# **Motherhood: Listening to Disabled Women**

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May 2023



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## **Acknowledgements**

I cannot express enough thanks to my supervisor Dr Claire Lucille Azzopardi-Lane and my co-supervisor Professor Gillian Martin, for their continuous support in my research study. Their immense knowledge, guidance, meticulous suggestions, and useful critiques were key motivators throughout this journey. Thank you so much for stimulating my ambition to work harder.

I would also like to express my deepest appreciation to the participants – seven resilient and inspirational disabled mothers who never stopped chasing their dreams. Thank you for sharing your story, inner feelings, and thoughts with me. Thank you for your sincere input to this research study. This dissertation would not have been possible without your participation. You are all exceptional women and I feel honoured to have met you.

Last but not least, I would like to thank my other half, Mario, who followed the same course of studies. We joined our heads together and supported each other endlessly to let our dream come true. Today, with greatest satisfaction, we check off another wish from our bucket list and now, onto the next, because dreams make life worth living.

### **Dedication**

Dedicated to strong disabled women who keep on chasing their dreams.

Take courage, believe in yourself, meet life's challenges head on and you will blossom.

When the sharpest words wanna cut me down

I'm gonna send a flood, gonna drown 'em out

I am braved, I am bruised

I am who I'm meant to be, this is me

Look out 'cause here I come

And I'm marching on the beat I drum

I'm not scared to be seen

I make no apologies, this is me...

Keala Settle and The Greatest Showman Ensemble

#### **Abstract**

This qualitative research study examines the lived experiences of disabled women pursuing motherhood in Malta and their perceptions about disability and parenting. Seven disabled mothers from different impairment groups were interviewed and data was analysed using thematic analysis. Critical disability studies was chosen as the conceptual framework, and discussion was done within a Foucauldian approach. Findings suggest that stereotypes and prejudices regarding disability and motherhood persist, with intersectional identities of gender and disability increasing the likelihood of stigma. Invisible disabilities are less understood, and society is more compassionate towards physically disabled persons. Consequently, persons with invisible disabilities frequently have to prove their eligibility for services and supports, thus causing needless distress. There is a prevailing belief that disability can be inherited from mother to offspring. This is looked down upon through ableist assumptions and eugenic beliefs. Disabled women's parenting abilities are often undervalued resulting in the possibility of child removal. Consequently, disabled mothers often have to prove their abilities as parents. Coping with daily stressors caused by the impairment, societal beliefs, and child removal can cause psychological distress. Nevertheless, disabled women generally find motherhood fulfilling and rewarding. They view their children as their motivation to persevere. Regardless of their impairment, they find alternative ways to care for them. Support from family, friends, and neighbours enables them to navigate the challenges of parenting. Disabled women pursuing motherhood can be better supported in attaining their maternal aspirations through an increased provision of services and adjustments that effectively cater for their individual needs.

Keywords: Disabled women, motherhood, intersectionality, stigma

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## **List of Abbreviations**

ADHD – Attention Deficit Hyperactive Disorder

CRPD – Commission for the Rights of Persons with Disabilities

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

#### Introduction

This research study explores the lived experiences of disabled women pursuing motherhood in a Maltese context. It also examines their perceptions about disability and parenting. Oftentimes, disabled women experience double discrimination because of their intersectional identities of both being a woman and having a disability. Disabled women are frequently discriminated on the basis of their gender, sexuality, and disability (Davaki et al., 2013). Intersectionality is a term coined by Professor Crenshaw, who sustains that multiple oppressions are not experienced separately but rather as one unified occurrence (Crenshaw, 1989). In a country like Malta, where culture is greatly influenced by Catholicism, exploration of sexual desires is still deeply criticized, especially if this occurs outside marriage, as well as if it is not intended for procreation (Azzopardi-Lane & Callus, 2014). Additionally, motherhood is mostly regarded "as a normal part of every woman's female identity" (Lappeteläinen, 2017, p. 140), even though lately, having children is becoming more of a choice for most women in the Western World (Azzopardi-Lane & Callus, 2016).

Nevertheless, disabled women are generally not expected to pursue the social norms of femininity and motherhood. Ableist assumptions portray disabled persons as non-sexual (Lappeteläinen, 2017). They are generally regarded as "eternal children" (Gould & Dodd, 2014, p. 32) and considered sexually, socially, and emotionally immature. Lawler et al. (2015) state that disabled women are commonly viewed as disabled first and not as mothers, so having an impairment compromises their capacity to fulfil their options of having children. According to Clarke and McKay (2014), when it comes to family formation, disabled persons generally experience more disadvantages than their non-

disabled counterparts. Disabled women are oftentimes perceived as in need of care, dependent, inadequate to assume the caring role of a mother, and having high risks of passing on their disability to their children (Frederick, 2017; Vaidya, 2015). Furthermore, their maternal skills are frequently doubted, and they are regarded as incompetent to raise a child (Frederick, 2017). Hence, they are sometimes recommended to terminate their pregnancy or else give their child up for adoption (Gould & Dodd, 2014). Over the years, there has been a transition from "eugenics to newgenics" (Malacrida, 2020, p. 467), with a shift from forced sterilisation to forced contraception. Generally, disabled women are not provided with accessible information about contraception. They are often not involved in decision-making, and arrangements about the use of contraception are mainly carried out by doctors and relatives (Malacrida, 2020; McCarthy, 2009; Walmsley et al., 2016).

This scenario severely limits the opportunities of disabled women to engage in and maintain intimate relationships, as well as have children, and raise a family of their own. However, research demonstrates that with effective social support services and parental coaching, disabled women can be competent mothers capable of meeting the required responsibilities (Aunos & Pacheco, 2013; Azzopardi-Lane & Callus, 2016; Selander & Engwall, 2021). Moreover, disabled women who embark on the journey of motherhood generally strive to challenge the deep-rooted assumption that having a disability severely diminishes their parenting abilities. Conversely, research shows that most disabled mothers manage to develop a number of effective strategies and also seek to adapt their environment so that they can ensure that their children are safe and well cared for (Cureton, 2015; Frederick, 2014; Powell et al., 2019).

#### **Background**

This research study was conducted in Malta, which consists of two inhabited islands of approximately 300 square kilometres found in the southernmost part of Europe. Malta is also a nation-state where Catholicism and related family values play a substantial influence on Maltese culture (Azzopardi-Lane, 2019). Furthermore, the fact that Malta is relatively small in size intensifies dependence on the family. This phenomenon is even stronger for disabled persons (Azzopardi-Lane & Callus, 2016). Callus (2013) states that support for disabled persons in Malta is generally provided within the family. Additionally, most persons with intellectual disability in Malta end up spending the greatest part of their lives living with their parents (Azzopardi-Lane, 2019). Bahner (2013) states that open discussions about sex and sexuality in the family context are rather unusual in countries like Malta, where this subject is still highly influenced by religious principles. Creamer (2009) also outlines the fact that traditional Christian discourses on disability are more likely to be disempowering. Disability is oftentimes interpreted as a punishment, a test of faith, as well as a sign of God's mysterious ways. Moreover, a disabled person is represented as "an eternal child" (Creamer, 2009, p. 50). This scenario is very concerning because it transmits the idea that disabled persons are non-sexual, irresponsible, and lack ability as well as accountability (Creamer, 2009). Strong ties with Catholicism create extra pressure on persons with intellectual disability (Azzopardi-Lane, 2011; Debattista, 2015; Farrugia, 2019). The sexuality of disabled persons in Malta, especially those who have an intellectual disability, is still very controversial (Azzopardi-Lane & Callus, 2014). This is mirrored in the paternalistic culture which is greatly regulated by Catholic norms. According to Callus et al. (2017), parents generally acknowledge friendships for young

adults with intellectual disability; however, they tend to disapprove and place restrictions on intimate relationships. This is because they fear abusive relationships, sexually transmitted diseases, and the appropriateness of their children becoming parents (Haynes, 2016).

In spite of this scenario, over the past ten years, the sexuality of disabled persons has gained greater recognition on record (Azzopardi-Lane, 2019). This was demonstrated in 2012 when Malta ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; Callus & Camilleri-Zahra, 2013). Article 23 of the UNCRPD focuses on the rights of disabled persons to express their sexuality, form intimate relationships, marry, have children, and raise families (UNCRPD, 2006). Additionally, Article 6 specifically addresses disabled women and claims that their "human rights and fundamental freedoms" (UNCRPD, 2006, p. 7) cannot be discriminated against. The ratification of this convention was followed by the National Disability Policy in 2014 which adopted the principles of Article 23 as a foundation (Azzopardi-Lane, 2019). The National Disability Policy addresses sexuality and parenthood and puts forward a set of guidelines related to these matters, some of which are access to sexual education, goods, services, and supports for disabled persons that are fundamental in accomplishing their role as parents. It also highlights measures that are needed in order to achieve the objectives that have been set. Some of these measures are the provision of accessible information on reproductive wellbeing and childcare, training of service providers on disability awareness and etiquette, as well as supported parenthood schemes (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014). Along the same lines, Malta's 2021-2030 National Disability Strategy provides a roadmap for the implementation of

actions that should be taken to achieve desired objectives related to disability, relationships, sexuality, and parenthood. It outlines the importance of training for professionals including doctors and nurses, carers and personal assistants, support for disabled mothers including single disabled mothers in their motherhood, and inclusive marriage-related courses offered by the Catholic church, just to mention a few (Ministry of Inclusion and Social Wellbeing, 2021). Regardless of this, the expression of sexuality and parenthood of disabled persons in Malta continues to be suppressed. There is also substantial lack of existing research in these areas and the lived experiences of disabled persons are still underexplored.

