still cherishes the Christian values instilled in him during his young formative years and still lives by them, he admits that a number of experiences he went through after acquiring his impairment have lately distanced him from regular church attendance.

Abigail is in her early forties, married and is employed full time. She has been visually impaired for the past twenty odd years and through the use of her guide dog feels very safe when going out and about, carrying out her daily activities. Besides attending Mass regularly on Sundays, Abigail forms part of a smaller community, or group, within the parish – composed of couples, single or separated persons, young and not so young – who meet once or twice a week. Even during the current COVID-19 pandemic, when restrictions made it impossible for the group to meet physically, they kept on meeting online – something which Abigail felt helped her a lot during those difficult moments. Pointedly remarking that this group is not part of the local Charismatic Movement, she stresses the fact that she is accepted as Abigail within the group which, in turn, makes her feel that she forms an integral part of an extended family.

Sharon is twenty two years old, has a full time job and is still at University furthering her studies as a part-time postgraduate student. She uses a wheelchair due to an impairment in her muscles which, besides making it difficult for her to keep her balance, also impacts the movement of her hands. Sharon lives with her parents and although she still lives the values she was brought up with as a Catholic, nowadays she only attends church functions occasionally. She feels that the Church, as an institution, is not loyal to Christ’s teachings.

John was in full time employment until last year, but then at the age of thirty decided to return back to University to further his studies as a full time student. John was born with cerebral palsy and is a wheelchair user. He describes himself as an outgoing person, always on the lookout for fresh challenges. He used to attend the SDC in his early teenage years and looks at his spiritual growth as an ongoing process. He admits that some years back he went through a period of rebellion but is now seeking to work hard again at deepening his relationship with God. John attends church regularly and even tries to find some time for personal prayer.

Peter comes from a family of four, is forty two years old, and lives on his own. He has been a self-employed person since graduating from the University of Malta in 2006 and is active in disabled persons' organisations. Peter, who considers himself to be a practicing Catholic attends church regularly to hear mass but admits that he can be a better Christian. He has been visually impaired since the age of thirteen and was still attending the Society of Christian Doctrine until then. Conceding that the years following the onset of his impairment were very turbulent, Peter says that he eventually picked himself up and from then on has always looked for ways to get involved in the life of the parish

3.4 Data Collection

All the data for this study was collected through in-depth semi-structured interviews which lasted from slightly less than one hour to nearly two hours each. This mode of data collection has proved to be the most fruitful in IPA studies primarily because one to one interviews offer the possibility for rapport to be built, provide enough time for the participant to think and be heard out, as well as allowing the possibility of discussion to take place if need be (Reid, Flowers & Larkin, 2005).

It was these characteristics of data collection that I sought to exploit during all the contacts I had with the participants. The overarching aim of this IPA study was to explore whether the participants felt welcome by the respective communities and, as a result of their relationship with their community, whether they felt this was sustaining or hindering them in their spiritual journey. During the interview, rather than opting to follow a set, predetermined course, I had to be vigilant so as to be able to move in the direction the experiences of the participants were taking us, in order to gather the maximum amount of rich data that would enable this goal to be reached.

Keeping all this in mind, rather than a set of questions, I prepared individual interview schedules that were flexible and which I then adapted accordingly during the interview itself. In preparing this schedule I kept in mind that the questions that I would be putting to the participants would not be leading ones but would rather serve to guide them in sharing their lived experiences, with unscripted, follow-up questions inserted for clarifications while moving along with the participants into areas that were not planned beforehand (Englander, 2012). The interview schedule was provided to participants at least one week before the interview was to be held so that they knew in advance what we were going to talk about and could be better prepared on the day. The three visually impaired participants were offered the possibility to have their information letter, consent form as well as interview schedule printed in Braille. However all of them indicated to me that they had full accessibility to all the information provided through their screen readers.

I intended to hold face to face interviews and in fact, in the information letter, I had offered participants the choice of either holding the interview at their residence, at my place of work or at any other venue convenient for them with transport being made available to them. However, due to the new reality ushered in by COVID-19, only one participant opted for a face to face interview with the other four preferring the online alternative. In all of the cases, I talked to the participants several times prior to the interview, making sure that they had all the information they needed about the research study as well as to discuss details, such as the date and time of the interview and which online method they felt most confident with to conduct the interview.

Making contact with the participants helped to build a rapport, an essential element in obtaining quality data from them, which rapport was strengthened in the opening stages of the interview by making them feel at ease and comfortable to express themselves (Smith, et al., 2009). Participants were given the option to reply in either English or Maltese, with all of them opting for the Maltese language. The interview was recorded – with their consent

– and transcribed verbatim as close as possible to when it was conducted. In line with emancipatory research principles, the transcript of the interview was emailed to each participant to be verified and modified according to their wishes, thus giving them full control over their stories (Hodge, 2008). All participants, having reviewed the transcripts, came back to me, indicating that the document was a faithful reproduction of that which was said during the interview.

3.5 Ethical Issues

Conscious of the fact that being ethical is fundamental to producing quality research results, as well as in avoiding being of detriment to the disability research field and the participants themselves (Zarb, 1992), I have adopted an ethical approach throughout - and not as an afterthought.

I consider the issue of informed consent to be critical in the whole process. All the necessary information, including the consent forms (Appendices 2a, 2b) were presented in a way that could be easily accessed and studied to ensure that participants were fully aware of what they were consenting to. I made certain that their queries were answered by calling them days before the interview was held, while they acknowledged their consent by signing the forms and sending them back to me before the interview. In giving their consent, participants were aware that they could choose to decline to answer any questions asked, as well as to withdraw from the study up to one month after giving their interview in which case all data collected would have been erased.

Prime importance was also given to the safeguarding of the anonymity of participants through the use of pseudonyms as well as to the strict confidentiality of all information. All printed material was kept in a secure place to which only I had access, while all digital information was password protected. All data collected from participants – except those transcription extracts quoted in this paper – will be destroyed on completion of the study and publication of the results, that is by January 2022.

Throughout the study, I was guided by the University's Research Code of Practice while approval by the Faculty Research Ethics Committee was obtained before contacting any potential participants.

3.6 Analysing the Data

Any analysis of data derived from an interview has to have as its starting point the total familiarisation with the transcribed material, which can only be achieved by reading and rereading the transcript, immersing oneself in the available data, up to the point of "becoming intimate with the material" (Marshall & Rossman, 2010, p.213). Following that advice, I did immerse myself in the data, one transcript after the other, up to the point that the participants' experiences accompanied me wherever I went and in whatever I did, throughout those weeks during which I was analysing and interpreting the findings. This helped me to engage in an interpretative relationship with the transcript so as to arrive at the ultimate aim of "capturing and doing justice to the meanings of the respondents" (Smith & Osborn, 2015, p. 39).

Having achieved this familiarity with the participants' lived experience, I went over the transcript several times, every time jotting notes alongside those parts that I considered to be important in the participant's experience, as suggested by Smith and Osborn (2015). Once this exercise was completed, my attention shifted to my annotations, transforming them into themes that best captured the particularity of the experience, but at the same time were open enough to be conceptual (Smith et al., 2009). I then studied these themes, looking out for connections between them that enabled me to cluster them together under what can be called a super-ordinate theme that "brings together a series of clearly related other themes" (Smith et al., 2009, p.97). This procedure was followed for all five participants with all the themes that emerged from each interview being grouped under the respective super-ordinate theme. Presenting all the emergent themes under their respective super-ordinate themes in tabular form helped provide the reader with a concise visual representation of the findings. Although all themes were gathered under a number of higher-order themes, the analysis still left room for the difference in meanings given by the participants, contributing to a complete and thorough understanding of the phenomenon being studied (Reid, Flowers & Larkin, 2005).

3.7 Dissemination of Findings

Having assumed responsibility to adhere to the principles of emancipatory disability research, I have to ensure that once finalised, this thesis goes "beyond the sterile confines of university lecture theatres and seminar rooms" (Barnes, 2014, p. 24) so as to serve "as a means of giving voice to participants' experiences" (Hodge, 2008, p. 29).

The first step in the dissemination process will be to present the finished report to the local Ecclesiastical authorities. However, more than simply present the end results, we (meaning those participants who are willing to do so and myself) will strive to engage with the appropriate persons, especially with the individuals presiding over the four-year plan of renewal *One Church One Journey* which I have discussed in the previous chapter. The main scope here will be to emphasise the importance of having disabled persons involved in this journey of the local Church. The second step will be to approach the College of Parish Priests and invite ourselves to deliver a presentation of the findings of this study at their annual convention. The final step will be to contact the moderators of the seventy Parish Pastoral Councils and ask to be given space in their annual assembly to present the study. In parallel to this dissemination process within the Church structures, I will seek to reach out to members of the various Disabled People's Organisations, make them aware of this study and identify individuals who would be willing to get involved in any action plans that result from our meetings with the Church entities.

3.8 Conclusion

In this chapter, I have presented the methodology that I adopted throughout my research process. I have also outlined the ethical principles I followed all along and discussed my plans for effective dissemination of the study. In the chapter that follows, I will be presenting the findings together with their discussion and interpretation.

Chapter 4

Findings: Discussion and Interpretation

Chapter 4 Findings: Discussion and Interpretation

In this chapter - which is definitively the most important section of this dissertation, given that this research is of the emancipatory genre, interpretative and idiographic - I will be presenting the findings that emerged from the interviews that I carried out with the five protagonists of this study. Conscious of the fact that, at this stage, the third hermeneutic level will come into play - the reader trying to make sense of my interpretation of the participants' meaning-making of their experience – I will be presenting the results "in a full narrative account which is comprehensible, systematic and persuasive to the reader" (Smith & al., 2009, p.109). As I explained in my methodology chapter, I started off my analysis of the data by carrying out an in-depth analysis of the interviews in a sequential manner, after which I extracted the themes that emerged and grouped them under three main super-ordinate themes. I will be presenting each theme, discussing it in relation to the conceptual framework I presented in the introductory chapter whilst supporting it with literature reviewed in Chapter 2 as well as through other studies I will be referencing in this chapter. However, before going into the specifics of each particular theme, I thought it would be best to bring to life the protagonists of this study by presenting my interpretation of their narrative. In this manner the reader will become acquainted with each protagonist before the themes are discussed and thus will be in a better position to grasp the similarities and divergences of the lived experiences of the participants.

4.1 The Participants

I have already briefly introduced the participants of this research in the previous chapter (page 44). In presenting that short resume of each participant, I had to be miserly with the amount of detail I could divulge about them since, on this tiny island state of ours, putting together such key personal information as type of impairment, educational level and some employment details can render the participant easily identifiable. What is more important for this study, however, is the lived experience that each one of them brought with them, and which, when interpreted formed the basis of the analysis.

Table 4.1, shown below, captures the main characteristics of the participants. I have compiled this table to serve as a quick reference for the reader, facilitating getting to know the protagonists.

Participant	Age	Type of Impairment	Career
David	40	Visually Impaired	Employed Full Time Part Time Postgraduate Student
Abigail	44	Visually Impaired	Employed Full Time
Sharon	22	Physically Impaired	Employed Full Time Part Time Postgraduate Student
John	31	Physically Impaired	Currently Full Time Postgraduate Student (Employed full time till last year)
Peter	42	Visually Impaired	Self Employed Full Time

Table 4.1: The Participants at a Glance

4.2 The Journey: Interpreting Participants' Experiences

The main scope of this study has been to explore the manner in which our parish communities sustain the spiritual journey of disabled persons. As I argued in my introductory chapter, such knowledge can only be generated through the lived experience of this phenomenon by disabled persons. By adopting IPA as the methodology to arrive at what this lived experience means for the participants, my approach was bound to be interpretative while concurrently taking on an idiographic stance (Larkin, Watts & Clifton, 2006). In presenting the following salient parts of the participants' narrative I have applied the concept of the hermeneutic circle in that to arrive at an understanding of the whole you have to look at the parts, while to comprehend the part you look at the whole: digging deeper into particular passages during the interview helped me shed light on the whole experience (Smith et al., 2009). I have captioned each narrative by using a particular phrase as expressed by the participant during the interview which best captures the meaning the individual gave to the experience.

4.2.1 "I might as well talk to the wall"

David still remembers fondly his teachers at catechism classes and those he had later on at the Society of Christian Doctrine, where he spent his Christian formative years up to school leaving age. He has only words of praise towards them and recounts a couple of anecdotes that highlight his positive experiences which helped him embrace Christian values. He also concedes that attending the SDC served as a golden opportunity for him to socialise. However, all this was to change in early adulthood with the onset of his impairment. At that time David was an active person within a socio-religious group and when most in need of support he found none. In line with what research shows, acquiring his impairment when still young put his relationship with his peers under strain, particularly because of how society perceives disability, rendering him socially isolated (Stokes, Turnball & Wyn, 2013). David started doubting his faith, questioning all that he had previously accepted "in an uncritical manner."