#### Aims, Significance of the Research Study and Research Questions

Much of the available information about disabled women, their reproductive lives, and motherhood has been obtained from second-hand sources. Many studies have been based on professional opinion, and the experiences of disabled women have been scarcely explored (Höglund & Larsson, 2019; König-Bachmann et al., 2019; Walsh-Gallagher et al., 2013). Furthermore, research in the Maltese context is rather lacking. Therefore, the aims of this research study are to shed light on this phenomenon, to give voice and empower disabled women, to investigate the opportunities and barriers that they face in their reproductive lives while emphasizing the need for more inclusive practices, as well as to explore their perceptions about disability and motherhood. Hence, the adopted research questions are as follows:

- What are the experiences of disabled women pursuing motherhood?
- How do the experiences of disabled women impact their perception about disability and motherhood in a Maltese context?

Hopefully, findings may serve as groundwork for more inclusive policies and practices which will potentially contribute to positive change in social attitudes towards disabled women expressing reproductive choices and being mothers in contemporary society.

#### **Conceptual Framework**

I chose critical disability studies as a conceptual framework because this approach challenges assumptions about disability (Shildrick, 2012) and explores what "continues to impede the evolution of equitable conditions" (Shildrick, 2009, p. 2). Critical disability studies originated in the 1970s from the activism of disabled persons (Reaume, 2014). As a critical disability studies researcher my interest is not to look into why disabled women pursuing motherhood are compared with normative standards but the rationale behind these standards and the denial of difference. In view of this, I chose to adopt Foucault's concept of power relations in order to explore how everyday practices materialise.

According to Foucault "people know what they do; frequently they know why they do what they do; but what they don't know is what what they do does" (Foucault, as cited in Dreyfus & Rabinow, 1982, p. 187).

#### **Positionality**

Positionality "reflects the position that the researcher has chosen to adopt within a given research study" (Savin-Baden & Major, 2013, p. 71). The researcher's positionality in a research journey is very important because it influences how the research is conducted, the outcomes and results, as well as the choice of topic that is going to be investigated (Holmes, 2020). The fact that I am a woman and a mother gave me an insider position. Consequently, I was better able to understand and interpret the language used by the participants including colloquial and gesture language. Furthermore, most of the

participants in this research study realised that I was able to understand the role and responsibilities of being a mother and that I could relate to their experiences; as a result, I was very much trusted by participants. This stance was very important for me because in my opinion I was able to secure more honest answers. However, it is also worth mentioning that I am not a disabled mother; therefore, I was not able to have full understanding of the participants' perspectives. I lack any understanding of what it is like to parent with a disability and how disabled mothers experience life differently.

Additionally, I was constantly aware and careful to detach myself from engrained societal prejudices that are associated with disabled women and parenting so that the true voice of the participants could be heard. The chosen area of investigation was mainly inspired by the multiple instances of intolerance and prejudices towards disabled parents from various professionals that I encounter while carrying out my duties as an inclusion coordinator in mainstream schools. In my opinion, prejudices are commonly used to simplify reality. Rather than looking deep down for the real problem in order to find an effective solution, some professionals stop at the prejudice, and most often the blame is pointed towards the disability. Prejudices are very difficult to overcome and many times, if contradicted by facts, these are denied, and the prejudices remain unquestioned. However, research in this area provides a clearer picture and an improved understanding of this phenomenon. Hence, I aspire that my research study sheds more light on the opportunities and barriers that disabled mothers encounter during motherhood while also emphasising the need for more tolerance and more inclusive practices.

#### Terminology

Throughout this research study reference to disabled persons, as well as disabled women is done using identity-first rather than person-first language. This decision was inspired by Foucault's concept of power relations in regard to discourse. There is a lot of power in the everyday discourses that we use. Foucault considers discourses to be a system of representation (Hall, 1992). Discourses mirror cultural beliefs, attitudes, and social hierarchies at a particular historical moment. They also shape how we see each other and reflect the value that we assign to diverse identities. Discourses also influence our behaviour (Foucault, 1982; Hall, 1987). Furthermore, from the social model perspective, persons have impairments and not disabilities. The term persons with disabilities confuses impairment and disability. It also implicates disability as something caused by the individual rather than society. A disability is caused by society's reluctance to accommodate the needs of persons with impairments. Therefore, the term disabled persons is used to refer to persons with impairments who are disabled by barriers constructed by society (Inclusion London, n.d.). Using the term disabled women also manifests identification with a collective culture identity. It unites this minority group and helps to identify the causes of their oppression and discrimination. It also helps to generate social change (Inclusion London, n.d.).

#### **Dissertation Overview**

This dissertation is composed of six chapters, starting with the introduction which presents the context of my research topic, the motivation for undertaking this journey, and the importance of this research study. The chapter that follows is the literature review where the experiences faced by disabled women in realising their reproductive rights,

particularly their right to found and raise a family, are discovered. Literature conducted both locally and internationally is used throughout this review. This chapter concludes with a section that explores disabled women and motherhood through the lens of Foucault. Chapter 3 captures the choice of conceptual framework, the research approach that was adopted, and the research tool that was used to generate data. It also describes how data was analysed, the ethical considerations, and the strengths and limitations. Compensations that address these limitations are also highlighted. Chapter 4 brings forward the findings, that is, the unique experiences of seven disabled mothers and their perception of disability and motherhood in a Maltese context. Individual experiences and perceptions are categorized under four themes, which are the joy of motherhood, assumed incompetence, stereotypes and prejudices, and physical versus invisible disabilities. Chapter 5 provides an in-depth discussion of the findings. Findings are critically discussed through the lens of Foucault's concept of power-relations in regard to discourse, normalization, disciplinary-power, power-knowledge, and bio-power. The final chapter includes key findings, recommendations, strengths and limitations, implications for further studies, and concluding comments.

#### **Literature Review**

#### Introduction

This chapter will explore in depth the experiences faced by disabled women in realising their reproductive rights, particularly their right to found and raise a family. Being a mother is an important role for disabled women because it may defeat their enforced predominant identity of being disabled. Furthermore, disabled women generally demonstrate eagerness and enthusiasm to show their commitment and ability to care for their children (Gould & Dodd, 2014). Despite this, available literature overwhelmingly states that they experience discriminatory attitudes and widely ingrained prejudicial assumptions which question their ability and right to experience motherhood (Frohmader, 2009).

The first section of this literature review will examine the UNCRPD, in particular Article 23 and Article 6, which focus on the sexual and reproductive rights of disabled persons and disabled women, respectively. This will be followed by an exploration of disabled women's sexuality and how their bodies are generally viewed as unattractive, defective, worthless, and unable to produce healthy offspring. Successively, reference will be made to eugenics and how these practices still prevail through forced contraception, opposition to their pregnancy, abortion, and lack of autonomy experienced by disabled women. Additionally, reference will be made to disabled women's perceived inability to raise children, their presumed incompetence, and the removal of their children. This will be followed by an analysis of services and supports for disabled women pursuing motherhood. This literature review will conclude with a section that explores disabled

women and motherhood through the lens of Foucault. Literature conducted both locally and internationally will be used throughout this review.

#### **Sexual and Reproductive Rights**

On the 13<sup>th</sup> of December 2006, the United Nations General Assembly approved both the Convention on the Rights of Persons with Disabilities as well as the Optional Protocol (Callus & Camilleri Zahra, 2013). This was a great accomplishment and an important turning point for the disability sector because the UNCRPD was the first international legally binding treaty that explicitly focused on the rights of disabled persons (Lang et al., 2011). The UNCRPD has the ability to promote, protect, and ensure that disabled persons receive full realisation of fundamental human rights. It also has the potential to ascertain that they enjoy equality under the law (Lang et al., 2011). This treaty came into effect in May 2008, and Malta was among the first countries that signed both the Convention, as well as the Optional Protocol, both of which were ratified in October 2012 (Callus & Camilleri Zahra, 2013).

Article 23 of the UNCRPD concentrates specifically on the sexual and reproductive rights of disabled persons. It emphasises their entitlement to retain their fertility on parallel grounds to others. It also guarantees their right to marry, set up a family, and choose without hindrance the number and spacing of their children. Furthermore, the UNCRPD deplores any kind of discrimination in matters related to relationships, marriage, parenthood, and family (UNCRPD, 2006). Meanwhile, Article 6 is entirely dedicated to disabled women because, regrettably, they are subject to multiple discriminations and are oftentimes hindered from enjoying their fundamental rights. Disabled women must have full control over their bodies, fertility, and sexuality (UNCRPD, 2006). According to

Devandas Aguilar (2017), the attainment of their sexual and reproductive rights is very important because it is a requirement for their empowerment, as well as for their participation in all domains of society. Moreover, the principles of dignity, equality, as well as respect for diversity are preserved through the fulfilment of these rights (Devandas Aguilar, 2017).

Disabled women have to strive in a society that mainly caters for the non-disabled and that is dominated by men, so they are more disadvantaged than non-disabled women and also than disabled men (Porter, 2018). Furthermore, according to Azzopardi-Lane and Callus (2016) the role of motherhood for disabled women further intensifies their experiences of disablement. They encounter an array of misjudgements related to relationships, reproduction, and child rearing. Even though disabled women have the same desire and legitimate right to become mothers as their non-disabled counterparts, society still continues to underestimate their sexual and reproductive rights, as well as their parenting abilities (Arcella et al., 2009; Frohmader & Ortoleva, 2012). Their maternal skills are constantly being questioned, and disabled women are often considered unable to fit in the traditional female role of motherhood (Frederick, 2017). Consequently, their experiences cannot be analysed only through the single lens of gender. Instead, an intersectional approach has to be adopted and all the different social categories including disability and social status must be taken into consideration. This way, all identity markers, as well as their connections, are examined. Each and every identity marker informs and shapes the others and together they outline the complexity of disabled mothers' lives. The depth and breadth of their experiences can only be captured through an intersectional approach (Collins & Bilge, 2016).