As he sought ways in which he could feel accepted by the community, intransigence from the clergy and the attitude of congregants left him lamenting that he did not "feel welcomed when entering the church" where "the atmosphere was too clinical and lacking warmth". David recounts several instances when he took up the issue of inclusivity and the way disabled persons are seen as objects of pity or persons in need of healing with various members of the clergy, but he sums up the outcomes of his efforts as being akin to talking to the wall. Even meeting with the highest authorities at the Curia failed to make any inroads in raising awareness and fostering inclusion of disabled persons in the community.

David’s experience resonates with the concept of disabled persons being misfits in the Church as proposed by Naomi Lawson Jacobs in her doctoral thesis entitled *The Upside Down Kingdom of God* (2019). Drawing on the work of Rosemarie Garland-Thomson (2011), Jacobs argues that disabled persons are often prevented from fitting within the Church, be it within its buildings, the worship contexts or in social interactions. They are welcomed in the Church, but only conditionally: as long as they manage to discipline themselves into fitting in the Church’s spiritual tradition and social norms. These areas of misfitting are so deeply ingrained in the Church’s culture that they tend to be invisible both to the non-disabled leadership of the Church as well as to the other congregants (Jacobs, 2019).

4.2.2 “We are called to be a sign of God’s Love”

Abigail has been part of a small community or group within her parish for the past seventeen years. They meet regularly, on average twice a week, to pray together as well as to socialise. Since the outbreak of the Covid-19 pandemic they have been meeting online, something which has helped Abigail immensely especially when she was passing through a difficult period brought about by bereavement. “Being part of this community has made a big difference for me” she maintains. Had it been otherwise “I would not have been so close to the Word of God and to the Sacraments; my formation into the person I am would not have been possible had I not attended Church and the community meetings regularly”.

Abigail is not treated with kid gloves within the group: she is expected to give her input at par with any other member. No one shows any signs of pity towards her because of her impairment. This makes her feel so accepted and welcome that “at times I forget about my impairment”. She is convinced that growing up spiritually has made her a happier person, at peace with herself. Moreover, as a true Christian, she sums her mission as “being a sign for others: that is what our religion, Christianity, is all about - being a sign of God’s love on earth”.

Reflecting on Abigail’s experience brought to mind what Hans S. Reinders - a contemporary theologian and professor of ethics - proposes in his powerful book *Receiving the Gift of Friendship*. Reinders makes the argument that “we need friendship if we are to flourish as human beings. The theological justification…is that friendship with our fellow creatures is our vocation” (2008, p.162). This is what Abigail is talking about when she says that our mission is to be a sign of God’s love: every person deserves to be chosen as a friend because that is what God does with us - chooses each one of us to be His friend. The friendship Reinders is talking about here is not the friendship with those persons who are viewed as important persons or whose character and personality are lauded by their peers. He is referring to true Christian friendship, that is, a commitment towards the marginalised, those that in the eyes of the world have a life that is deemed to be next to worthless. Our communities need to adopt this notion of friendship as their core value in order to combat the exclusion of disabled persons (Reinders, 2011).

4.2.3 “The way that I see it is that sometimes the Church is not loyal to Christ’s teaching”

Sharon’s experience is diametrically opposite to Abigail’s. Since her early formative years at catechism classes and at the youth centre she could feel the stigma of being different, leading to exclusion by her peers: “there were times when I used to feel marginalised”. In her early teenage years she underwent a lot of interventions at hospital, both locally and abroad. Then, at seventeen, she was diagnosed with cancer: “How is it possible that I have to face all this? I felt a sort of rebellion”. She says that her faith suffered through such experiences and nowadays, although she still cherishes the values she was brought up with, she only goes to church occasionally, preferring to pray at home.

Hearing the interpretation of Biblical passages during Sunday mass homilies made her feel as if for the Church, disabled persons are inferior to non-disabled people. Twice during our interview she recalled her secondary school religion teacher pointing out to the whole class that “you are a freak of nature”, her voice cracking with emotion: “That hurt me a lot”, she confesses. Sharon cannot stand such labels that are used to define her when in fact “I believe that my impairment is that which makes me Sharon, that which defines me. In other words I do not feel the need of getting healed: my impairment is part of my identity”.

Sharon, here, is highlighting the fact that the way she perceives herself - as a person with an impairment but not only the impairment – and the way the community constructs her identity, are discordant (Kelly, 2001). Although Sharon does not deny her impairment together with the difficulties that it brings with it, she sees herself as being more than simply her impairment; however, the social identity is too strong and prevails during her interactions with the community. Sharon, therefore, sees herself as being in the community but not forming part of it: “the person with impairment has to operate with a double level of meaning” (Kelly, 2001, p.403). In trying to come to terms with this ambiguous world, Sharon explains: “I created this distinction in my mind, this distinction between God (or Jesus) and the Church – God welcomes everyone, but the person who told me that I’m a freak of nature, that is the Church”.

4.2.4 “For me, the spiritual journey is a process”

“The repetition of contact with people and the meanings given to these contacts constitute the life-world” with the community being “the everyday life-world of contacts” that an individual has (Kelly, 2001, p.397). The meanings Sharon gave to her experiences within the community throughout her formative years as well as in her early adulthood - at school, catechism classes and at the youth centre - left her feeling marginalised. John’s lived experience of his life-world lies at the other end of the spectrum when compared to Sharon’s.

> I never encountered any particular problems, neither at catechism lessons nor at M.U.S.E.U.M. [Society of Christian Doctrine], for example somebody trying to exclude me from participating. I never faced any issues: at M.U.S.E.U.M., even whilst playing football – and, as you can imagine, I am quite limited as to how much football I can play – I used to take up the goalkeeper position together with a friend of mine or my teacher. I was never treated in a manner that was different from the others.

John sees this period of his life as the first phase of his spiritual journey, which he considers to be an ongoing process. “At this stage I just used to attend [catechism and church] without giving much thought to it”, he explains “but, then, during my teenage years I started distancing myself ”. However, now he is entering another phase, seeing everything under a different light. “Now, it is not simply a matter of just attending church regularly. I want to go over and above that, like making time for personal prayer”. Ultimately, for John, the most important thing for him is to practice his Christian belief in his daily activities. “I am not perfect, and it is not easy to live what you believe in, but I will do my utmost to keep moving on in this direction”.

In his endeavours to walk the talk, John feels that the Church is failing him when, for example, during homilies disability is always depicted in a negative light or that persons with impairments are portrayed as persons to be pitied. “The terminology used casts the impression that having an impairment is equivalent to imprisonment for the individual. I admit I face difficulties, but ultimately I do reach my objectives in life”. He feels that it is not fair that disabled persons work hard to change people’s attitude towards them and then all their work is undone by the clergy. The Church must acknowledge the need of this awareness among the community, not least because “unfortunately a bad example has a much greater effect than a positive example – that is the reality.”

4.2.5 “My involvement within the community was of benefit to the community as well”

> I believe that the Church has to work harder at including disabled persons. I am not saying that nothing has been achieved. But much more needs to be done…and it is not a question of resources…it’s a matter of lack of will, a matter of not enough thinking being put in.

Peter keeps pointing out, at various instances throughout our interview, that since his younger days when he was still attending the village youth centre till this very day, he has always made it a point to get involved in the life of the community. Conceding that sometimes he had to impose himself on others, he is proud that his goal of being included in the parish's activities – to the extent of even participating in the Good Friday procession (prior to COVID-19 times) – was always achieved. This is the challenge that faces disabled persons and the community alike: the true involvement in the life of the parish.

Peter found the going tough since human experience is built through intersubjectivity (Finlay, 2012). For Austrian social phenomenologist Alfred Schutz, the essence of the social world "was its commonness, the fact that it is a world shared by the multiplicity of individuals living and acting within it, in mutually interlocking acts" (Zaner, 1961, p.71). As Peter opens up, describing what it meant for him seeking to share his lifeworld with others, he muses upon the rejections he had to contend with: "it happened to me…I have been rejected trying to be part of the community…I suffered, but I learned as well…it's trial and error…that's the way to grow up".

Peter does not live under the illusion that having disabled persons actively forming part of our communities is an easy task: "We still have to put in a lot of hard work. Society does not make it easy for us to get involved. But once we get there, it will benefit both the disabled person as well as the community itself ".

4.3 Emergent Themes

Having set the stage of this analysis chapter by getting the reader acquainted with the protagonists, it is now time to start discussing the themes that emerged from the interviews. In presenting these themes I will compare and contrast similarities and divergences between the participants. Table 4.2 below provides the reader with a summary of the findings, rendering it easier to capture and visualise the salient themes, gathered under three super-ordinate themes.

A Conditional Acceptance: “Lukewarm Reception”	**Objects of Care and Pity: “But I have a Lot of Qualities”**	**The Community: “When I was in need…”**
The Invisible Faithful	Objects of Pity [*Miskin(a)/Jaħasra*]	“No one there for me”
“A Lukewarm Reception”	Nothing About Us…	At Par With Others
Barriers to Accessibility	Lack of Agency	At the Periphery
Ableism	Inadequate Theology	

Table 4.2 Emergent themes grouped under three super-ordinate themes

4.4 A Conditional Acceptance: “Lukewarm Reception”

Although over the past forty years disabled persons, mostly thanks to the work done by disability rights movements, have witnessed a shift from charity to rights treatment resulting in numerous benefits for them, it is crucial to keep in mind that love and friendship cannot be experienced through rights and choice (Reinders, 2011). Love and friendship, or acceptance, depend on others and people enter into relationships because they want to and not because they are forced to do so through imposition. It is the lack of acceptance - or let us say, conditional acceptance - that appears to make some disabled persons feel they are not welcome within the Church.

I have gathered the first set of themes under the super-ordinate theme of conditional acceptance by the community at large - be they fellow parishioners, clergy, catechism teachers, or community members - with the subtitle “lukewarm reception”, taken from the narrative of one of the participants. This conditional acceptance manifests itself in a variety of forms, sometimes overtly noticeable but in other circumstances quite subtle or nuanced.

4.4.1 The Invisible Faithful

In starting to talk about the inclusion of disabled persons within the Church, the first questions that have to be addressed are those that have to do with who is included and who is not, coupled with on what terms and, significantly, what they are included in (Barton & Armstrong, 2001). David certainly does not feel that disabled persons are considered to form an integral part of the Church:

> Let me tell you: with regards to sermons I am one who pays quite a lot of attention and I find that most of them just speak at face value and by and large disability never features anywhere. You hear the majority of sermons and it is as if, by and large, persons with disability do not exist!

Sharon experienced this lack of acceptance when she was still a young child attending catechism lessons. Her impairment not being overtly visible led the priest in charge to belief that she was feigning her disability. This non-acceptance, and all that she had to live through whilst attending catechism lessons, have left a marked effect on her as she vividly explains:

> At the time that I started attending catechism lessons I used to wear something similar to a pair of boots [callipers] so that my legs would be held straight. I used to wear them for quite a long time. The priest in charge used to think that I was similar to the boys who came in their football boots so that after lessons they would go straight to training. So the priest, seeing me making use of a wheelchair, would tell me: 'come on, you do not need a wheelchair, you are going for football!' Berating me [*jiksirni*] like that in front of all the others used to make me feel ashamed…back then I was still a very shy person…it was already difficult for me being different from the other children at that tender age…it was difficult for me having to explain that I had such and such an impairment…I feel that this experience had quite a negative impact on me.

The attitude of the other congregants at church made Sharon feel unwelcome when attending Sunday mass. Attitudes, which are something personal and subjective, incorporate feelings, thoughts and actions (Guglielmi, 1999). Current studies of social attitudes highlight inconsistencies in what people say their attitudes are towards disabled persons and in the way they actually behave towards them (Nario-Redmond, 2020). Sharon found it hard to reconcile the faith supposedly professed by the congregants present at church with their judgemental behaviour towards her:

> When we [my mother and myself] used to go to church every Sunday I did not use to kneel down during mass since I had problems with my knee and was in pain – I was even operated upon my knee. Even though I used to bow down, all those around me used to look daggers at me. I used to feel I was being judged. Although I knew that I was more than justified in not kneeling down, the fact that I was being wrongfully judged used to irk me a lot.