#### **Sexuality and Disabled Women's Bodies**

Disabled women have the same needs and desires as their non-disabled counterparts (Farrugia, 2019; Plagens-Rotman et al., 2021). However, they are often portrayed as unattractive, especially those who have a physical disability (Zewude & Habtegiorgis, 2021). According to Moin et al. (2009), their disability may negatively impact their development of sexual relationships. In fact, when compared to non-disabled women, they experience greater hardships in establishing and maintaining relationships. They are also less likely to get married, as well as to engage in reciprocal sexual activity. Moin et al. (2009) also state that women with physical disabilities have lower body image, sexual self-esteem, sexual satisfaction, and life satisfaction than non-disabled women. This discrepancy is found to be more significant among young adult disabled women than mature ones. This phenomenon may be attributed to the fact that body image and sexual identity may be of greater importance to young adult women than to mature women (Moin et al., 2009). Participants in this research study consisted of 70 disabled women and 64 non-disabled counterparts. Among those with a disability, there were more single women, more divorced, and fewer married than among those without a disability. Curiously enough, this demographic data conforms with the reported results.

Apart from being considered unattractive, disabled women are oftentimes regarded either as non-sexual beings and unable to engage in sexual relationships, or as hypersexual and their sexuality has to be contained (Malacrida, 2009; Vaidya, 2015). In her writing about her own experiences of growing up, Ghai (2002), an Indian academic who was diagnosed with polio at the age of two, mentions the notion of desexualisation of girls. Ghai (2002) narrates how her male and female cousins used to be banned from

sleeping in the same room; however, no restrictions were imposed on her, and she was usually allowed to share a room with her male cousins. This scenario clearly transmits the message that disabled girls are constructed under the public gaze as non-sexual and different from their non-disabled counterparts. Nevertheless, both McCabe and Holmes (2013) and Shah (2017) challenge these misconceptions and affirm that disabled persons are neither non-sexual nor sexually inactive. In fact, Brown and McCann (2018) and Kelly et al. (2009) report that persons with intellectual disabilities desire meaningful relationships ranging from friendships to sexual intimacy just like others. Additionally, Turner and Crane (2016) state that these persons also consider sexual pleasure to be a crucial feature of relationships and sexuality.

An additional misconception that revolves around disabled women's bodies is that many times they are viewed as defective and worthless. Disabled women are often portrayed as weak, dependent on others, and passive, and therefore, unable to assume family and care roles (Wolowicz-Ruszkowska, 2016). Gupta (2013), who became paralysed in her early twenties after a road accident, writes about her experiences of love, marriage, and intimacy. In her writings, Gupta (2013) particularly captures the ongoing struggles that she has encountered in a world that focuses only on limitations and views disabled bodies as faulty and futile. Gupta explains that this situation has left a negative impact on her feelings about her self-worth and has generated a lot of insecurities. Additionally, disabled women are generally perceived as unable to produce healthy offspring and as having high risks of passing on their disability to their children (Azzopardi-Lane & Callus, 2016; Frederick, 2017). According to Limaye (2015), these situations may generate adverse implications on disabled women. In fact, in her research study, which was

conducted with seven mothers with different impairments, Limaye (2015) explains how they have experienced tension during pregnancy, instigated by the attitudes of both family members, as well as medical professionals, who believed that the children will be born with an impairment. These participants state that the delivery of their healthy babies was a relief for them and brought along great joy and satisfaction (Limaye, 2015).

The above-mentioned false beliefs oftentimes generate negative repercussions such as the frequent exclusion of disabled people from sex education. It is widely reported that many times disabled people are either not included in sex education (Campbell, 2017; Nelson et al., 2020; Santinele Martino, 2017; Wos et al., 2020) or else they are provided with insufficient information (Frawley & Wilson, 2016; Jahoda & Pownall, 2014; Löfgren-Mårtenson, 2012). Consequently, when compared to others, they generally have decreased levels of sexual knowledge (Shah, 2017). Furthermore, according to Shah (2017), parents, educators, as well as health professionals are generally unprepared and unskilled to teach disabled persons about this subject. Similarly, Azzopardi-Lane (2022) reports that delivery of sex education for persons with intellectual disability in Malta is still in its early stages, as some professionals still experience feelings of discomfort while delivering sex education, and that generally the underlying cause for this factor may be attributed to the cultural taboo that still encircles this subject. Azzopardi-Lane (2022) states that delivery of sex education must take a proactive approach rather than persisting with a reactive one. Sex education is frequently provided only when a problem is apparent or else when disabled persons are already immersed in a real problem which is oftentimes related to socially inadequate sexual behaviour or unplanned pregnancies.

Regrettably, decreased levels of sexual knowledge positions disabled persons in situations where they are more vulnerable to relationships that are exploitative and disempowering, to unplanned pregnancies, to sexually transmitted diseases, and to sexual violence (Shah, 2017). Additionally, inappropriate sex education for disabled persons may create harmful repercussions on both their physical, as well as their psychological health and wellbeing. It may lead to decreased self-esteem, self-doubt about their status as sexual beings, and confusion about their sexual identity (Shah, 2017). Good quality sex education is not only important for disabled persons to learn about sexual rights, expression, and safety but also about resisting and reporting sexual violence, thus contributing to the empowerment and social realization of disabled persons as sexual beings (Shah, 2017). Additionally, the assumptions that disabled women are non-sexual and sexually inactive may also unfavourably impact the quantity and quality of healthcare services that they receive. Disabled women generally experience poor access to routine healthcare services that are related to reproductive care, as well as poor involvement in screening tests for females (Tilley et al., 2012). Sporadic access to appropriate sexual and reproductive healthcare services negatively impacts the quality of life of disabled women.

#### **Eugenics**

From the late 19<sup>th</sup> century onwards, eugenicists believed that the root cause of social problems such as crime, alcoholism, and prostitution was bad genetic traits (Walmsley, 2005). According to McConnell and Phelan (2022), the eugenics movement insisted that "bad heredity had to be weeded out and good heredity fostered to produce respectable, productive citizens" (p. 2). This movement was convinced that the human species could be improved by introducing forced sterilization of "the feebleminded"

(McConnell & Phelan, 2022, p. 3). According to Mitchell and Synder (2003), this terminology did not only refer to persons with intellectual disability but included amongst others those with a visual, hearing or congenital impairment, those who suffered from chronic depression or schizophrenia, and alcoholics. Eugenicists also supported sex-segregated institutionalization (McConnell & Phelan, 2022). Additionally, sexual sterilization laws and policies were introduced in several countries in the Western World, and by the Second World War approximately 60,000 persons had been sterilized in the United States and at least another 400,000 in Nazi Germany (Fabre & Schreiber, 2017; Reilly, 2015). After the Second World War the domination of the eugenics movement faded, and shortly afterwards the emergence of deinstitutionalization occurred. By the late 20<sup>th</sup> century, the majority of large institutions for persons with intellectual disability in upper-income countries were either closed or else in the process of closing down.

Furthermore, sterilization laws were revoked, and eventually the sexual and reproductive rights of these persons were formally acknowledged (McConnell & Phelan, 2022).

Despite these advancements, according to McConnell and Phelan (2022), eugenic practices still prevail. Malacrida (2020) describes this phenomenon as a development from "eugenics to newgenics" (p. 467), in which there has been a shift from forced sterilization to forced contraception. This notion has been explored by McCarthy (2009), who examined the use of contraception among women with learning disabilities.

Participants in this research study consisted of 23 women aged between 20 and 51. All of them stated that they did not receive any form of accessible information about contraception from their doctors. Consequently, most of them were not aware of how their contraception works. They also did not understand why they were suggested a

particular contraception and not another one. Furthermore, the majority of these women believed that once they started using contraception, they would continue using it indefinitely. Most participants claimed that they were not involved in the decision to start contraception, but arrangements were made by someone else, mainly their doctors or parents. This scenario may probably be attributed to the fact that most participants were accompanied by their parents when they visited their doctor to get contraception.

McCarthy (2009) further adds that there seems to be a very weak link between participants' involvement in sexual activity and their perceived necessity for contraception. This notion has also been affirmed by Walmsley et al. (2016), who found that the majority of participants in their research study, who were all women with intellectual disabilities, used contraception to manage menstruation. The contraceptive pill and the implant were generally used to regulate periods and reduce pain and discomfort related to the menstruation cycle. Ironically, several women in this research study continued to experience pain because of lack of systematic follow-up and review (Walmsley et al., 2016). McCarthy (2009) states that one of the most concerning findings in her research study is the fact that some girls with learning disabilities are given contraception in their early teenage years without taking into consideration the possible health implications associated with this. It is worth nothing that during the teenage years it is normal for young girls to start displaying signs of sexual interest; therefore, McCarthy (2009) outlines the fact that parents as well as medical professionals have to be cautious about confusing normal sexual development with actual sexual activity. All young girls in this study were taken to their doctors by their mothers, hence opting out of using contraception was immensely difficult for them (McCarthy, 2009). The decision about the use of contraception is not an easy one, and any woman should reflect on the related pros and cons. For sure, when compared to their non-disabled counterparts, disabled women are at a disadvantage in this proceeding.

Additionally, disabled women may also face opposition to their pregnancy both from family members, as well as from healthcare professionals (Streur et al., 2020; Walsh-Gallagher et al., 2012). Subsequently, they are pressured to terminate their pregnancy and abort the foetus. There are also others who end up hiding their pregnancy until they are well advanced in the process for fear of the reactions of those around them (Azzopardi-Lane & Callus, 2016). Social practices continue limiting opportunities for disabled persons to develop positive sexual identities, to decide whether or not and with whom to be sexually active, and whether and when to have children. Infringement of their right to have control over their own bodies continues to be justified by the presumption that disabled persons, especially women with intellectual disability, lack self-governance and are unsuitable for parenthood (McConnell & Phelan, 2022). Research shows that many disabled women are not being provided with opportunities to make their own family planning decisions (McCarthy, 2009; Walmsley et al., 2016).

#### **Assumed Incompetence**

Disabled persons are generally regarded as "eternal children" and are considered to be sexually, socially, and emotionally immature (Gould & Dodd, 2014, p. 32).

Additionally, disabled women are oftentimes perceived in need of care and dependent on others, and therefore inadequate to assume the caring role of a mother (Vaidya, 2015).

Their maternal skills are frequently doubted, and they are considered incompetent to raise a child (Frederick, 2017). Society is more likely to suggest that they should not have

children. Moreover, those who challenge these stereotypes and embark on motherhood generally experience higher parenting benchmarks (Azzopardi-Lane, 2021): they have to perform much better than their non-disabled counterparts in order to fall within the ideal standards of parenting. Consequently, many times they have to struggle to prove their validity as mothers (Gould & Dodd, 2014; Theodore et al., 2018). Most disabled mothers make every effort to comply with society's expectations of motherhood and they adopt several practices that can make up for their limitations. Amongst others, it has been reported that some mothers with visual impairment pin bells to their toddlers' clothes so that they will be able to track them. They also pull their strollers rather than push them in order for them to be able to use their white canes and hold guide dogs at the same time. Furthermore, they manage to measure medicine by placing tactile markers on syringes (Frederick, 2014). On the other hand, those who have a physical impairment frequently decide to adapt their home environment, such as having changing pads on the floor rather than using a changing table because these are more accessible for them. In this way they are able to independently change diapers and dress their infants (Powell et al., 2019).

Despite of all this effort, disabled mothers still face a lot of scrutiny and surveillance from those around them while raising their children (Frederick, 2015; Gould & Dodd, 2014; Malacrida, 2009). Malacrida (2009) reports that disabled mothers often feel looked over, judged, and criticized. They constantly have to prove their abilities and show that they are competent mothers. In order to ensure that their performance is satisfactory, many times they engage in self-policing and become over-conscious of their performance (Malacrida, 2009). Most disabled mothers constantly feel undermined and

threatened. Consequently, the effect on their self-esteem can be overwhelming and they may feel defeated and helpless (Reeve, 2014). They may also experience internalised parental incompetence and self-stigma. They start believing that they can never live up to being a good mother. Self-stigma also amplifies their sense of guilt and disempowerment (Malacrida, 2009; Theodore et al., 2018).

Nevertheless, the identity of being a mother is of great value for disabled women (Gould & Dodd, 2014; Shewan et al., 2014; Wolowicz-Ruszkowska, 2016). For some, motherhood may be a source of strength because they constantly have to confront society's engrained stereotypes and prejudices. For others it may be a source of resilience because they manage to overcome their limitations by being creative and inventive problem-solvers (Wolowicz-Ruszkowska, 2016). Moreover, motherhood may serve as a defence against their enforced primary identity of being disabled (Gould & Dodd, 2014; Shewan et al., 2014). Overall, motherhood generally creates a sense of self-fulfilment, satisfaction, and happiness for most disabled women (Wolowicz-Ruszkowska, 2016).

#### **Removal of Children**

Stereotypes and prejudices portray disabled persons as incompetent and childish; therefore, they are generally considered to be unsuited to appropriate parenting (Traustadóttir & Sigurjónsdóttir, 2008). Consequently, during child-rearing they face a lot of scrutiny and surveillance (Frederick, 2015; Gould & Dodd, 2014). According to Malacrida (2020), disabled mothers generally experience an increased risk of scrutiny. This is because they are normatively expected to nurture their children selflessly. Several disabled mothers have reported experiences of living with a constant sense of fear that they will be scrutinized (Frederick, 2014). In fact, it has been reported that some disabled

parents do not make use of available support services because they fear that if they seek help, they will be labelled as incompetent, and hence increase the possibility of child removal (Aunos & Pacheco, 2020).

Various studies have demonstrated that parents who have intellectual disabilities are more likely to lose permanent custody of their children than any other group of parents (Aunos & Pacheco, 2020; Gould & Dodd, 2014; Theodore et al., 2018). Cognitive limitations are often associated with parenting incompetence (Lightfoot & DeZelar, 2016; Proctor & Azar, 2013; Tefre, 2017). As a result, the diagnosis of intellectual disability is often presented as the predominant reason for the removal of children without assessing other possible risk factors (Callow et al., 2017; Sigurjónsdóttir & Rice, 2017). Sometimes, this presumption of parenting inadequacy even happens as early as pregnancy without any proof of wrongdoing being observed (Aunos & Pacheco, 2020). According to Sigurjónsdóttir and Rice (2016), there is a deep-seated assumption that the lower the intelligence quotient, the higher the risk of neglect, even though there is no scientific evidence of this. However, Frederick (2014) reports that the main reason for removal of children is not only limited to having an intellectual disability. Instead, any impairment – physical, sensory, or mental – can be a predominant reason for termination of parental rights. Contrastingly, studies have identified several contextual and environmental factors that affect parenting more than a diagnosis of disability, some of which include poor housing, poverty, limited support networks, and a history of domestic violence (Azzopardi-Lane & Callus, 2016; Emerson & Brigham, 2014; McConnell et al., 2011; McGnaw et al., 2010; Rice & Sigurjónsdóttir, 2018; Wade et al., 2011).

Oftentimes, there is an overwhelming interference from "powerful others" (Gould & Dodd, 2014, p. 31) in disabled mothers' lives. Most often than not, society implies that they should not have children. On the other hand, when they do have children, they are frequently monitored and insinuated to that they are not up to the standard of adequate parenting. Consequently, "powerful others" remove their children. According to Frederick (2014), the state very often relies on judgements about parental adequacy from social workers and medical professionals, even though these may not be sufficiently knowledgeable about disability. Furthermore, social workers and medical professionals are more likely to own the same negative attitudes as the general public. Gould and Dodd (2014) also report that few mothers have advocates, and at times a decision is even taken without going through the courts. Additionally, mothers generally don't have much control or choice over the final decision, and their children are often given up for adoption. Throughout this process, disabled mothers frequently experience intense feelings of helplessness. As a matter of fact, they can seek help but for many mothers this means that they have to turn to those who removed their children. Moreover, if they express their feelings, these can be used against them and serve as proof that the removal of their children was necessary in the first place (Gould & Dodd, 2014). Even worse, it can also be used to remove more of their children. As a result, disabled mothers often conceal their emotions, and their only consolation will be that one day they will rejoin their children. In the meantime, they have to make do with the offered contact time which once again is decided upon by "powerful others" (Gould & Dodd, 2014).

In line with this, Gould and Dodd (2014) explored the experiences of nine mothers with mild learning disabilities who had their children removed. All participants faced

parenting scrutiny and presumed incompetence. The reasons behind the removal of their children remained uncertain for most of them. They described the child protection process as confusing and unfair. Mixed in with the loneliness of bereavement, these mothers experienced several other physical traumas including lack of appetite, weight loss, sleeping difficulties, vivid dreams, as well as symptoms related to post-traumatic stress disorder such as having flashbacks (Gould & Dodd, 2014). Similar findings are also reported by Azzopardi-Lane and Callus (2016) in their research study about disability and parenting, where a single mother who had a congenital severe mobility impairment experienced disbelief about motherhood both by her parents, as well as by medical professionals. Regrettably, this mother did not receive the support that she needed in order to be able to look after her son and as a result she was left with no other option than to put him into foster care. Additionally, her visits were limited to two hours a week and when she asked for an extension, her request was turned down (Azzopardi-Lane & Callus, 2016). According to Lightfoot and DeZelar (2016), children who are being removed from their parents on the premise of parental disability are less likely to have a case plan goal of reintegration with their parents. This is very concerning because it implies that disabled parents are not being offered appropriate accommodations within the child welfare system, as well as being more prone to discriminatory practices.

Disabled mothers show great resilience and face their parenting challenges with strength. Research demonstrates that with appropriate training, information, and support they can be competent parents capable of meeting the required responsibilities (Aunos & Pacheco, 2013; Darbyshire & Stenfert Kroese, 2012; MacLean & Aunos, 2010; Selander & Engwall, 2021).

## Services and Supports

The UNCRPD (2006) claims that disabled persons should be supported in exercising their right of having a family of their own and raising children. With the appropriate services and supports, these persons can become competent parents (Lightfoot et al., 2018). Adequate and effective services and supports improve their parenting abilities and help in keeping their families together (Aunos & Pacheco, 2013; Darbyshire & Stenfert Kroese, 2012). On the other hand, limited services and supports negatively affect their wellbeing, as well as that of their children. They also adversely impact their children's development (Darbyshire & Stenfert Kroese, 2012; Llewellyn & Hindmarsh, 2015; Wade et al., 2011). Parenting failure is generally attributed to the intellectual disability; however, it is the lack of services and supports that is to blame (Azzopardi & Azzopardi-Lane, 2021; Azzopardi-Lane & Callus, 2006; Collings & Llewellyn, 2012). Lightfoot and LaLiberte (2011) define parental support as "technologies or personal supports that enhance family functioning in families headed by a parent ... with a disability" (p. 390). Technologies may include a smartphone which provides reminders or an adapted crib. Personal supports may include a mentor, as well as formal and informal supports such as parenting classes, house cleaning services, after-school tutoring, and babysitting (Lightfoot et al., 2018; Lightfoot & LaLiberte, 2011). According to Proctor and Azar (2013), formal sources of support are limited; hence, many disabled parents generally depend on informal supports. Additionally, they are most likely to depend on family members for support (Lightfoot et al., 2018). In a research study carried out by Lightfoot et al. (2018), participants, who consisted of 25 disabled mothers and 5 disabled fathers, preferred informal supports over formal ones. They stated that informal supports

are broad, practical, flexible, and encompass emotional assistance, whereas formal supports are many times overwhelming, confusing, and not always helpful (Lightfoot et al., 2018).