For Peter it appears that disabled persons are an afterthought as regards to what goes on within the parish. He picks up what happened as a consequence of the measures taken to contain the spread of COVID-19 as an example to prove his point:

> Presently we are living through the COVID pandemic, no? For me, being visually impaired, someone changing a pattern which I am used to, makes me feel lost, because a blind person visualises the environment in his mind. What happened now because of COVID? They changed the position of the benches in the church, admittedly to safeguard the public's health, but…. Nobody, even though they know that I attend church regularly, had the decency to tell me "Listen, we have rearranged the benches in such and such a manner"…then we have the issue of the sanitiser…it is obvious that nobody thought about me…

Peter insists that he enjoys participating in Church activities but "to participate I had to invite myself most of the times". Through his insistence he managed to take part in the Good Friday procession when he pointed out that most of the village persons participated and therefore "why should I be the odd one out?"

I find that the concept of liminality helps to shed light on these ambiguous relationships described by the participants. Disabled American anthropologist Robert Murphy linked the anthropological concept of liminality – which is the state of ambiguity or disorientation experienced by participants caught in a ritual transition, coming out from one stage but not yet in the state which they will eventually arrive at once the rite is over - to the social experience of disability (Murphy et al., 1988). Disabled persons are often caught in this permanent state of liminality wherein they are viewed as being in an undefined social state: neither ill nor well, neither socially alive nor dead, neither fully excluded nor included, neither rejected nor fully accepted (Ravaud & Stiker, 2001). Liminality brings to the fore the “pervasive, indeterminate limbo-like state of being-in-the-world” (Gill, 2001, p.359) which excludes disabled persons from the community, depriving them of their full humanity.

4.4.2 “A Lukewarm Reception”

It could very well have been this lack of acceptance, this not being neither in nor out, that had driven David and his peers within a local Disabled People’s Organisation to seek a meeting with the Archbishop. During our interview, David referred twice to the meeting they managed to set up with the Archbishop. He enthusiastically explained how they came up with the idea of putting up a presentation to the highest local ecclesiastical persons, highlighting their achievements and success stories. The end result, however, turned out to be a big let-down:

> What I know for sure is that when I was president of a DPO I proposed that we should open a communication channel with the Curia. However, although it was yes, yes, yes, in fact they always remained a step back and nothing materialised. Then, later on, when I was involved within another DPO we had approached Archbishop Cremona, but there were a lot of mixed feelings. He seemed to be impressed by what we presented him with, but no action followed. I do not think that it was his fault, but much more those around him. You see, I mean the attitude was lukewarm. As the Maltese saying goes ‘A fish stinks from the head’, in the sense that if you have the wrong attitude [*attitudni mbażwra*] right at the top, imagine as you go down the line….

John passed through a similar experience and feels that the Church’s hierarchy are not humble enough to admit certain mistakes they commit:

> In the past I was part of a DPO which was quite vociferous on disability issues. We sought to meet the Archbishop and eventually we met once, discussing mainly issues of accessibility and awareness training. However, unfortunately, there was no response. The mentality with regard to accessibility is that the church made of stone comes first and the person second, which is in contradiction to the Church's teaching. In my opinion this goes against that which we are taught. It appears to me that the persons at the top want to show that what they say stands at all costs [*iridu li tgħaddi tagħhom*]…they need to be humble enough to admit that what we are saying, after all, makes sense because we are following the Church's teaching and wish to participate more fully in the community…they must not remain adamant not to change simply to have it their own way…this intransigence really frustrates me…

4.4.3 Barriers to Accessibility

Selwyn Goldsmith (1932-2011) was an English disabled architect and disability activist who wrote extensively about the design of buildings, promoting the idea of a universal approach to design. Calling for a paradigm shift in architectural design, he argued that "buildings are constructed by and for people who move around on two legs, not those who use sticks or wheels" (Drake, 2001, p.421). In his last publication, aptly entitled *Universal Design*, Goldsmith made the point that actually, disabled persons were architecturally disabled because buildings were in fact next to impossible for them to use, but these same persons would not have been neither disabled nor discriminated against had the principles of universal design been applied (2000).

Similarly, Church design has, in the vast majority of cases, revolved around the needs of the majority of church goers, side-lining the requirements of those disabled members forming part of the community (Jacobs, 2019). This lack of sensitivity towards the needs of this minority has resulted in creating great difficulties for disabled persons to access these places of worship as well as to navigate inside them and, in some instances, made it impossible for them to reach certain areas, such as confessionals or altars. David was very direct in making the point that it is not acceptable that disabled persons still have to face barriers to accessibility, be they physical or otherwise:

> …then you also have another matter, that of accessibility, in the sense that for example if you review the report issued by the investigations office of the CRPD you will come across numerous issues with regards to accessibility. Where are a number of these issues to be found? - in the Church! There was even this case I came to know about through a colleague of mine: an existing ramp to a church was removed by a 'wise' parish priest and replaced by a lifter. Now the problem is that persons who have restricted mobility would have become dependent on third parties for access because of this decision…instead of an envisaged improvement, the situation was made worse. And then you also have the issue of accessibility to information…

In its Equal Opportunities Act (Persons with Disability) annual report 2017/2018 - which is the last available report to date - the Commission for the Rights of Persons with Disability (CRPD) lists twelve pending cases of complaints presented to the commission because of lack of accessibility to churches in Malta and Gozo: ten cases relating to lack of accessibility to the churches in question and another two within the churches. The oldest cases have been lodged way back in 2007 while the latest were filed in 2016 (CRPD, 2020).

These are only the cases for which a formal complaint has been raised at the Commission and, therefore, whilst this is a further confirmation of the existence of the problem of accessibility, it does not in any way shed any light on the extent of the problem.

Abigail is very much in tune with David on this issue of accessibility and feels very strongly about it. For her, lack of accessibility goes against Christian principles:

> Unfortunately this issue of accessibility has alienated a lot of disabled persons from the Church. I know a lot of wheelchair users who are angry at the Church and at the clergy because of lack of accessibility. For what does it take to install a ramp or do the necessary changes? Why do we love the structures more than the human being? Even for God himself, the human being comes first! By refusing to make the Church accessible – even moving the altar, if need be – the message you are sending to disabled persons is ‘you are not welcome! This place is not for you; go and seek somewhere else!’

John harbours this same sentiment, that the Church gives priority to its architecture over the needs of the person:

> One of the matters that irritates me the most is that the Church waits for a complaint to be lodged with the CRPD to act on providing suitable access for disabled persons. And often, the ramp that is installed is a temporary one, so it then happens that it is eventually removed – often under the guise of safety - and we need to complain again. I do not subscribe to the reasoning that because the steps leading to the church have a historical value they are not to be touched. The people who need to enter the church should come first. After all, it is not

> the steps and the building that make the Church, but the people who form part of it.

Peter, besides inevitably referring to physical barriers of accessibility, sees barriers to accessibility of information to be of a greater relevance in his case. Echoing Goldsmith's (2000) concept of universal design, he argues thus:

> When something is not planned from the design stage to be accessible, let me take for example the parish's website: if it is not designed to be read by visually impaired persons it will then create quite a hassle to be modified for such a requirement to be met at a later stage. However, if this feature was part of the design, the problem would have been nipped in the bud. Accessibility issues have to be tackled at the onset of any project…afterwards things complicate themselves!

Barriers to accessibility are a clear example of the social oppression and exclusion disabled persons are subjected to by society and surely not through any deficiency from their part. This fact, therefore, places the moral responsibility on society, and in these cases which we are discussing in this study, the Church, to remove these imposed barriers and enable disabled persons to participate fully at par with the rest of the community (Shakespeare, 2013).

4.4.4 Ableism: Using derogatory terms such as maimed or cripple

Ableism can be defined as a belief that mistakenly presents impairments as inherently and naturally horrible resulting in prejudice and discrimination towards individuals just because they are classified as being disabled regardless of the type of impairment and whether it is visible or not (Nario-Redmond, 2020).

> Once, I was hearing mass at my hometown and there was a time when mass was being celebrated by a priest from outside our parish. During the sermon, this priest brought up the subject of disabled persons, using the antiquated term cripple [*immankat*]. I remember the first time it was in 2010 and I started debating within myself whether to tell him about it or not, considering it was the first time I had heard him say it. I remember the second time I heard him say it, quite some time had passed until I happened to be at his mass again – it was around 2015 now, something like that – I said this time no, I will not let him keep on calling me a cripple, this time no! So I went to look for him in the sacristy and told him: "Listen, be careful when you refer to disabled persons. Do you know what the word cripple [*immankat*] implies: it is as if a person has something missing! It is true that I have a visual impairment, but there are other qualities which I have which make me the envy of others…"

Sharon experienced similar, but more direct occurrences: "When I was young, they used to call me the maimed [*l-immankata*]" she recalls, her voice cracking with emotion "this labelling hurts. I believe that it is my impairment that makes me Sharon, that defines me. In other words, I do not feel that I need to be healed from it since it is part of my identity"

4.5 Objects of Care and Pity: "But I have a lot of qualities"

I have grouped a second set of themes under the superordinate theme of Objects of Care and Pity, which highlights a fact that often escapes the community: the reality that a disabled person has a lot of qualities. Participants have experienced being seen as objects of pity and therefore persons to be cared for, whilst their potential to contribute to the community has often been discarded. Disabled congregants can be made to feel set apart from the mainstream faithful by being depicted solely as persons with needs, rendering them objects of care and pity (Jacobs, 2019). Disabled persons, therefore, end up as recipients and are rarely offered the possibility to actively participate in the life of the community.

4.5.1 Objects of Pity: *Miskin u Jaħasra*

Pity comes about when people feel sorry for somebody. Disability activists have rallied incessantly against disabled persons being seen as persons to be pitied since nobody befriends or employs somebody they pity (Nario-Redmond, 2020). When people are asked to describe those times in which they feel pity towards others they most often refer to persons with physical disabilities, those living in poverty through no fault of theirs and the victims of disasters, with pity being more pronounced for persons with impairments caused by circumstances out of their control (Weiner et al., 1982). Moreover, persons with conditions that are deemed to be permanent and out of their control, evoke higher levels of pity than those with conditions that are considered to be temporary. Therefore, since disabled persons are being pitied for permanent conditions, they become permanently pitiful with the pity shown actually masking the fact that they are being judged as being a perpetual tragedy (Boleyn-Fitzgerald, 2003). David describes this clearly:

> But certain priests, even for that matter, lay people, it seems their attitude is of *miskin u jaħasra* [pity] because this person has a visual impairment. But I have a lot of qualities: it is true that certain things lead to frustrations but most of the issues which I experience are coming from society itself because of the negative attitudes…that is what I cannot stand within the Church

John takes up this issue of being pitied right at the beginning of our interview:

> To be honest with you I feel that there are a number of priests that are not knowledgeable enough about the subject. What I mean is that I feel that there is a need for priests to be better informed about disability. Even the terminology they use has to be discarded. Also, the way they present disability, for example using words like *miskin* [someone to be pitied]. I hate this idea that disability must always be shown in a negative light. The usage of terms such as *miskin* and *jaħasra* can easily be avoided.

4.5.2 Nothing about us…and the F1 Driver

Disabled persons have traditionally been viewed as individuals who are helpless, dependent on others and not capable of taking their own decisions – a state of affairs that has been exacerbated by professionals and charities alike (Callus & Camilleri Zahra, 2017). The opinions of disabled persons, even on the subject of disability itself, are therefore not sought since they are considered to be without any merit. The situation seems to be pretty much the same within the local Church, at least in David's opinion:

> I admit that the Church has its own delegate who works with disabled persons, but who can tell you what disability is, better than a disabled person himself? This is like, let's say, I try to talk to someone, let's say about driving, about Formula 1, and all this person knows about Formula 1 is coming from the fact that he has a Matchbox F1 car on the shelf. The most he can tell you is that his hobby is that of collecting Matchbox cars. But if you want to know what life is like driving a Formula 1 car, you have to talk to the person who drives that car and this is where I feel the Catholic Church, especially here in Malta, has failed grievously…

David here is emphasising the fact that broadly speaking, the Church has failed to honestly and truly engage with disabled persons and, most importantly, to listen attentively to their stories and experiences instead of simply talking about or doing things for them. David is here clearly manifesting his exasperation at the lack of consultation and involvement at the decision-making levels of the hierarchy. What often happens is that they are either completely ignored, talked about or talked to by the various communities but never included as persons who can contribute at an equal level with the other faithful (Creamer, 2009).

In fact, in practice, engaging with disabled persons in matters that concern them is bound to pay dividends. John recounts how in the village where he lives the parish was facing a problem of where and how to position the ramp to provide access for wheelchair users:

> The church’s ramp needed to be relocated and it took months, if not years of debate and no solution could be found. One day, the mayor asked me to give my input since I am disabled and from the locality. It was clear to me that the case officer could not give the right direction since he was unaware of certain matters. So, I attended this meeting and something that had been procrastinating for months to be solved, we managed to settle in four hours. I am not saying that it was only because it was me who was involved but…

4.5.3 No Agency

Several similarities can be drawn between the cultural construction of disability and that of childhood, both being dependent social categories (Priestley, 2003). Such cultural constructions lead to the infantalisation of disabled persons, leaving them without agency, as detailed here in David's experience:

> It was around July of 2016 and I remember I attended a function organised by the Charismatic movement…and then while we [a female friend of mine and myself] were looking for a place to sit, as soon as we decided to go next to a fan so that we would feel comfortable, someone called out "No, no, you cannot go there. You have to stay in the front". And when I looked around and saw all those people around me…the way they treated me as if I were a little child…and someone else, who I knew as a hairdresser in the village, told me "come on, heed what the grown-ups are telling you". And I gave her a dressing down, I remember vividly "You should be ashamed of yourself," I told her. "So you are telling me that I do not have the right to choose"…and she retorted "Because you wouldn't know where you're going!" I quipped back: "The problem is your darn patronisation."

4.5.4 An Inadequate Theology

Fingers have often been pointed at the Church for being the source of damaging stereotypes regarding disabled persons with the root cause lying in the traditional anthropomorphic images of God who is made to look much more like non-disabled persons than disabled people, thus qualifying disabled persons as inferior (Creamer, 2009). Many disabled persons, particularly those who have rejected the medical model of disability, hold that traditional images of God are bent towards able-bodiedness and the perfect body, therefore shoring up negative stereotypes of disabled persons. David could not hold back from reacting when, during a faith healing session, it was suggested that God disowns disability:

> And then the cherry on the cake was hearing the faith healer saying that God does not want Autism. I said to myself, “This person, I want her head as soon as we are done from here”. But when I tried to approach her they informed me that she could not talk to me because she was tired. And unbelievably, a priest was blocking my way to talk to her. I said, “I will never forget this. This is a very poor way of tackling things”. And to tell you the truth this is one of the factors why I distanced myself from the Church, among other factors.

Sharon went through a near traumatic experience in her school days thanks to her Religion secondary school teacher, whose lack of neighbourly love, poor theological knowledge and total disregard of ethical behaviour had a marked effect on Sharon at such a tender age. Sharon’s voice was quivering with outrage and indignation as she recalled the episode:

> One day, when we started discussing the topic of disability in our religion class the teacher told me that disabled persons are freaks of nature since God does not create anything that is not perfect. God is perfect and therefore, if a person has a disability that individual must be a freak of nature…and I still remember distinctly how angry I was and I challenged her views that day. I was really hurt.

Indeed, wounds are often inflicted without stones and sticks! Sharon returns again to this point later on during the interview, when she was describing how she used to feel whilst listening to sermons during mass:

> It often appeared to me that the way we, disabled persons, are portrayed is as if we are lower in value than non-disabled persons. But then, my feeling was that Jesus used to welcome everybody. So I used to come up with this distinction in my mind

> between God, or Jesus, and the Church: God is ready to accept everybody but then for the Church we are similar to what that teacher had told me, as if we are freaks of nature, but that is the Church. That is the reason why I have distanced myself from the Church, even in relation to the sacraments…

As I have pointed out in my introduction, disability studies in general has shown little concern about religion, let alone discussed images of God. Most disabled persons find current theological thought as not being concerned at all with their reality, thus excluding them and in certain circumstances proving to be oppressive in their regard (Creamer, 2009). It is only thanks to a handful of disability activists that alternative images of God have been proposed, these being the Interdependent God (Black, 1996), the Accessible God (Block, 2002), and the Disabled God (Eisland, 2005) which I discussed in my literature review chapter. Besides offering very strong and meaningful alternatives to the traditional images of God, these models go a long way to show that God identifies with disabled persons. Furthermore, these models serve to shed further light on God’s nature.

Disability activists and persons close to them have often lamented the fact that Biblical texts have been poorly interpreted with regards to disabled persons. A case in point is Amos Yong, theologian and author whose younger brother was born with Down Syndrome. Yong sees as a great challenge the redemption of Biblical texts that have over the centuries been tragically applied to disabled persons since they were only interpreted at a superficial level (2007). The plain interpretation of such texts has resulted in the oppression of disabled persons and therefore a new hermeneutic which goes against an ableist and normate reading of the text is needed for the deliverance of a renewed message. Conscious of this fact, David pointed out the need of a better interpretation of Biblical readings by local clergymen:

> In the Bible, disability is talked about in an ambiguous mode: it is either talked about as punishment, for example you have a king who is oppressing the Jews, then while he is riding his chariot, something happens and he ends up with a severe physical disability. Or it is depicted as a moment of trial such as in the story of Tobit who was blinded by the birds' droppings and then his son, with the help of Archangel Raphael found a fish, caught it and touched a part of the fish with his father's eyes…And then you have the story of Bartimeus who came before Jesus, asked to be healed, and eventually Jesus healed him. Now I am saying all this at face value. But if I were to go at a deeper level - and, I am sorry to say, a lot of the clergy do not appreciate this – the Bible is not something that God sent a UFO and threw the Bible at us. It is obvious that the Bible was written by humans and every chapter reflects a particular cultural context.

4.6 The Community: The Key to the Sense of Belonging within the Church

The final set of themes comes under the super-ordinate theme of community. Mirroring that which happens within society in general, life within Church communities is influenced by social stigma, and therefore, the presence of disabled persons within them is more the exception than the rule (Reinders, 2008).

4.6.1 “No one was there for me”

However, this lack of inclusion is difficult to understand within the Christian tradition since love of neighbour is a vocational call to all Christians. Rejection is therefore hard to accept as was the case with David:

> During the time when I was diagnosed with my impairment I used to be, at that time, the one to whom anyone [forming part of this socio-religious group led by a Jesuit] who happened to be in need used to turn to; anyone needing support used to open up with me and as far as I could, I always offered my support. I remember, for example, once there was a friend of mine who twice lost his job, and I used to take the initiative and offer support…and then at the time my impairment set in, it is as if all at once, at the time I was most in need, I felt there was no one for me, and that really hurt me. I could not stand it and left the group.

Sharon's experience is very much in line with David's. She feels that she was marginalised by the youth community:

> When I used to attend the Youth Centre, I always wished that they would seek to involve me in their activities. However, for some reason, whenever they planned activities that were to be held outside the premises, I was always excluded. It could have been that they were afraid to shoulder responsibility in the case that something happened to me…but there were times when I really felt marginalised and excluded.

Sharon explained that after all what was needed was some planning in advance. First of all, the group should have sought to get to know her and her needs. Following this, it would have been much easier for a plan to be drawn up ensuring her involvement in the activities.

What Sharon is here suggesting, was in fact that which happened in John's case. He cites various instances when he was involved in the centre's activities, on the same level as his peers:

> It was never the case that the leaders at the youth centre said that they did not want to shoulder responsibility because John is a wheelchair user. They always said let's see what needs to be done: if the group went to Gozo, I went with them, if they went to Porziuncola House [Retreat house], I was there with them for a three day retreat…

4.6.2 At Par with Others

Abigail's experience is the total opposite of David's, testimony of the fundamental importance of being accepted and truly belonging within a loving community. Abigail spells it out very clearly:

> Forming part of this community has made a huge difference for me. In my community I am not looked at as a person with a disability. They see me as Abigail: surely they are conscious of me being visually impaired but they do not treat me as if I'm not one of them. If, for example, I open up with them that I am passing through a tough patch…that I am fed up of praying…nobody blames this on my disability.

Abigail goes so far as to state that she feels herself so much welcomed and has this sense of belonging within the group, that at times she nearly forgets her impairment:

> I feel so much accepted that sometimes it happens that I nearly forget about my impairment. For example, every Wednesday we have a group session on The Word of God. Around once every month it may be my turn to prepare for this session. I Google the citations that I need to prepare beforehand and then I talk about them during the session. Although I am blind, I will not refrain from giving my input. Perhaps it may be that I am asked to lead the prayers…it is no problem for me, I am not going to shy away…

For Abigail, the huge benefit of belonging to such a group came to the fore when she was most in need:

> For example, last summer I was passing through a very difficult period following the death of my grandmother. But my friends within the community used to chat with me daily. We have a chat for the community and every day they would be there asking me how I was feeling, shoring me up with words of encouragement, giving me hope for the future. That is what I needed most at that time…I even forgot about my impairment at that stage.

Peter’s experience is a mix of what the other participants went through, mostly because he did not give up but kept on harping that the community needed to be open for disabled persons:

> When I used to attend the youth centre, I was the only one who was visually impaired. It was difficult for me to get involved because the activities were not geared for persons like myself. If there is no thought about how to involve persons like me, it is difficult…we are human beings and therefore we must find ways and means so that no one feels excluded…at the youth centre there were situations where I used to feel excluded because it was obvious that they were not thought out for me…I appreciate that it might have presented some problems, but with some good will…that is why there is the need for training…in fact I did not become a member of the group in a natural manner. I was more or less imposed on the group by the priest in charge… and because of that I suffered…I could feel I was not being accepted…

4.6.3 At the Periphery

People are often at a loss how to approach and communicate with disabled persons loaded as they are with prejudices, stereotyping as well as lack of familiarity with disability. This leads them to behave in peculiar ways when they decide to take the plunge and approach a disabled person, as was this case with a neighbour of David:

> Another incident, which I remember with a chuckle, happened as I was crossing the road - it was, I believe, a neighbour of mine. He told me, “Let me give you something” and he put a rosary beads in my hand, and I believe this was handmade by himself. When I showed it to my mother she told me, “This is a really beautiful rosary beads, who gave it to you?” I believe it was one of my neighbours who, as I was crossing the road just said “Hello” gave me the rosary beads and “Bye”…but that was all.

Peter describes this reluctance or uncertainty when it comes to including disabled persons within the community as the fear of the unknown:

> People within the community are afraid to approach the disabled person. There is the fear of the unknown. A good number of them think it twice or thrice before taking the first step towards me. That goes to show how much work is still waiting to be done.

To make up for this lack of presence of disabled persons within the community, a good number of parishes organise masses and celebrations specifically for disabled persons. Inadvertently, therefore, they perpetuate the myth that disabled persons cannot form part of the mainstream community since they have ‘special needs’ and require specific skills to handle. Such activities fuel segregation of disabled persons from the wider community, pushing them to the fringes. Abigail recounts how for the past nine years or so, during the annual festivities of the patron saint of the village she resides at, her community held a celebration:

> inviting disabled persons and the vulnerable – a word that is being used a lot lately but which I am not so keen on using myself. We hold a mass for them with singing and clapping and afterwards we have a party on the parvis. They enjoy it, but then, I say, must we hold parties in order that disabled persons come to church? The fact that to connect with disabled persons one has to organise outings or parties specifically for them, in my opinion it is not on…it's not the norm.

4.7 Highlighting Recurrent Themes

The amount of data that I have gathered through the five interviews is considerable and in the analysis above I had to be selective as to which parts I could reference directly. In order to give a fuller picture of the themes touched upon by each participant and simultaneously identify the recurrent themes, I have built up Table 4.3, shown below, which gives a graphic summary of themes that emerge from the lived experience of each participant.

The three themes that were present in all of the participants' interviews are those related to accessibility issues, disabled persons seen as objects of pity and the way the relationship between the community and participants developed along the years.

When talking about accessibility, participants did not refer solely to physical accessibility but also to accessibility of information. Moreover, most of the participants felt ill at ease with the message that the lack of physical accessibility gave them, rather than with the barriers themselves. The lack of will to seek timely remedies to such issues for them signified that the Church cared more for the architecture than for the person.

When disabled persons are addressed as persons to be pitied, they are being projected as persons of an inferior status, unfortunate individuals caught in a continuous struggle with great suffering (Hughes, 2014). It comes as little surprise, then, that all participants felt strongly against the expression of such emotions by the Church hierarchy and the community alike which serve to nothing except to reinforce the stereotype that disabled persons are broken individuals in need of healing.

The theme that was the most extensively talked about by the participants was the way in which the smaller group or community related to them throughout their life cycle. Starting off from when attending catechism lessons, to youth centres to experiences in their adult life, participants described how the quality of their relationship - or lack of relationship – with their peers within these groups heavily influenced their spiritual growth.

Participant Theme	**David**	**Abigail**	**Sharon**	**John**	**Peter**
Invisible Faithful	✓		✓		✓
A Lukewarm Reception	✓			✓	
Barriers to Accessibilities	✓	✓	✓	✓	✓
Ableism	✓		✓		
Objects of Pity: Miskin(a)/Jaħasra	✓	✓	✓	✓	✓
Nothing About Us…	✓	✓		✓	✓
Lack of Agency	✓				
Inadequate Theology	✓		✓		✓
‘No one there for me’	✓		✓		
At Par with Others		✓		✓	✓
At the Periphery	✓			✓	✓

Table 4.3 Identifying Recurrent Themes

These recurrent themes are very much in line with the findings of an exploratory qualitative study carried out in Brisbane, Australia that sought to examine the awareness of the parish to the need of including disabled persons in a “genuine and meaningful way” (Dennis & Murdoch, 2001, p. 45) within the community. The study found that the Church structures were resistant to change, with disabled persons having to fit in the setup rather than the parish changing to fit them in. The researchers called the community a myth, in that the fear of the unknown coming from the lack of familiarity with disabled persons as well as stereotypical attitudes resulted in the marginalisation, albeit mostly unintentional, of disabled persons.