Research also demonstrates that persons who support disabled mothers, whether they are relatives or else paid support, tend to take over their mother's role rather than assist them in obtaining and developing parental skills. This situation may be generated from a deficit model, as well as from the prevalent notion of overprotection whereby disabled parents are considered to be inadequate parents, dependent on others, and unable to care for their children (Azzopardi & Azzopardi-Lane, 2021; Lappeteläinen et al., 2017; Theodore et al., 2018). These situations may be avoided if disabled mothers are provided with proactive parental skills training before they actually become parents. Adopting a preventive approach that prioritises early intervention, as well as recognising the fact that support is most likely to be needed long term, may be more effective than providing crisis-driven support (Azzopardi & Azzopardi-Lane, 2021; Collings et al., 2017; Stewart et al., 2016; Stmadova et al., 2017). Parental skills training programmes are crucial for disabled parents, especially for those who have intellectual disabilities. Research shows that programmes that are tailored to meet the specific needs of these parents, such as home-based programmes, have been proved effective in supporting parents to develop their parenting skills (Azzopardi & Azzopardi-Lane, 2021; Bauer et al., 2014; MacIntyre et al., 2019). According to Bauer et al. (2014), these programmes help to build on the skills parents already have. Moreover, Azzopardi and Azzopardi-Lane (2021) state that service users of home-based programmes are generally more compliant, participate more, and feel more comfortable when compared to others attending mainstream

programmes. Additionally, professionals generally regard attendance to mainstream parenting skills programmes as futile for parents with intellectual disabilities (Azzopardi & Azzopardi-Lane, 2021). On the other hand, MacIntyre et al. (2019) state that parents with intellectual disabilities value group-based programmes as well. These programmes bring together parents who have similar experiences to share. Apart from helping them to develop parenting skills, these programmes enhance their social networks, promote their self-advocacy skills, and help them to recognize their own strengths and be more assertive (MacIntyre, 2019). Additionally, Tarleton (2014) states that programmes that combine home-based and group-based learning are even more effective. Evidence shows that the mentioned programmes also improve parent and child interactions, child development, as well as the wellbeing, self-esteem, and confidence of parents (Macbeth et al., 2015; Tarleton, 2014).

Koolen et al. (2020) reviewed 19 qualitative research studies with the aim to analyse the perceptions of parents, professionals, and informal system members regarding the support needs of parents with intellectual disabilities. The gathered data indicates that parents would like professionals and other support staff to treat them seriously, as they do with non-disabled parents. Data from professionals also mentions this notion, but their focus is on raising awareness about the limitations of disabled parents. Focusing on limitations rather than on parenthood may be attributed to the professionals' prejudicial beliefs about the abilities of parents with intellectual disabilities (Koolen et al., 2020). Meppelder et al. (2014) report that the parental abilities of parents with intellectual disabilities are oftentimes questioned and doubted by support staff. Additionally, Jones (2013) states that professionals may focus more on limitations because

of the responsibility they feel about the safety and vulnerability of the children involved. Regrettably, when professionals focus on limitations and are uncertain about disabled parents' parental skills, it becomes difficult for them to meet their needs and take them seriously as full parents (Koolen et al., 2020). According to Collings et al. (2017), as well as Aunos and Pacheco (2013), parents are also very positive about family-centred practices. This approach values their strengths and preferences, and promotes collaborative decision-making, hence balancing power relations. Family-centred practices strengthen family functioning and wellbeing and help to build meaningful relationships with professionals (Collings et al., 2017). Despite the growing evidence in favour of adopting a family-centred approach, only gaps of good practices exist, alongside several persistent barriers that are hindering the wider implementation of this approach (MacIntyre et al., 2019; Sigurjónsdóttir & Rice, 2017). Barriers include the negative assumptions about the capacity of disabled persons to become parents and raise children, as well as the sparse knowledge among professionals about the availability of adequate services and supports for disabled parents and their families (Sigurjónsdóttir & Rice, 2017).

Even though more disabled women are becoming mothers, having access to good quality maternity care may be difficult (Malouf et al., 2017). Oftentimes, healthcare professionals may not be convinced about disabled women's ability to cope with pregnancy and motherhood (Lawler et al., 2013). Furthermore, research shows that professionals may lack experience in providing care for pregnant disabled women (Malouf et al., 2017; Mitra et al., 2015; Mitra et al., 2017). During maternity care disabled women are more likely to encounter inadequate and inappropriate communication than their non-disabled counterparts. More often than not, information is not disseminated

effectively, they are not listened to, and they are not given time to ask questions (Malouf et al., 2017). Azzopardi and Azzopardi-Lane (2021) also highlight the difficulties that are commonly encountered by parents with a hearing impairment. Generally, healthcare professionals do not know how to sign; hence, these parents have to be accompanied by someone who can act as an interpreter. This arrangement may not always be possible, and participants have stated that in these scenarios they are left stranded and are placed in a position of vulnerability and powerlessness. On the other hand, expectant parents have also reported that professionals appeared to be initially surprised when they were accompanied by a third person to act as an interpreter. Moreover, quite often disabled mothers experience invisibility because professionals are more likely to address the hearing person. This scenario indicates the need for further training amongst healthcare professionals about the various support needs of parents from different impairment groups, as well as to increase their awareness of how to behave with these persons (Azzopardi & Azzopardi-Lane, 2021). Malouf et al. (2017) also state that during maternity care disabled women are more likely to experience limited involvement in decision making, their concerns might not be taken seriously, and they often encounter difficulty in establishing a trusted and respected relationship with clinical staff.

Mainstream services generally lack accessibility for disabled parents (Azzopardi & Azzopardi-Lane, 2021). This phenomenon is not limited only to the health sector but also extends to the education system. Despite the fact that parental involvement in their children's education has long been encouraged by both literature and policy, disabled parents still encounter challenges when they seek to support their children's education (Humphrey-Taylor, 2015; Stalker et al., 2011). Research once again indicates that the

biggest barrier is the perceptions of schools and their staff, who consider disabled parents to be lacking parenting skills. Presumptions of incompetence may be very concerning for disabled parents, as they fear that schools may report them to child protection services because they assume that their children are neglected or else they are acting as carers for their disabled parents (Stalker et al., 2011). Disabled parents also report ineffective communication and access both to buildings and information. Moreover, they are generally not consulted about policies and practices. This may be attributed to the fact that schools do not recognise the relevance and the benefits of getting them involved (Stalker et al., 2011).

Another essential service for disabled mothers is that provided by personal assistants, especially for those who have extensive physical disabilities. Studies on disabled mothers and personal assistants highlight the fact that service users generally create parenting strategies. This is done so that they can safeguard their mothering role. Generally, mothers insist that assistants focus on practical support such as feeding and changing nappies, while they assume the responsibility of social and emotional care such as providing comfort and setting rules in everyday life (Aune, 2013; Poter et al., 2020; Selander & Engwall, 2021). However, according to Poter et al. (2020), setting clear boundaries between the two different roles is not always easy. Assistants may have differing opinions in regard to parenthood, upbringing methods, and parenting strategies; therefore, striking a balance between service users' demands and assistants' beliefs may be challenging. In their research study, Selander and Engwall (2021) explored the perceptions of parents, as well as those of personal assistants about supported parenting. All parents reported that initially they felt distressed about the fact that they needed

realised that they needed help in carrying out everyday parenting tasks. However, by time they came to realise that they were acting in their child's best interest because personal assistants were actually enabling their children to have experiences that might have been unattainable if they were not supported (Selander & Engwall, 2021).

Parenting with a disability may be challenging but, with appropriate and effective services and supports, disabled mothers will be able to embrace this journey with satisfaction. Services and supports empower disabled mothers to increase their confidence, as well as their competence in parenting. They help them become competent parents and also enhance their children's development.

# Disabled Women and Motherhood Through the Lens of Foucault

Power is a predominant notion in Foucault's philosophical work. According to Foucault (1978; 1982), power is not simply the oppression of the powerless by the powerful; instead, power operates in strategic and diffuse ways in everyday relations between individuals within social groups. According to Foucault (1994), "power relations are rooted in the whole network of the social" (p. 345); therefore, power has to be examined as something that is not an objective possession but one that is created within social discourse. Foucault explains that knowledge generates power "by constituting people as subjects and then governing the subjects with the knowledge" (Ritzer, 2010, p. 615). Power spreads through the entire society and materialises into social realities which influence individuals' behaviours. Individuals may either affirm their identities or else resist the effects of power.

Foucault also sustains that power is exercised through discourse. Discourses play a fundamental role in society because they "construct social reality" (Tremain, 2017, p. 33). Discourses regulate how subjects are constructed; hence, rather than focusing solely on what discourses portray, Foucault encourages us to immerse ourselves into the various implications of these constructs (Allan, 1996). Disempowering discourses suppress and marginalise individuals, such as in the case of disabled women who are socially represented as passive recipients of help and not as women competent of nurturing (Frederick, 2017; Vaidya, 2015). Despite the fact that disabled women are generally perceived as non-compliant with societal norms, an increasing number are still opting to have children (Malouf et al., 2017). Thus, they are resisting the presumptions of what social statuses they may accomplish (Grue & Tafjord Laerum, 2002). Through their resistance to socially constructed discourses they are positioning themselves within other discourses, including the discourse of motherhood.