The research project *The Upside-Down Kingdom of God*, a participatory study carried out by Naomi Jacobs (2019) on disabled people's experiences in Churches and theologies of disability, which I have referred to several times, draws several conclusions from the experiences of the participants. Among the key expectations of the participants to her study are better access to help them participate, support to become active members of the community, opportunity to share their unique gifts through listening to their stories while refraining from turning them into objects, accepting them as they are. I find the overlap of these conclusions with those of this study to be quite striking.

4.8 Conclusion

Interpreting the narratives of the participants has brought forth their contrasting lived experiences which share commonalities but also lead to unique lifeworlds. In the next, final chapter, I will draw the main conclusions of the study, which, following IPA's inductive approach, can be used as a basis for a plan of action to bring about change.

Chapter 5

Conclusion

Chapter 5: Conclusion

In this final chapter, I will be presenting a summary of the main findings in relation to the main questions I set out to explore. I will then indicate what I perceive to be the main limitations and strengths of the study and conclude by suggesting some recommendations for future research.

5.1 Main Findings

One of the three main questions that I posed at the beginning of this study was whether disabled persons felt that they are welcome within our parish faith communities. In my introduction, I also clarified that the disability I am talking about is that which "relates to the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and/or social barriers" (Swinton, 2001, p.42). Moreover, the study is situated in our local Church communities, in a Church that promulgates a Gospel of unconditional love and acceptance based on a ministry of Christ who always sought to befriend those who were marginalised by society. Disabled persons, therefore, expect that within our parish communities they find a corrective to the stereotypical negative attitudes, values and lack of comprehension so dominant within the wider society (Swinton, 2001). The lived experiences of the participants of this study show that this, unfortunately, is not always the case.

5.1.1 Beyond the Impairment

For all the participants, one of the major obstacles for them to feel accepted by the community was the patronising attitude of the clergy and other congregants which turned them into objects of pity, denying them the respect they deserve as persons created in the image of God. For some of the participants, the experience had a deeper meaning since offensive language was used – in the case of Sharon being called “a freak of nature” and in David’s “a cripple” (*immankat*). Participants expressed their disappointment at these attitudes which “emphasize their disability and ignore their unique personhood” (Moller, 2012, p. 160).

The manner in which we tend to depict God in our own image is at the root cause of why it becomes difficult for disabled persons to be accepted as being equal members of the community. Our quest to understand God, in other words, doing theology, “is always an embodied and interpretative enterprise; we inevitably use our bodies and our minds” (Swinton, 2010, p. 276). Merleau-Ponty’s phenomenological approach that the “body is the very basic of experience…our point of view of the world” (Hughes & Paterson, 1997, p. 335) implies that the image of God for persons with impairments is going to be radically different from that of their non-disabled peers. Merleau-Ponty’s suggestion of the embodiment of the mind, which means that “being-in-the-world is something more like being-in-the-body-in-world” (Scully, 2012, p.60), translates into disabled persons coming up with an image of God that is congruent with their lived experience of their impairment. As I have outlined in my literature review section, disability theologians have argued that throughout the Church’s history the theologians that mattered have always been non-disabled persons, with the consequence that the experience of disability has never featured in the Church’s doctrine and tradition (Swinton, 2010).

5.1.2 Accessibility and Authenticity

This lack of involvement of disabled persons in the heart of our communities, which has been highlighted by the participants, makes them call into question the authenticity of the Church. Barriers to accessibility are not limited only to those relating directly to physical access or to access to information and communication but include also the attitudes, values and actions of the members of the community. When Sharon, during our interview, explains that when attending church "I felt I was being judged" because she could not kneel down, and continues that "this is not loyal to Christ's teaching", she is making the point that when the community "fails to see the beauty of those who are different, it fails to recognise the nature of the beauty of Christ" (Swinton, 2001, p.47).

Accessibility also means giving time, energy and resources to the practical and organisational changes that are needed to be implemented and this, in turn, requires consultation, especially on matters affecting the direct participation of disabled persons, since no one can presume to know their needs (Archdiocese of Malta, 2006). All participants mentioned the fundamental importance of their direct involvement, with both David and John giving their experiences of how they sought to persuade the Archbishop of such a need.

Only once disabled persons are visibly present and participating in all the Church's activities can we say, with St. Paul: "In Christ: there is neither Jew nor Gentile, neither slave nor free, nor is there male and female [non-disabled nor disabled], for you are all one in Christ Jesus" (Gal 3:28).

5.1.3 Friendship in the smaller Community

The super-ordinate theme that provided the most contrasting experiences – and which had the most lasting and deep implications in the participants' spiritual journey – was that which dealt with the nature of their relationships with the members of smaller groups, such as those in a youth centre or formative group, present within their lifeworld. Undoubtedly, a lot of factors are at play within such groups – and I have already touched upon a number of them – but a determining factor is surely that which Peter defined as "the fear of the unknown”. Lack of familiarity with disabled persons generally results in the isolation of the person with impairment. On the other hand, for disabled persons, this translates into having to concurrently deal with “the effects of the impairment as well as with the effects of the social and cultural response to the impairment” (Scully, 2012, p.70).

The effect of the type of relationship with the smaller group ranged from a total rejection: “no one was there for me” in David’s case, to real friendship leading to “at times I felt as if the impairment was not there at all” in the case of Abigail. The community which Abigail talks so fervently about in her interview makes me think of it as very close to a “Christian community where discrimination and prejudice are abandoned and uncompromising love is embraced” (Swinton, 2010, p.306), which is the ideal community we need to build within our Church.

5.2 That Which was left Untold

As I have shown while discussing the themes that emerged from the participants’ experiences, these themes are all to be found in literature, albeit with some minor contextual divergences. However, the opposite cannot be stated, in that some themes I have reviewed in chapter 2 were not mentioned as being experienced by participants. Being considered as objects of charity is one of them.

This came as a bit of surprise to me because even local studies have shown that the influence of the Catholic Church in Malta with regards to disabled people together with its appeals to people’s Christian values has “instilled within our society a model of disability based on charity” (Xuereb, 2019, p. 82). The reason for this discrepancy is most probably attributable to the fact that the participants of this study happen to come from a particular socio-economic group: they are all well-educated and hold full time professional jobs which therefore may exclude them from being seen as such by the community.

Another theme that did not feature in this study's participants' experience is the lack of leadership possibilities for disabled persons, including themselves, within the community. The reason for this discrepancy with other research findings possibly has its roots in the invisibility of disabled persons within the local hierarchy, but needs to be explored further before arriving at any meaningful conclusions.

5.3 Limitations and Strengths

Certainly, the biggest limitation of this research lies with the researcher. Being a novice in the field of qualitative research, it is clear that my minimal skill-set at conducting this IPA research was a limiting factor. Even as I write this concluding chapter, it is evident to me that the experience I have gathered through carrying out this study already indicates areas in which I could have improved the quality of my work.

Another significant limitation was the restricted availability of empirical data in this area of study. This meant that I could compare and contrast my findings with only a very few studies besides the other texts which I reviewed and referred to extensively during my discussion.

Yet another limitation has been brought about by the restrictions that have been brought into effect due to the COVID-19 pandemic. The first impact of the restrictions was the fact that only those disabled persons who have access to, and knowledge of, technology could participate in the study. Secondly, and perhaps much more significant, is the fact that I could only hold one face to face interview, with the other four having to be done remotely. I believe that face to face interviews are bound to produce richer data, mainly due to the fact that it becomes easier to build rapport which will, in turn, get the participant to feel more involved in the project.

To counter these significant limitations I have sought to ensure the trustworthiness and credibility of this study, by assiduously following the four broad principles that need be applied in the case of qualitative research as proposed by Smith, Flowers & Larkin (2009), these being:

sensitivity to context - demonstrating sensitivity throughout the whole process starting with the range of literature that I reviewed, to acting through gatekeepers for purposive sampling through the interview as well as the ethical handling and faithful quoting of verbatim quotes;

commitment and rigour – shown through the homogeneity of the sample I worked with, as well as by the thoroughness and completeness of the analysis of the data derived from well-planned and carefully executed in-depth interviews; also by ensuring that all participants' experiences were quoted equitably;

transparency and coherence – exhibited through the detailed explanation of the methodology I adopted and a write-up that is logical and consistent throughout;

impact and importance – in choosing an area of study that is of significance to disabled persons, in presenting this report in a manner that is interesting and stimulating for the reader and in committing to follow up the study through a plan for the dissemination of the findings.

5.4 Recommendations

Considering that this is the first local study in the field of disability studies and religion, the areas still to be explored are numerous. The next logical step would, therefore, be to investigate other types of impairments coupled with different methodologies. My first recommendation would be to conduct a similar research study with intellectually disabled persons as participants while adopting an ethnographic approach. More time and resources would most probably be needed to carry out such a project but the rewards that can be reaped in the shape of a more authentic Church can be huge. Another suggestion would be to take a life-course approach and conduct studies with participants who are at different stages of their lives. These studies can then vary across different impairments and spanning different socio-economic groups.

A secondary question of this study sought the opinion of the participants as to what changes (if they thought any were required) they would like to see the Church implement within its communities so as to enhance the active participation of disabled persons. Coming from disabled persons themselves, these recommendations surely carry more weight than mine and deserve being given due consideration, as is also in line with the emancipatory principles I adopted for this study. The issue of awareness raising among the clergy and faithful was definitely their topmost recommendation. Participants emphasised the fact that disability is still seen as a tragedy, with the majority of people failing to see the person beyond the impairment. The last stage of the dissemination strategy of this study discussed in Chapter 3 stipulates that contact be made with the Parish Pastoral Councils to present this study during the annual parish assembly. That would be the opportune time to discuss delivering such awareness training. Two of the participants said that they are aware that such awareness training was already offered before but the offer was never taken up. The assembly would be the ideal forum to discuss why this training is not viewed to be of importance to the community. Other recommendations include tackling the issue of accessibility in its broadest sense and the necessity of having disabled persons participating within parochial commissions. The possibility of the parish reaching out to those disabled persons who face difficulties to join the community should also be taken into consideration.

5.5 Conclusion

When in December 2020, on the occasion of the International Day of Persons with Disabilities, as I was finalising my work on the literature review of this study, I heard Pope Francis saying: “I trust that, in parish communities, more and more people with disabilities can become catechists, in order to pass on the faith effectively, also by their own witness” (Castellano Lubov, 2020, para. 23), my feeling was that the Pope was not being pragmatic, setting unreachable goals while giving false hope to disabled persons. As I got to know the participants and understood the meanings they gave to their lived experiences, my feelings turned to wishing that my grandchildren would have had such persons as their catechists – surely they would have received a richer Christian formation at their hands (my own children are the age of the participants).

As I near the completion of this project and reflect on what this experience has meant to me, I can arrive at only one key finding, which I can summarise in one sentence: I set out to find out how our parish faith communities sustain the spiritual journey of disabled persons; I found out how disabled persons can sustain the Church in its spiritual journey of “modestly act[ing] as such” (Karl Rahner, 1979, p. 726).

References

References

Abberley, P. (1992). Counting us out: A discussion of the OPCS disability surveys. *Disability, Handicap & Society, 7*(2), 139-155.

Altman, B. M. (2001). Disability definitions, models, classification schemes, and applications. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 97-122). California, USA: Sage Publications.

Archdiocese of Malta. (2006). *Lejn Knisja dejjem aktar incluziva*. Blata l-Bajda, Malta: Media Centre Publications.

Archdiocese of Malta. (2020). *One Church, One Journey: A process of ecclesial renewal*.

Retrieved from: https://journey.church.mt/wp-content/uploads/2020/06/One-Church-One-Journey-EN.pdf

Armitage, R., & Nellums, L. B. (2020). The COVID-19 response must be disability inclusive. *The Lancet Public Health, 5*(5), 257.

Ashworth, P. (2015). Conceptual foundations of qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods 3rd. edition* (pp. 4-24). London: Sage Publications.

Ashworth, P. D. (2006). Seeing oneself as a carer in the activity of caring: Attending to the lifeworld of a person with Alzheimer's disease. *International Journal of Qualitative Studies on Health & Well-Being,* 1(4), 212-225.