According to Foucault (1977), normalisation involves comparison, differentiation, and exclusion. While it is the norm for non-disabled women to become mothers and they frequently experience pressure to have children (Gould & Dodd, 2014), for disabled women motherhood is far from the obvious. Literature on this subject shows that oftentimes they face opposition to their pregnancy and are also pressured to terminate it and abort the foetus (Frederick, 2017; Streur et al., 2020; Walsh-Gallagher et al., 2012). More often than not, disabled women are considered as not good enough for mothering and unable to conform with the ideal standards of parenting (Gould & Dodd, 2014; Theodore et al., 2018). This process of normalising judgement generally gives rise to practices of disciplinary power which Foucault refers to as the panoptical gaze because of

its controlling capacity (Foucault, 1977). In fact, literature reports that disabled mothers experience greater surveillance than their non-disabled counterparts and they are more likely to lose permanent custody of their children (Aunos & Pacheco, 2020, Frederick, 2015; Gould & Dodd, 2014; Theodore et al., 2018).

Foucault (1978) also introduces the notion of biopower to explain that from one point of view individuals have become subjects to disciplines that are principally carried out by practices of surveillance and measurements to control, correct, and normalise deviations from standardised norms, while from another standpoint, biopower is also exerted at the level of the whole population, where individuals are governed by the knowledge-power process linked to normalisation within social networks (Tremain, 2005). Foucault (1978) refers to this as biopolitics, which functions by setting up standards and expectations. Tremain (2017) argues that disability conforms to both forms of biopower, where "a certain regime of power has produced impairment as both the prediscursive – that is, natural and universal – antecedent of culturally variant forms of disability and a problem for this regime of power to which the regime offers solutions" (p. 52). Moreover, biopower works by giving the impression of choice; however, choices are set within strict parameters which are convenient to the nation's desire to produce productive and efficient subjects. In fact, Tremain (2005) states that "the production of these seeming acts of choice (these limits on possible conducts) on the everyday level of the subject makes possible the consolidation of more hegemonic structures" (p. 8). Despite the great advancements for disabled people, including disabled women, in acquiring dignity, equality, as well as respect for diversity, more often than not, sexuality and parenthood are not offered as options to disabled persons. Disabled women are frequently exposed to forced contraception (McCarthy, 2009; Walmsley et al., 2016), forced sterilisation (Elliott, 2017; Patel, 2017), as well as pressure to terminate their pregnancy (Streur et al., 2020; Walsh-Gallagher et al., 2012). Therefore, within biopower-operated systems choice is merely a false impression.

#### Conclusion

The literature presented in this chapter shows that despite the fact that disabled women have the same desire and legitimate right to become mothers as their nondisabled counterparts, society still continues to underestimate their sexual and reproductive rights, as well as their parenting abilities. Socially constructed discourses often portray disabled women as unattractive and regards them as either non-sexual beings or else as hypersexual. They are also viewed as defective, worthless, dependent on others, and unable to assume family and care roles. Additionally, they are frequently perceived as unable to produce healthy babies and incur high risks of passing on their disability to their children. In light of this scenario, disabled women are generally considered as non-compliant with societal norms and unable to conform with the ideal standards of parenting. This process of normalising judgement often gives rise to disciplinary power, and therefore, disabled women frequently face opposition to becoming mothers both from relatives, as well as from medical professionals. Consequently, they are often forced to take contraception or else to terminate their pregnancy. On the other hand, women who challenge socially constructed discourses and become mothers are generally regarded as incompetent and unable to parent. They face higher parenting benchmarks than their non-disabled counterparts and they experience a lot of scrutiny and surveillance from those around them. They also have greater risks of

losing permanent custody of their children. Despite all this, disabled women do become mothers and position themselves within discourses of motherhood. With appropriate training and support disabled women have proven to be able to meet the required responsibilities and standards. Furthermore, motherhood oftentimes generates a sense of fulfilment, satisfaction, and happiness for most disabled women. This concluding summary has captured the main points within my literature review. What follows is the methodology chapter.

# Methodology

#### Introduction

Disabled women pursuing motherhood in a Maltese context are the protagonists of this research study. Their experiences and perception about disability and motherhood are fundamental aspects, hence, a methodology that empowers and gives them voice ought to be chosen. With this in mind, a qualitative approach using in-depth face-to-face semi-structured interviews was implemented to answer the following research questions:

- What are the experiences of disabled women pursuing motherhood?
- How do the experiences of disabled women impact their perception about disability and motherhood in a Maltese context?

This approach was also chosen because of the sensitive nature of the phenomenon under investigation, as well as because it provides the possibility to capture rich and subjective experiences from participants (Bryman, 2012). This design also enabled data gathering to be tailored to address the aims of this research study, which are to explore the experiences of disabled women in their reproductive lives while accentuating the need for more inclusive practices, as well as to analyse their perceptions about disability and motherhood in a Maltese context. Additionally, a number of emancipatory research principles was used in order to voice participants' insights of motherhood. According to Meekosha and Shuttleworth (2009), emancipation is a "cornerstone" (p. 48) of critical disability studies; therefore, this approach was adopted as a conceptual framework. Critical disability studies centralise disabled persons. Furthermore, their unique experiences generate the context for discussion (Meekosha & Shuttleworth, 2009).

concepts of power relations in regard to discourse, power-knowledge, normalisation, disciplinary-power, and biopower.

## **Choice of Conceptual Framework**

Critical disability studies focus on lived realities and consider the experiences of disabled persons pivotal in interpreting their positions in the world (Goodley, 2011). This methodology places disabled persons as experts in both their own past, as well as present; therefore, a substantial part of critical disability studies is to ensure that this field of study is not only about but also by disabled persons (Reaume, 2014). Additionally, this methodology centres the understanding of disability as a cultural, historical, and political experience, and analyses how society influences our perceptions of disability (Goodley, 2011). Hence, Foucault's work, which centres around power relations, sits very well within critical disability studies. For this reason, I considered this approach the most appropriate for my research study. In light of this, emergent themes will be critically examined through the lens of Foucault's concepts of power relations.

A rich Foucauldian analysis of disability scrutinizes beliefs and practices that surround disability (Tremain, 2005). According to Tremain (2015), impairment and disability are both products of power relations. Furthermore, Tremain (2008) states that a category of impairment has been created to legitimize governmental practices. Persons who do not fall within strictly governed norms are subject to disqualification and exclusion (Tremain, 2008), which Foucault refers to as "biopower" (Foucault, 1978, p. 143). According to Tremain (2008, p. 102), "biopower normalises people in order to make them governable". Both critical disability studies and a Foucauldian approach challenge attitudes that pathologize physical, intellectual, and sensory difference as needing

adjustment, and instead advocate for equality and reasonable accommodation in all aspects of disabled persons' lives (Goodley, 2011; Meekosha & Shuttleworth, 2009; Reaume, 2014). "Critical disability studies seek to change conventional notions of disabled persons as pitiable, tragic victims who should adjust to the world around them" (Reaume, 2014, p. 1248). Instead, this methodology seeks to position these persons as primary agents of societal changes.

Additionally, critical disability studies question discourses, interpret culture, and explore diversity (Meekosha & Shuttleworth, 2009). In fact, Goodley (2013) reports that "critical disability studies start with disability but never end with it" (p. 632). Critical disability studies immerse in the social model but also create opportunities for academics to explore other viewpoints regarding disability. According to Meekosha and Shuttleworth (2009), as well as Goodley (2011), critical disability studies adopt a Foucauldian approach of discourses, knowledge, and power structures that construct disability. Furthermore, my research study incorporates Foucault's (1997a) notion of critique which Foucault interprets "as an act of defiance, as a challenge, as a way of limiting these arts of governing and sizing them up, transforming them, of finding a way to escape from them" (p. 29). Hence, critique does not oppose power and its aim is not to overcome power relations, but instead, it is an exercise aimed to shift established power relations away from their domination and to adopt practices of freedom (Foucault, 1997b). Therefore, according to Foucault, critique relates to emancipation because it challenges certain forms of power with the intention to achieve fewer constraints, oppressions, and intimidations. Consequently, critique in itself is a specific form of power because it plays part in the

power relations that it wants to change. The effects of critique are very important because they are instrumental in generating societal changes (Foucault, 1997b).

#### **Emancipatory Disability Research**

According to Barnes and Sheldon (2007), research which is guided by an emancipatory approach is more likely to be of a qualitative nature as in the case of my research study. The reason behind this is because a qualitative approach provides participants with the opportunity to be in control of their responses and hence, have greater influence on the outline of the research study (Barnes & Sheldon, 2007). Emancipatory disability research aims to empower disabled persons because research is used as a tool to unravel disablement (Barnes & Sheldon, 2007). It seeks to explore and deconstruct conventional assumptions of disability, as well as to establish an effective dialogue between researchers and disabled persons (Barnes 2008; Barnes & Sheldon, 2007). Since research about disability and motherhood in Malta is quite limited, I decided to incorporate this approach within my research study because emancipatory disability research enables participants to voice their own positions, knowledge, and experiences of the phenomenon under investigation. However, it is highly important to acknowledge that I did not adopt a full emancipatory research approach, because participants were not involved throughout the whole process of this research study as dictated by Barnes (2008).

#### **Generation of Data**

Following the Faculty Research Ethics Committee's approval of my proposal, I approached the Commission for the Rights of Persons with Disability (CRPD) to act as a gatekeeper. The email to this gatekeeper is included in Appendix A. I also used social

media platforms in order to recruit participants. The blurbs for social media platforms in English and Maltese are included in Appendices B and C, respectively. Information letters were distributed by CRPD including an easy-read format for women with intellectual disability because, as reported by Callus (2017), accommodations are fundamental when conducting research within an emancipatory framework. The information letters are available in Appendices D, E, F, and G. Purposive sampling was adopted, and participation was open for women from various impairment groups who are aspiring or actively planning to be mothers, or are pregnant or already mothers. The age bracket was set for 18 years and over. Seven mothers who have different conditions including physical, intellectual, hearing, and visual impairment showed willingness to participate in this research study. In light of the available timeframe this was considered a reasonable sample size, because a larger sample might have prevented in-depth engagement with each participant. Additionally, a larger sample would have generated a vast amount of data, and rich analysis might have been difficult to produce. According to Smith and Osborne (2008), a comprehensive analysis of each case can only be realistically obtained if the sample size is small.