Barnes, C. (1992). Qualitative research: Valuable or irrelevant? *Disability, Handicap & Society*, *7*(2), 115-124.

Barnes, C. (2014). Understanding the social model of disability: Past, present and future. In N. Watson, A. Roulstone & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 12-29). London: Routledge.

Barton, L., & Armstrong, F. (2001). Disability, education, and inclusion. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 693-710). Thousand Oaks, California: Sage Publications.

Belser, J. W., & Morrison, M., S. (2011). What no longer serves us: Resisting ableism and anti-Judaism in New Testament healing narratives. *Journal of Feminist Studies in Religion, 27*(2), 153-170.

Benton, T., & Craib, I. (2011). *Philosophy of social science: The philosophical foundations of social thought* (2nd ed.). London: Palgrave Macmillan.

Bergant, D. (1994). "Come, let us go up to the mountain of the lord": Biblical reflections on the question of sacramental access. In E. Foley (Ed.), *Developmental disabilities and sacramental access: New paradigms for sacramental access* (pp. 13-32). Collegeville, Minnesota: The Liturgical Press.

Bezzina, L. (2018). *Masters' and LL.D. dissertations on disability in Malta.* Retrieved from http://crpd.org.mt/wp-content/uploads/2018/11/CRPD-Systematic-Review-November-2018.pdf

Black, K. (1996). *A healing homiletic: Preaching and disability*. Nashville, TN: Abingdon Press.

Block, J. W. (2002). *Copious hosting: A theology of access for people with disabilities*. New York: Continuum.

Boleyn-Fitzgerald, P. (2003). Care and the problem of pity. *Bioethics,* 17(15), 1-20.

Brinkmann, S. (2012). Qualitative research between craftsmanship and McDonaldization. A keynote address from the 17th qualitative health research conference. *Qualitative Studies, 3*(1), 56-68.

Callary, B., Rathwell, S., & Young, B. W. (2015). Insights on the process of using interpretative phenomenological analysis in a sport coaching research project. *The Qualitative Report, 20*(2), 63-75.

Callus, A. M., & Camilleri-Zahra, A. (2017). Nothing about us without us. *Mediterranean Review of Human Rights,* (1), 1-26. Retrieved from https://www.um.edu.mt/library/oar/handle/123456789/32954

Callus, A. (2014). From 'for' to 'of': A typology of Maltese disability 0rganisations. *Disability & Society, 29*(1), 1-15.

Cameron, H. E. (2016). Beyond cognitive deficit: The everyday lived experience of dyslexic students at university. *Disability & Society, 31*(2), 223-239.

Camilleri, J. M. (1999). Disability: A personal odyssey. *Disability & Society, 14*(6), 845-853.

Camilleri, J. M., & Callus, A. M. (2001). Out of the cellars. Disability, politics and the struggle for change: The Maltese experience. In L. Barton (Ed.), *Disability, politics & the struggle for change* (pp. 79-92). London: David Fulton.

Cardona, G. C. (2013). Overcoming disabling barriers: Disability and attitudes to disability within the Maltese context: An insider's perspective. *Disability & Society, 28*(2), 279-284.

Castellano Lubov, D. (2020). Disabled persons’ gifts enrich the church & world. Retrieved from https://zenit.org/2020/12/03/pope-francis-disabled-persons-gifts-enrich-the-church-world/?utm_medium=email&utm_campaign=Pope%20Francis%20Disabled%20Persons%20Gifts%20Enrich%20the%20Church%20%20World%201607013702%20ZNP&utm_content=Pope%20Francis%20Disabled%20Persons%20Gifts%20Enrich%20the%20Church%20%20World%201607013702%20ZNP+CID_839e7fc6d209a0bf1dac91668bca1baf&utm_source=Editions&utm_term=Pope%20Francis%20Disabled%20Persons%20Gifts%20Enrich%20the%20Church%20%20World

Chenail, R. J. (2009). Making phenomenological inquiry accessible: A review of Jonathan A. Smith, Paul Flowers, and Michael Larkin's interpretive phenomenological analysis: Theory, method and research. *The Qualitative Report, 14*(2), 156-160.

Coggins, M. L. (2017). Fake it until you make it (or until you find your place). In M. Jarman, L. Monaghan & A. Quaggin Harkin (Eds.), *Barriers and belonging: Personal narratives of disability* (pp. 195-200). Philadelphia, Pennsylvania: Temple University Press.

Creamer, D. (2006). Theological accessibility: The contribution of disability. *Disability Studies Quarterly, 26*(4).

Creamer, D. B. (2009). *Disability and Christian theology: Embodied limits and constructive possibilities*. New York: Oxford University Press.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage.

CRPD. (2020). *Equal opportunities act (persons with disability) annual report 2017/2018.* Retrieved from https://parlament.mt/media/108381/crpd-annual-report-2017-2018.pdf

Dei Verbum. Vatican Council II. Dogmatic constitution on divine revelation. Retrieved from https://www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_const_19651118_dei-verbum_en.html

Dennis, R., & Murdoch, T. (2001). Disability focus groups: A strategy for including people with disability in parishes. *Journal of Religion, Disability & Health, 5*(4), 45-59.

Denscombe, M. (2014). *The good research guide: For small-scale social research projects* (5th ed.). Berkshire, England: Open University Press.

Denzin, N. K., & Lincoln, Y. S. (2011). Introduction: The discipline and practice of qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 1-20). Thousand Oaks, California: SAGE Publications.

Discern. (2018). *Census 2017: Malta Sunday Mass attendance.* Malta: Progress Press.

Drake, R. F. (2001). Welfare states and disabled people. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 412-429). Thousand Oaks, California: Sage Publications.

Eareckson Tada, J. (2010). *A place of healing: Wrestling with the mysteries of suffering, pain, and God's sovereignty*. Colorado Springs, USA: David C Cook.

Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. In W. S. Rogers, & C. Willig (Eds.), *The sage handbook of qualitative research in* *psychology* (pp.193-209). doi:https://dx-doi-org.ejournals.um.edu.mt/10.4135/9781526405555.n1

Eiesland, N. (2005). Meeting the disabled god. *PMLA*, *120*(2), 584-586.

Eiesland, N. L. (1994). *The disabled God: Toward a liberatory theology of disability*. Nashville, TN: Abingdon Press.

Englander, M. (2012). The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology*, 43, 13-35.

Evans, E. C. (1969). Physiognomics in the ancient world. *Transactions of the American Philosophical Society, 59*(5), 1-101.

Faith Inclusion Network. (2015, October 13). *Interview with Stephanie Hubach* [Video]. You Tube. https://www.youtube.com/watch?v=qsKIJ-C2PDc

Finlay, L. (2012). Unfolding the phenomenological research process: Iterative stages of "Seeing afresh". *Journal of Humanistic Psychology, 53*(2), 172-201.

Ford, C. A. (2020). On social love and hard truths in Fratelli Tutti. Retrieved from https://berkleycenter.georgetown.edu/responses/on-social-love-and-hard-truths-in-fratelli-tutti

Frendo Anthony, J. (2003, June 8,). The diocesan synod today. *Times of Malta*

Gaillardetz, R. R., & Clifford, C. E. (2012). *Keys to the council: Unlocking the teachings of Vatican II*. Minnesota: Liturgical Press.

Garland, R. (2015). *The impact of the family, Church and state on the aspirations of young people with disability in Malta: a cultural perspective* (Master's thesis). Retrieved from https://www.um.edu.mt/library/oar/bitstream/123456789/6519/1/15MADIS005.pdf

Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, *26*(3), 591-609.

Gauci, M. V. (2018). *Enabling technology in the workplace: Exploring the dis/ability-assemblage* (Unpublished doctoral dissertation). Centre for Disability Studies, University of Leeds, United Kingdom.

Gaventa, W., C. (2018). *Disability and spirituality: Recovering wholeness*. Waco, Texas London: Baylor University Press.

Gill, C. J. (2001). Divided understandings: The social experience of disability. In G. Albrecht L., K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 351-372). Thousand Oaks, California: Sage Publications.

Goggin, G., & Ellis, K. (2020). Disability, communication, and life itself in the COVID-19 pandemic. *Health Sociology Review, 29*(2), 168-176.

Goldsmith, S. (2000). *Universal design: A manual of practical guidance to architects*. Oxford, UK: Architectural Press.

Gosbell, L. A. (2015). *"The poor, the crippled, the blind, and the lame": Physical and sensory disability in the Gospels of the New Testament* (Doctoral dissertation, Macquarie University, Sydney, Australia). Retrieved from https://scholar.google.com/scholar?hl=en&as_sdt=0%2C5&q=Gosbell%2C+L.+A.+%282015%29.+%E2%80%9CThe+poor%2C+the+crippled%2C+the+blind%2C+and

+the+lame%E2%80%9D%3A+Physical+and+sensory+disability+in+the+Gospels+of +the+New+Testament+&btnG=

Guglielmi, R. S. (1999). Psychophysiological assessment of prejudice: Past research, current status, and future directions. *Personality and Social Psychology Review, 3*(2), 123-157.

Hartsock, C. (2007). *Sight and blindness as an index of character in Luke-Acts and its cultural milieu* (Doctoral dissertation). Retrieved from https://baylor-ir.tdl.org/bitstream/handle/2104/5058/Chad_Hartsock_phd.pdf?sequence=3

Hickman, L. N. (2018). *A disability theology of limits for responding to moral injury* (Doctoral dissertation). Retrieved from https://dsc.duq.edu/etd/1474/

Hodge, N. (2008). Evaluating lifeworld as an emancipatory methodology. *Disability & Society, 23*(1), 29-40.

Huff, J. L. (2002). Review: Narrative prosthesis: Disability and the dependencies of discourse. *NWSA Journal: Feminist Disability Studies, 14*(3), 201-204.

Hughes, B. (2014). Fear, pity and disgust: Emotions and the non-disabled imaginary. In N. Watson, A. Roulstone & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 67-77). London: Routledge.

Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society, 12*(3), 325-340.

Hume-Dawson, R. B. (2017). Flourishing with polio: A spiritual, transformational, and disabilities studies perspective. In M. Jarman, L. Monaghan & A. Quaggin Harkin

(Eds.), *Barriers and belonging: Narratives of disability* (237-244). Philadelphia, Pennsylvania: Temple University Press.

Imhoff, S. (2017). Why disability studies needs to take religion seriously. *Religions, 8*(9), 186. doi:10.3390/rel8090186

Jacobs, N. L. (2019). *The upside-down kingdom of God: A disability studies perspective on disabled people's experiences in Churches and theologies of disability* (Doctoral dissertation, SOAS University of London). Retrieved from http://eprints.soas.ac.uk/32204

Jerusalem Bible. (1974). London, UK: Darton, Longman & Todd (Original Publication Date: 1968).

Johnstone, B., Glass, B. A., & Oliver, R. E. (2007). Religion and disability: Clinical, research and training considerations for rehabilitation professionals. *Disability & Rehabilitation, 29*(15), 1153-1163.

Kelly, M. P. (2001). Disability and community: A sociological approach. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 396-411). Thousand Oaks, California: Sage Publications.

Kitchin, R. (2010). The researched opinions on research: Disabled people and disability research. *Disability & Society, 15*(1), 25-47.

Larkin, M., Eatough, V., & Osborn, M. (2011). Interpretative phenomenological analysis and embodied, active, situated cognition. *Theory and Psychology, 21*(3), 318-337.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120. doi: 10.1191/1478088706qp062oa

Lichtman, M. (2014). *Qualitative research for the social sciences.* Sage Publications Inc. doi: https://dx-doi-org.ejournals.um.edu.mt/10.4135/9781544307756

Lukefahr, O. (1998). *A Catholic guide to the Bible*. Missouri, USA: Liguori Publications.

Mairs, N. (1993). *Ordinary time: Cycles in marriage, faith, and renewal*. Boston, Massachusetts: Beacon Press.

Marshall, C., & Rossman, G. B. (2010). *Designing qualitative research* (5th ed.). California: Sage.

McEvoy, J. (2006). Church and world at the second Vatican council: The significance of Gaudium et Spes. *Pacifica: Australasian Theological Studies, 19*(1), 37-57. Retrieved from https://core.ac.uk/download/pdf/14939029.pdf

McGrath, A. E. (2011). *Christian theology*. United Kingdom: John Wiley & Sons.

Miller, P. (2020). Converging and diverging themes: A synthesis of contemporary theological literature on disability. *Journal of Disability & Religion, 24*(4), 431-444.

Mitchell, D. T., & Snyder, S. L. (2000). *Narrative prosthesis: Disability and the dependencies of discourse*. Ann Arbor: University of Michigan Press.

Moller, E. (2012). Experiences of people with disabilities in faith communities: A journey. *Journal of Religion, Disability & Health, 16*(2), 154-171.