One-time interviews were conducted at a time and place chosen by participants, so that they were able to select a setting in which they felt most comfortable. Moreover, upon participants' request, some of the interviews were held online using Zoom as a platform. I explained the nature of my research study and their involvement in it and participants signed the consent forms. An easy-read format was made available for those who needed it. Interviews lasted approximately 60 minutes and, upon consent, were audio-recorded. On the other hand, online interviews were recorded using the Zoom

audio-recording function. The consent forms are included in Appendices H, I, J, and K. I formulated a number of open-ended questions on the phenomenon under investigation; however, as reported by Beresford (1997), interviews to a certain degree were led by the participants, and discussions emerged as a result of the interaction between participants and me. Moreover, as indicated by both Denscombe (2010) and Schutt (2009), the content, as well as the order of the questions varied across participants according to the responses they provided. Initially, participants responded to a set of demographic questions which were followed by two general questions. These were planned with the intention to obtain rich responses (Schutt, 2009). The last two questions were created in order to make space for reflection, as well as to give participants the opportunity to put forward recommendations that would support disabled women pursuing motherhood within a Maltese context. The interview guides are available in Appendices L and M. Recorded data was transcribed verbatim after each interview. Transcripts were passed on to participants to read and approve before they were used. This was done with the intention to give voice to disabled mothers, as well as to provide them with more power and control over the research study.

## **Data Analysis**

Thematic analysis was used to analyse data using the six steps identified by Braun and Clarke (2006) as guidelines which are familiarisation with data, coding, searching for themes, reviewing themes, defining and naming themes, and writing up. Transcripts were individually examined. In order to become familiar with their content, as well as to understand them both analytically and critically, I read the transcripts multiple times. Each reading generated new insights. Afterwards, I identified and highlighted significant parts

of data that were relevant to my research study, keeping an eye open for similarities, contradictions, overlaps, differences, and amplifications so that a broader commentary could be produced. Once this step was completed, I wrote down emergent themes. This process was repeated for each transcript. All themes from all transcripts were gathered and I searched for connections between them. Some themes complemented each other while others stood out; therefore, these were tackled separately. With this information in hand, I was able to prioritize and create a final table of themes. A sample of this process is available in Appendix N. Ultimately, as suggested by Braun and Clarke (2012), themes were reviewed against transcripts in order to make certain that they were consistent and confirmative with participants' feedback. Themes were chosen on the basis of their frequency in transcripts, as well as their richness (Smith et al., 2009). Importance was given to logic order between chosen themes (Smith & Osborne, 2008). Moreover, rich verbatim extracts from transcripts were highlighted in order to be used to support findings, thus warranting credibility and trustworthiness (Morse et al., 2002).

## **Ethical Considerations**

Approval from the Faculty Research Ethics Committee was requested. Once obtained, information letters, consent forms, and easy-read versions were distributed. The information letter contained details about my identity, the nature of the study, the objective behind it, as well as the undertaken procedures. Participants' role was explained, and participants were offered the possibility to clarify any concerns.

Participants were also informed that involvement in the research study was voluntarily, and they were able to withdraw at any time without justifications. They were also informed that they would be audio-recorded. Zoom audio recordings were protected by

end-to-end encryption and recordings were stored on the my computer and not on the cloud. Participants were assigned a pseudonym to protect their identity; however, they were notified that considering the size of the context the research has been done in, they could be identified. The made-up names that link the data to the identity were stored securely and separately from the data, in an encrypted file on my password-protected computer, and only I had access to this information. Soft copies of transcripts were encrypted. Gathered data has only been used for research purposes and will be deleted upon one year of completion of the research study, in June 2024.

Due to the nature of the research topic participants shared sensitive experiences. This might elicit emotional distress; hence, particular attention was given to minimise psychological risk as much as possible. This was done by offering assurances of privacy, creating an environment where participants felt comfortable sharing their experiences, using judgement-free language and facial expressions, and being on the lookout for cues that might indicate distress. Participants were also provided with referral information for access to counselling should the need arise. Information about Richmond Foundation, Support Line 179, and kellimni.com was provided. The provided information regarding support services is available in Appendices O and P. Additionally, society may discriminate against disabled women, putting them in a position of vulnerability. Oftentimes, society individualises disability. For long, disability has been recognised as arising from the individual difference or impairment, hence victimising disabled persons, in particular disabled women, who are subject to multiple discrimination and are recurrently hindered from enjoying their fundamental rights. However, disability goes beyond the experience of individual persons. Instead, it is society that disables persons, including disabled women,

by forcing on them barriers that are over and above their impairment. This approach to the vulnerability of disabled persons is highlighted in the UNCRPD, which defines disability as resulting "from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on equal basis with others" (UNCRPD, 2006, p. 1). In light of this, during the undertaken procedures vulnerability was protected by avoiding the use of stigmatising labels, avoiding undue pressure to talk about experiences which participants have shown reluctance to share, adapting interviews to the needs of participants, including the need for short breaks, and finding meaningful ways to honour the participants for finding the time and willingness to share their experiences. Additionally, a small toiletry gift was given to participants as a token of appreciation.

#### **Strengths and Limitations**

As stated by Denscombe (2010), a significant strength of qualitative research is that collected data was rich and in-depth, hence, the investigated topic was discovered in detail. Face-to-face, semi-structured interviews allowed flexibility so, at times when useful insights were not captured, questions were tweaked to improve responses. This approach also allowed me to be more speculative and provided the ability to probe for underlying thoughts. During face-to-face interviews I was able to observe participants' body language and facial expressions, which further enriched the content of data. Open-ended questions also offered participants the opportunity to raise issues that matter most for them (Denscombe, 2010). Additionally, a notable strength of purposive sampling is that participants were selected because of their uniqueness within a given population (Schutt, 2009). Therefore, participants were knowledgeable of the phenomenon under

investigation. While determining the sample size I kept in mind the concept of saturation, which Hennink and Kaiser (2022) define as an indicator that a particular sample is adequate for the phenomenon under investigation. During the data collection process I came to a point where no additional insights were identified and collected data was of a repetitive nature, thus indicating that my sample was sufficient for the phenomenon studied. According to Francis et al. (2010), when saturation is reached, data collected is indepth and diverse, so it warrants validity. However, conclusions still have to be drawn with cautiousness, because no evidence-based details can be provided on how saturation was determined (Hennink & Kaiser, 2022). Participants were also given a copy of their transcript to read and approve before this was used, hence, they were provided with more power and control over the study. This study also adds to a very limited body of research on this topic in this particular context.

Additionally, according to Goodley et al. (2019), a remarkable strength of critical disability studies is that the researcher adapts an attitude of tolerance to contrasting and conflicting viewpoints and perspectives. However, throughout the analysis and reporting of findings I remained mindful not to reproduce separation and prejudice (Goodley et al., 2019). The fact that I am a woman as well as a mother gave me an insider position.

However, I am not a disabled woman; therefore, I was not able to have full understanding of the participants' perspectives. Additionally, several limitations are associated with the chosen data collection method, including the interviewer effect. Participants might have shaped their responses on what they perceived was expected from them, rather than sharing their own perceptions. Another limitation is inhibition, where participants might have refrained from disclosing relevant data due to my presence (Denscombe, 2010).

Moreover, being a non-disabled researcher with lack of experience in conducting research with disabled persons presented challenges, especially in maintaining the connection between self-advocacy and inclusive research (Callus, 2019). Due consideration was given to the elimination of potential bias both during the interviews, as well as in the analysis of data. Neutrality was maintained as not to influence responses during the interviews, and data was analysed with an unbiased mind.

## Conclusion

This chapter has thoroughly captured the choice of the conceptual framework, the research approach that was adopted, and the research tool that was used to generate data. It has also described how data was analysed, the ethical considerations, as well as the strengths and limitations. Compensations that have been made to address these limitations were also highlighted. The chapter that follows will present the findings.

# **Findings**

#### Introduction

Following an in-depth description of the methodology used in this research study, this chapter aims to bring forward the findings. This research journey unravels the experiences and perceptions of seven mothers in a Maltese context. These mothers have different conditions, including physical, intellectual, hearing, and visual impairment. Table 1 below provides demographic information pertaining to these mothers. Rather than detailing their specific disability, I opted to list the disability category, aiming to enhance their anonymity.

Table 1

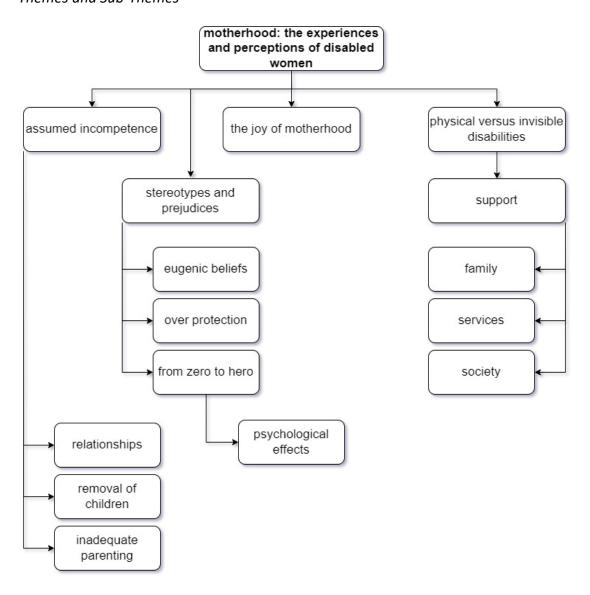
Demographic Data

Fictitious Name	Age	Disability Category	Number Their		
			Status	of Children	Ages
Beth	35	physical	separated	2	4, 14
Sue	41	intellectual	single	2	4, 9
Ann	41	physical & psycho-social	married	2	10,
					15
Emma	42	sensory	married	2 (twins)	23
Kate	36	physical	annulled	1	8
Amy	37	sensory	married	1	4

Generated data from face-to-face interviews was analysed and themes and sub-themes were identified. The key themes that emerged are the joy of motherhood, assumed incompetence, stereotypes and prejudices, as well as physical versus invisible disabilities. These themes will be thoroughly explored in this chapter and substantiated by participants' quotations. Figure 1 below provides a clear presentation of these themes and sub-themes.