Murphy, R. F., Scheer, J., Murphy, Y., & Mack, R. (1988). Physical disability and social liminality: A study in the rituals of adversity. *Social Science & Medicine*, *26*(2), 235-242.

Nario-Redmond, M. R. (2020). *Ableism: The causes and consequences of disability prejudice*. New York, USA: Wiley Blackwell.

Neuman, W. L. (2014). *Social research methods: Qualitative and quantitative approaches* (7th ed.). Essex, England: Pearson.

O'Connor, T. S. (2008). Book review: Copious hosting. *Journal of Religion, Disability & Health, 6*(4315), 99-105.

Oliver, M. (1996). *Understanding disability: From theory to practice.* New York: Palgrave.

Oliver, M. (1999). Final accounts and the parasite people. In M. Corker & S. French (Eds.*), Disability discourse* (pp. 183-191). Buckingham, UK: Open University Press.

Pope Francis. (2020). *Fratelli Tutti: Encyclical letter on fraternity and social friendship*. Libreria Editrice Vaticana. Retrieved from http://www.vatican.va/content/francesco/en/encyclicals/documents/papa-francesco_20201003_enciclica-fratelli-tutti.html

Priestley, M. (2003). *Disability: A life course approach.* Cambridge, UK: Polity Press.

Rahner, K. (1979). Towards a fundamental theological interpretation of Vatican II. *Theological Studies, 40*(4), 716-727.

Ravaud, J., & Stiker, H. (2001). Inclusion/exclusion: An analysis of historical and cultural meanings. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 490-514). Thousand Oaks, California: Sage Publications.

Reese, T. (2020). Five things to look for in Pope Francis' new encyclical, 'Fratelli Tutti'. Retrieved from https://www.ncronline.org/news/theology/signs-times/five-things-look-pope-francis-new-encyclical-fratelli-tutti

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*(1), 20-23.

Reinders, H. S. (2008). *Receiving the gift of friendship: Profound disability, theological anthropology, and ethics*. Grand Rapids, Michigan: Wm. B. Eerdmans Publishing Co.

Reinders, H. S. (2011). The power of inclusion and friendship. *Journal of Religion, Disability & Health, 15*(4), 431-436.

Schmidt. (2014). *Understanding hermeneutics*. New York: Routledge.

Scully, J. L. (2012). Disability and the thinking body. In K. Kristiansen, S. Vehmas & T. Shakespeare (Eds.), *Arguing about disability: Philosophical perspectives* (pp. 57-74). London: Routledge.

Selway, D., & Ashman, A. F. (1998). Disability, religion and health: A literature review in search of the spiritual dimensions of disability. *Disability & Society, 13*(3), 429-439.

Shakespeare, T. (2013). The social model of disability. In L. J. Davis (Ed.), *The disability studies reader* (pp. 214-221). New York: Routledge.

Sheldrake, P. (2012). *Spirituality: A very short introduction*. Oxford, UK: Oxford University Press.

Smith, D. E. (1987). Table fellowship as a literary motif in the gospel of Luke. *Journal of Biblical Literature, 106*(4), 613-618.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39-54.

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis*. London: Sage Publications.

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods 3rd. edition* (pp. 25-52). London: Sage Publications.

Spurrier, R. F. (2019). *The disabled church*. New York: Fordham University Press.

Stiker, H. (1997). *A history of disability*. Ann Arbor: The University of Michigan Press.

Stokes, H., Turnbull, M., & Wyn, J. (2013). *Young people with a disability: Independence and opportunity research report 39.* Youth Research Center. Retrieved from https://education.unimelb.edu.au/yrc/assets/docs/yrc-publication-docs/research_report39.pdf

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *British Journal of Sociology, 47*(4) Retrieved from https://www-jstor-org.ejournals.um.edu.mt/stable/591081

Swinton, J. (2001). Building a church for strangers. *Journal of Religion, Disability & Health, 4*(4), 25-63.

Swinton, J. (2010). Who is the God we worship? Theologies of disability; challenges and new possibilities. *International Journal of Practical Theology, 14*(2), 273-307.

Swinton, J. (2012). From inclusion to belonging: A practical theology of community, disability and humanness. *Journal of Religion, Disability & Health, 16*(2), 172-190.

Tabone, C. (1994). Secularization. In R. G. Sultana, & G. Baldacchino (Eds.), *Maltese society: A sociological inquiry* (pp. 285-300). Malta: Mireva Publications.

Tomkins, L., & Eatough, V. (2018). Hermeneutics: Interpretation, understanding and sense-making. In C. Cassell, A. L. Cunliffe & G. Grandy (Eds.), *The SAGE handbook of qualitative business and management research methods: History and traditions* (pp. 185-200) Sage Publications. doi:https://dx-doi-org.ejournals.um.edu.mt/10.4135/9781526430212.n1

United Nations. (2006). *United Nations Convention on the Rights of Persons with Disabilities.* Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

van Manen, M. (2007). Phenomenology of practice. *Phenomenology & Practice, 1*(1), 11-30.

Vatican News. (2021). Holy See calls for increased attention to the effects of the pandemic. Retrieved from https://www.vaticannews.va/en/vatican-city/news/2021-02/holy-see-coronavirus-united-nations-jurkovic.html

Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., Senu, H., & Holland, F. (2014). The Accordion and the Deep Bowl of Spaghetti: Eight Researchers' Experiences of Using IPA as a Methodology. The Qualitative Report, 19(24), 1-15. https://doi.org/10.46743/2160-3715/2014.1216

Waldock, K. E., & Forrester-Jones, R. (2020). An exploratory study of attitudes toward autism amongst church-going Christians in the south east of England, United Kingdom. *Journal of Disability & Religion, 24*(4315), 349-370.

Watts Belser, J., & Morrison, M. S. (2011). What no longer serves us: Resisting ableism and anti-Judaism in New Testament healing narratives. *Journal of Feminist Studies in Religion, 27*(2), 153-170.

Webb-Mitchell, B. (1993). *God plays piano, too*. New York: Crossroad.

Webb-Mitchell, B. (1994). *Unexpected guests at God's banquet: Welcoming people with disabilities into the Church*. New York, NY: Crossroad.

Webster, C.M. (2008). Paradox in the development of the non-disabled Church: Reflection on John 9: 1-41. *Journal of Religion, Disability & Health, 11*(3), 23-49.

Weiner, B., Graham, S., & Chandler, C. (1982). Pity, anger, and guilt: An attributional analysis. *Personality and Social Psychology Bulletin, 8*(2), 226-232.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York, NY: Routledge.

Williams, G. (2001). Theorizing disability. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 123-144). California, USA: Sage Publications.

Wilson, & T. D. (2002). Alfred Schutz, phenomenology and research methodology for information behaviour research. *The New Review of Information Behaviour Research, 3*(71), 1-15.

Wynn, K. H. (2007). Johannine healings and the otherness of disability. *Perspectives in Religious Studies, 34*(1), 61-75.

Xuereb, D. (2019). *The lived experience of guide dog owners* (Master's Thesis). Retrieved from https://www.um.edu.mt/library/oar/bitstream/123456789/52598/4/19MADIS010.pdf

Yong, A. (2007). *Theology and Down syndrome: Reimagining disability in late modernity*. Waco, Texas: Baylor University Press.

Yong, A. (2011). *The Bible, disability, and the Church: A new vision of the people of God*. Michigan, USA: William B. Eerdmans Publishing Company.

Zaner, R. M. (1961). Theory of intersubjectivity: Alfred Schutz. *Social Research, 28*(15), 71-93.

Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap & Society, 7*(2), 125-138.

Zenit. (2019). Pope reminds equal dignity and great contribution of disabled people. Retrieved from https://zenit.org/articles/pope-reminds-equal-dignity-and-great-contribution-of-disabled-people/

Appendices

Appendix 1a Information Letter (English Version)

Date:

Information Letter

Dear Sir/Madam,

Invitation to participate in a research study

My name is Franco Buttigieg and I am currently reading for a Masters Degree in Disability Studies at the University of Malta. As part-fulfilment of this course, I am carrying out a research study entitled “Towards Inclusive Parishes: how do Maltese Catholic communities sustain the spiritual journey of disabled persons?” This study is being supervised by Dr Maria Victoria Gauci. This letter is an invitation to participate in this study. Below you will find information about the study and about what your involvement would entail, should you decide to take part. The study will take place between June 2020 and April 2021.

The study aims to explore the lived experience of disabled persons within the Catholic community of the parish they belong to. The study will be investigating how inclusive our Catholic communities are in supporting disabled persons who want to belong. I would like to invite you to participate in this study since your participation would contribute to a better understanding of what is needed to make our parish communities more welcoming. Any data collected from this research will be used solely for the purposes of this study.

Should you choose to participate, your involvement will be that of attending for a one-to-one interview which will last for between one and a half to two hours and which will be conducted at a time and venue which are convenient for you. If need be, transport will be provided to and from this venue. The interview will be audio-recorded and then formulated into a transcript. The transcript of your interview will be given to you so that you can amend it if you so wish, to ensure that it faithfully represents what you intended to say during the interview. The interview will be conducted in English or Maltese, according to your preference. During the interview, some written notes will be taken of the main points that you will make. The experience of participating in this study should prove beneficial to participants as it may lead to positive changes within our communities. On the other hand, there is no associated risk of harm in participating.

Participation is on a voluntary basis: in other words, you are free to accept or refuse to participate without needing to give a reason. You can decide to withdraw from the study even after you have participated in the interview, while the research is still ongoing. However, you will have a deadline of one month after the interview to decide to withdraw, after which period your data will be locked into the study. If you decide to withdraw from the study you will neither need to give any explanation nor will there be any negative repercussions for you. Any data gathered from you prior to your withdrawal from the study will be destroyed at that point in time.

All the information gathered from you, while being treated confidentially, will appear under pseudonyms in the study so as to safeguard your anonymity. However, notwithstanding all the precautions that will be taken to hide your identity, it may happen that some persons will, through association of facts and events, come to identify you as a participant in this study. All the data that will be collected will be kept in a secure place and destroyed once the study is completed and the results published, that is by January 2022. You will be signing a consent form if and when you decide to participate in the study.

Please note also, that as a participant, you will have the right under the General Data Protection Regulation (GDPR) and the Malta Data Protection Act 2018 to access, rectify and where applicable ask for the data concerning you to be erased.

A copy of this information sheet is being provided for you to keep for future reference.

Should you require further information and would like to participate in the study kindly contact me via email on [redacted] or by phoning me on [redacted]. You can also contact my supervisor, Dr Maria Victoria Gauci, via email on [redacted] or by phoning her on [redacted].

I thank you for taking the time to read this information letter and for considering to participate in the study.

Regards

Franco Buttigieg

Appendix 1b Information Letter (Maltese Version)

Data:

Information Letter bil-Malti

Għażiż Sinjur/a

Stedina biex tipparteċipa f'riċerka

Jiena, Franco Buttigieg, qiegħed insegwi kors f'livell ta' Masters fl-istudji dwar id-Diżabilita' fl-Universita' ta' Malta. Bħala parti minn dan il-kors jien qiegħed nagħmel studju riċerkat, imsejjaħ "Towards Inclusive Parishes: how do Maltese Catholic communities sustain the spiritual journey of disabled persons?" (Lejn Parroċċi nklussivi: l-komunitajiet Kattoliċi Maltin tagħna, kif qegħdin isostnu lill-persuni b'diżabilita' fil-mixja spiritwali tagħhom?). Dr Maria Victoria Gauci hija s-supervisor tiegħi f'dan l-istudju. Permezz ta' din l-ittra qed nistiednek tipparteċipa f'dan l-istudju riċerkat. Hawn taħt issib l-informazzjoni kollha dwar l-istudju u x'ikun l-involviment tiegħek jekk tiddeċiedi li tieħu sehem fih. L-istudju ser iseħħ bejn Ġunju 2020 u April 2021.

L-istudju hu mmirat li jeżamina l-esperjenza ta' persuni b'diżabilita' fil-komunita' Kattolika tal-parroċċa tagħhom. L-istudju ser ikun qed jistħarreġ kemm huma nklussivi dawn il-komunitajiet Kattoliċi u kemm jgħinu lill-persuni b'diżabilita' fil-mixja spiritwali tagħhom. Nixtieq nistiednek tieħu sehem f'dan l-istudju peress li l-parteċipazzjoni tiegħek ser tgħin sabiex nifhmu iktar x'hemm bżonn isir biex il-komunitajiet parrokkjali tagħna jkunu iktar miftuħa ghal persuni b'diżabilita'. Kull informazzjoni miġbura matul din ir-riċerka ser tintuża biss għall-iskopijiet ta' dan l-istudju.

Jekk tiddeċiedi li tipparteċipa, l-involviment tiegħek ikun li tieħu sehem f'intervista personali, li ddum bejn siegħa u nofs u sagħtejn u li tinżamm f'post u ħin li jkunu konvenjenti għalik. Jekk ikun hemm il-bżonn, jiġi provdut trasport sabiex iwasslek l'hemm u lura. L-intervista tkun irrekordjata u mbagħad miktuba f'dokument (*transcript*). Id-dokument tal-intervista tiegħek jingħatalek sabiex temendah kif tixtieq ħalli jirrifletti preċiżament dak li inti tkun għedt fl-intervista. L-intervista ssir bil-Malti jew bl-Ingliż, skont kif tixtieq inti. Waqt l-intervista jittieħdu noti bil-miktub tal-punti ewlenin li tkun semmejt. L-esperjenza tiegħek f'dan l-istudju għandha tkunlek ta' benefiċċju għax taf twassal sabiex il-komunitajiet tagħna jkunu aktar inklussivi. Mhuwiex antiċipat li dan l-istudju għandu jkollu xi riskju ta' dannu għalik.

Il-parteċipazzjoni tiegħek hija fuq bażi volontarja: fi kliem ieħor inti fil-liberta li taċċetta jew tirrifjuta li tipparteċipa mingħajr ma tagħti ebda raġuni. Inti tista tirtira minn dan l-istudju meta trid, anke wara l-intervista, dment li l-istudju jkun għadu għaddej. Madanakollu, inti jkollok żmien ta' xahar wara li tkun tajt l-intervista sabiex tara jekk tkunx trid tirtira, għaliex wara dan iż-żmien dak li tkun għedt jibqa' parti mill-istudju.

Jekk tiddeċiedi li tirtira l-parteċipazzjoni tiegħek minn din ir-riċerka, la għandek għalfejn tagħti raġuni għal dan u lanqas ikun hemm ebda riperkussjonijiet. Kull informazzjoni li tkun għaddejt qabel l-irtirar tiegħek, tkun meqruda f'dak l-istadju.

L-informazzjoni kollha li tingħata minnek tiġi trattata bl-akbar kunfidenzjalita u tidher fl-istudju taħt isem fittizju sabiex tiġi rispettata l-anonimita' tiegħek. Madanakollu għalkemm qed jittieħdu dawn il-miżuri ta' prekawzjoni sabiex l-identita' tiegħek tiġi moħbija, jista jkun illi xi persuni jidentifikawk bħala parteċipant/a ta' dan l-istudju minħabba fatti jew ċirkostanzi partikolari. Kull informazzjoni li tinġabar tinżamm f'post sigur u tiġi meqruda ġjaladarba jiġi konkluż l-istudju u r-riżultati pubblikati, cioe sa Jannar 2022. Ġjaladarba tiddeċiedi li tipparteċipa f'dan l-istudju tingħata formola ta' kunsens li inti tiffirma qabel tagħti l-intervista tiegħek.

Nixtieq niġbidlek l-attenzjoni wkoll, li bħala parteċipant/a, jkollok id-dritt taħt il-General Data Protection Regulation (GDPR) kif ukoll taħt il-Malta Data Protection Act 2018, li taċċessa, tbiddel u fejn japplika titlob li titneħħa l-informazzjoni dwarek.

Kopja ta' din l-ittra ta' informazzjoni qegħda tingħata lilek biex iżżommha ghar-riferenza tiegħek.

Jekk tixtieq aktar informazzjoni u tixtieq tipparteċipa f'dan l-istudju, tista tikkuntattjani permezz ta' email fuq [redacted] jew iċċempilli fuq [redacted]. Tista wkoll tikkuntattja lis-supervisor tiegħi, Dr Maria Victoria Gauci, permezz ta' email fuq [redacted] jew billi ċċempillha fuq [redacted].

Nirringrazzjak li sibt il-ħin biex taqra din l-ittra u talli qed tikkunsidra tipparteċipa f'dan l-istudju.

Inselli għalik

Franco Buttigieg

Appendix 2a Consent Form (English Version)

Participant's Consent Form

Towards Inclusive Parishes: how do Maltese Catholic communities sustain the spiritual journey of disabled persons?

I, the undersigned, give my consent to take part in the study conducted by Franco Buttigieg. This consent form specifies the terms of my participation in this research study.

1. I have been given written and verbal information about the purpose of the study; I have had the opportunity to ask questions and any questions that I had were answered fully and to my satisfaction.
2. I also understand that I am free to accept to participate or to refuse or to stop my participation while the research study is ongoing without giving any reason and without any penalty. Should I choose to participate, I may choose to decline to answer any questions asked. In the event that I choose to withdraw from the study, I can do so up to one month after giving my interview and any data collected from me will be erased.
3. I understand that I have been invited to participate in a one-to-one interview during which I will be asked a number of questions in order to explore my experience of living my religious belief within my parish community as a disabled person. The scope of the interview will also be to arrive at a better understanding of what is needed to make our Catholic communities more welcoming. I am aware that the interview will last for between one and a half to two hours. I understand that the interview is to be conducted in a place and at a time that is convenient for me and that transport to and from this place will be provided if necessary. The interview will be conducted in English or Maltese, according to my preference.
4. I am aware that, if I give my consent, the interview will be audio-recorded and converted to text as it has been recorded (transcribed).
5. I am aware that my data will be pseudonymised: that is my identity will not be noted on transcripts or notes from my interview, but instead, a code will be assigned. The code that links my data to my identity will be stored securely and separately from the data, in a file on the researcher's password-protected computer and only the researcher will have access to this file. Any hard-copy materials will be placed in a locked cupboard. Any material that identifies me as a participant in this study will be stored securely for the duration of the study.

6. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.
7. I am aware that notwithstanding all the precautions taken to hide my identity, it may happen that some persons will, through the association of certain facts and events, come to identify me as a participant in this study.
8. I am aware that I will be given the opportunity to review the transcript of my interview once it is completed, and that I may ask for changes to be made if I consider this to be necessary.
9. I am aware that, if I give my consent, extracts from my interview may be reproduced in the final dissertation, always under a pseudonym (fictitious name).
10. I understand that my participation does not entail any known or anticipated risk.
11. I understand that my participation may prove to be beneficial to me and other disabled persons since it may lead to positive changes within our parishes.
12. I understand that under the General Data Protection Regulation (GDPR) and the Malta Data Protection Act 2018, I have the right to access, rectify, and where applicable, ask for the data concerning me to be erased.
13. I understand that all data collected, transcripts and other material will be securely stored for the duration of the study and will subsequently be destroyed on completion of the study and publication of the results, that is by January 2022.
14. I have been provided with a copy of the information letter and understand that I will also be given a copy of this consent form.

I have read and understood the above statements and agree to participate in this study.

Name of participant: ____

Signature:_____________________________________

Date:______________________

_________________________________ _________________________________

Franco Buttigieg

[redacted]

[redacted]

Dr. Maria Victoria Gauci

[redacted]

[redacted]

Appendix 2b Consent Form (Maltese Version)

Consent Form tal–parteċipant bil-Malti

“Towards Inclusive Parishes: how do Maltese Catholic communities sustain the spiritual journey of disabled persons?” (“Lejn Parroċċi nklussivi: l-komunitajiet Kattoliċi Maltin tagħna, kif qegħdin isostnu lill-persuni b’diżabilita’ fil-mixja spiritwali tagħhom?”)

Jiena, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi biex nieħu sehem fl-istudju li ser jitmexxa minn Franco Buttigieg. Din il-formola ta’ kunsens tispeċifika t-termini tal-parteċipazzjoni tiegħi f’dan l-istudju bbażat fuq riċerka.

1. Jiena ngħatajt l-informazzjoni dwar l-iskop ta’ dan l-istudju kemm bil-miktub u kemm verbalmant; kelli l-opportunita’ li nistaqsi domandi u kull domanda li kelli ġiet mwieġba kompletament, għas-sodisfazzjon tiegħi.
2. Nifhem li jiena fil-liberta’ li naċċetta jew li nirrifjuta li nipparteċipa u anke li nwaqqaf il-parteċipazzjoni tiegħi dment li dan l-istudju jkun għadu għaddej, mingħajr ma nagħti raġuni u mingħajr ebda penali. Jekk niddeċiedi li nieħu sehem, nista nagħżel li ma’ nweġibx xi domandi li jsiruli. Fil-kaz li nagħżel li nwaqqaf il-parteċipazzjoni tiegħi, nista nagħmel hekk sa xahar wara li nkun tajt l-intervista u kull informazzjoni miġbura mingħandi tiġi mħassra.
3. Nifhem illi l-parteċipazzjoni tiegħi ser tinvolvi ntervista personali li matulha ser mwieġeb numru ta’ domandi bil-għan li nesplora l-esperjenza tiegħi, bħala persuna b’diżabilita’, ta’ kif qed ngħix it-twemmin tiegħi fil-komunita parrokkjali. L-iskop tal-intervista jkun ukoll li naslu biex nifhmu aħjar dak li hu meħtieġ isir biex il-Knisja Kattolika issir aktar miftuħa għal persuni b’diżabilita’ fil-parroċċa tagħna. Naf illi l-intervista ddum bejn siegħa u nofs u sagħtejn. Nifhem li l-intervista tinżamm f’post u ħin li huma komdi għalija u li jekk ikun hemm bżonn transport, dan jiġi pprovdut. L-intervista ssir bil-Malti jew bl-Ingliż skont kif nixtieq jien.
4. Naf illi jekk nagħti l-kunsens tiegħi l-intervista tiġi rekordjata u maqluba f’dokument eżatt kif ġiet rekordjata (transcribed).
5. Naf illi l-informazzjoni kollha tiegħi ser tidher taħt isem fittizzju: jiġifieri l-identita’ tiegħi mhux ser tkun innotata fuq id-dokument (transcript) jew f’noti tal-intervista tiegħi, imma minflok tiġi assenjata kodiċi. Din il-kodiċi, li tgħaqqad l-identita’ tiegħi mal-informazzjoni tiegħi, tiġi miżmuma f’post siġur u separatament mill-informazzjoni, ġo file tal-komputer tar-riċerkatur li huwa protett permezz ta’ password u li r-riċerkatur biss għandu aċċess għalih. Kull dokument ikun maqful f’armarju li jissakkar. Kull materjal li jidentifikani bħala partiċipant\a ikun dejjem maqful f’post sigur tul l-istudju.

6. Naf illi l-identita’ tiegħi kif ukoll kull informazzjoni personali mhux ser tkun żvelata fl-ebda pubblikazzjoni, rapport jew preżentazzjoni li toħroġ minn din ir-riċerka.
7. Naf illi għalkemm qed jittieħdu dawn il-miżuri kollha ta’ prekawzjoni sabiex l-identita’ tiegħi tiġi moħbija, jista jkun illi xi persuni jidentifikawni bħala parteċipant/a ta’ dan l-istudju minħabba fatti jew ċirkostanzi partikolari.
8. Naf illi ser ikolli l-opportunita li nirrevedi d-dokument tal-intervista tiegħi (transcript) ġjaladarba jkun komplut u li nkun nista nitlob li jsiru t-tibdiliet neċessarji.
9. Naf illi jekk nagħti l-kunsens tiegħi, siltiet mill-intervista tiegħi jistgħu jinkitbu fir-rapport finali (dissertation), dejjem taħt l-isem fittizju.
10. Nifhem illi l-parteċipazzjoni tiegħi ma’ tinvolvi ebda riskju.
11. Nifhem illi l-parteċipazzjoni tiegħi tista tkun ta’ benefiċċju għalija u għal persuni oħra b’diżabilita’ peress li tista twassal għal tibdil għall-aħjar fil-komunitajiet parrokkjali tagħna.
12. Nifhem illi skont il-General Data Protection Regulation (GDPR) u l-Malta Data Protection Act 2018, għandi d-dritt li naċċessa, nbiddel u fejn japplika nitlob li titneħħa l-informazzjoni dwari.
13. Nifhem illi l-informazzjoni kollha miġbura, dokumenti u materjal ieħor ikunu miżmuma f’post sigur matul l-istudju u li jiġu meqruda meta l-istudju jkun komplet u r-riżultati ppubblikati, ċioe sa Jannar 2022.
14. Ġejt provdut/a kopja tal-ittra ta’ informazzjoni u nifhem li ser ningħata kopja ta’ din il-formola ta’ kunsens.

Niddikjara li qrajt u fhimt dak kollu hawn fuq miktub u nagħti l-kunsens tiegħi li nipparteċipa f’dan l-istudju.

Isem tal-parteċipant/a: ____

Firma:____________________________________

Data:______________________

Franco Buttigieg

[redacted]

[redacted]

Dr Maria Victoria Gauci

[redacted]

[redacted]