Figure 1

Themes and Sub-Themes



## The Joy of Motherhood

Almost all of the participants described motherhood with unabashed enthusiasm and affirmed that being a mother is one of life's most gratifying and rewarding experiences. Kate stated, "It is a great satisfaction for me to be a mother." Meanwhile, Amy added, "I live for my daughter. Being a mother is something immensely beautiful." Emma went a step further and proudly described her twin daughters as her "legacy." Most of the mothers, including Amy, confirmed that they would not imagine their life in any other way than being a mother. Amy stated, "I cannot imagine my life without my daughter." Furthermore, most mothers referred to the powerful emotion of maternal love. Amy described this emotion by stating, "The greatest love is that of a mother for her daughter." Beth, who is separated and had her eldest child taken away from her, very emotionally and with tears streaming down her cheeks also mentioned this powerful feeling. She explained that even though she is apart from her daughter, she still loves her with her whole heart:

They [her ex-husband and his family] turned my daughter against me. ... She does not want to see me. She does not text me. I phone her, she does not answer. My ex-husband does not inform me of what is happening. ... Still, she remains my daughter. I will always love her throughout my whole life. She is a part of me. (Beth)

On the other hand, Ann, who suffers from acute depression, confirmed that her two children are her reason to carry on. She confessed,

I want to live because of my kids. There are so many times I had dark thoughts of saying I cannot live. I need to end my life. But seeing them, hearing them ... No, I cannot do this to them. (Ann)

Sue's definition of motherhood took a different path. Like the rest of the participants, Sue explained that her love for her children is unconditional and endless and

both her children are very precious to her. However, her second birth is linked with feelings of resentment because five days after she gave birth her husband left her for another woman. During her second pregnancy Sue experienced immense fatigue which resulted in lack of attention towards her husband. Sue believes that this may have been a potential reason for her broken marriage. She stated, "If I did not have the second child maybe now we are still married." This experience has caused her a lot of mixed feelings about motherhood. Sue also mentioned the hardships that she had to go through as a single mother, some of which she is still experiencing. Five days after giving birth she was left alone with a newborn and another child to take care of. On top of this, Sue had to go through the separation process, for which she had to increase her hours at work in order to be able to afford the lawyers. At the same time she had to juggle motherhood. Sue stated, "Everything was more difficult because I was a mother. Motherhood for me is linked with the trauma of separation, so I cannot say that motherhood is always a bed of roses."

Motherhood also comes with responsibility. Beth mentioned the lack of sleep, as well as the constant worrying which come along with motherhood. Additionally, Kate explained that during pregnancy there were instances which were far more stressful for her than for someone who does not have an impairment. Kate has mobility difficulties and uses crutches, so she confessed that she is more prone to experiencing stumbles and falls. Consequently, during pregnancy she had to be extra careful not to fall or trip because this could endanger her baby. Kate explained that this situation added new stresses to her life. Similarly, Emma, who has a visual impairment, confessed that unlike other mothers who do not have an impairment, she never had the opportunity to relax

during family outings. She always felt anxious and had to be alert all the time. She explained, "I do not see, so I hear, and I listen to make sure that my children are safe."

Consequently, throughout the years Emma has built so much tension in her body that she suffers from muscular pain. Her muscles are so stiff that even though she is not anxious anymore, the damage has been done and the pain remains.

However, regardless of the responsibility and everyday challenges, most participants explained with satisfaction how they have adjusted to motherhood. They provided very detailed narrations of how they effectively look after their children in their own way. This is affirmed by Kate, who stated, "I try to give my daughter the same life just like the rest of the mothers. Everything the same. Maybe with a difference but in one way or another we manage to do everything" (referring to her daughter and herself). Kim, who has a physical impairment that affects her mobility, said, "I used to sit down on the floor to breastfeed. I also used to climb down the stairs on my bottom while holding the baby in order to avoid falling or tripping over." Similarly, Emma who has a visual impairment explained step by step how she used to prepare the feed for her children. She used to mark the ounces on the bottle with dark, thick marker. She also used to measure the powdered infant formula with a scoop and level it with the container's lid. During this process Emma relied heavily on her senses such as the sense of touch to determine the right temperature of the feed. Moreover, Sue, who has ADHD, stated, "Every morning I wake up an hour early to take my medication because it kicks in while I am doing the lunches. Still, I mean it is not a magic bullet." According to Sue, the effectiveness of her medication is at its best an hour after intake. Medication improves her focus and concentration ability. So, in order to ensure that her children are well prepared for

school, "lunches, bottles, uniform, brushing teeth, going to the bathroom", she makes certain to take her medication well before her children wake up. Most participants confirmed that they have embraced their impairment. They have adjusted to motherhood so well that by time they started making fun and joking about their exceptional life experiences. Emma stated that she also produces sketches and writes comedy based on the situations that she encounters as a mother with visual impairment.

All in all, motherhood was defined by participants as a pleasing experience, although Sue added that her second birth is linked to feelings of resentment. The powerful emotion of maternal love was a common factor among all interviewed mothers. In fact, motherhood for Ann is her reason to carry on with life despite all odds.

Motherhood also comes along with responsibility, but all of the participants have learnt to embrace their impairment and adjust to this new role in life, so much so that some of them take their daily challenges with a pinch of salt and make fun of them.

#### **Assumed Incompetence**

Reference to assumed parental incompetence was a recurring theme among participants and most of them explained that disabled women are prone to criticism when it comes to parenthood. Kate stated, "Very often we are criticized and our parenting abilities are constantly being questioned and doubted." Beth explained that there is a societal belief that disabled women are unable to engage in a relationship and set up a family of their own. Their impairment is often placed before their womanhood. Beth elaborated further and stated that parents of young disabled women tend to consider them as vulnerable, hence, as inappropriate to engage in a committed relationship. Beth added that if, on the other hand, these young women do get involved

in a relationship, then their parents are more likely to think that their partners may cheat, take advantage of them, or treat them badly.

Beth stated, "I met people who think that those who have cerebral palsy like me cannot be competent mothers because they are unable to take care of their children."

During her narration Beth appeared very emotional because her parenting abilities had been questioned even by her in-laws. When her mother-in-law found out that she was pregnant, instead of congratulating her she bluntly asked her, "How are you going to take care of the baby?" Furthermore, her mother-in-law was very influential on her son who was at that time Beth's husband. This ordeal continued even when the baby was born.

Beth's ex-husband often accused her of not being a good mother despite the fact that she was doing her utmost and putting all her attention on the baby. Her husband's false accusations were so embedded in Beth's mind that there were instances in her life where she experienced internalised parental incompetence. Assumed incompetence from immediate family members was also disclosed by Emma who said,

Our parenting skills are seriously doubted all the time. Our parents think that we will be a burden on the family, and they tell us, "I already take care of you. Now there will be this baby as well to look after." (Emma)

Kate went a step further and stated that misconceptions and comments about parental incompetence by those around her negatively impact her wellbeing. By time Kate became more resilient, and as much as possible she tries to ignore negative comments; however, she confessed that it may not be as easy as it seems. Additionally, Kate as well as Emma claimed that disabled women have to constantly prove their parenting abilities. They both explained that benchmarks are higher for disabled mothers. Kate stated,

We have to do an extra effort because we have to show the world that we can do it (referring to disabled mothers). For instance, if I am tired, still I have to push myself further and carry on. Unlike other mothers, if I take my time and rest I will be judged as irresponsible and unable to meet desired expectations. (Kate)

Assumed incompetence about the parenting abilities of disabled women may give rise to an increased risk of removal of their children. This was confirmed by Beth who stated, "They [her ex-husband and in-laws] took my daughter away from me. I was still very young at that time, and I believe that they did this because of my disability." Sue had a similar experience. Her son's educators keep blaming her about taking her son late to school. Sue confessed that no matter how hard she tries she does not manage to get to school on time because of her ADHD. The assistant head always remarks on her being late in front of the security guard at the school entrance, as well as in front of the other parents. With a heavy heart, Sue stated,

It is so shaming. I am late because I have a disability that affects my ability to manage time and get places on time and she [the assistant head] just makes me feel like shit every single time ... I do not know how many times I walk away from school crying. (Sue)

Sue explained that even the class teacher has a very poor perception of her, as well as a negative attitude towards her. This topic of being late was also brought up by both the teacher and the assistant head during a meeting in which her son's individual educational plan was being discussed. Sue reported how her ex-husband was all ears. In fact, right after the meeting Sue received a phone call from him demanding custody of both their children because he believed that she was being incompetent as a mother. With a sense of disappointment Sue stated,

Come on. They are fed, they have clean clothes, they have a decent lunch, I put a roof over their head, but because I cannot show up on time, oh my God, I am a

terrible mother. ... One comment from the teacher could have cost me my kids. (Sue)

A similar situation was also narrated by Kate. When she started the separation process, she was terrified about the potential risk that her daughter could be taken away from her because of her impairment. She explained, "Obviously, we [disabled mothers] are used to the fact that we are judged as incompetent mothers because of our impairment." Kate explained that sometimes disabled mothers experience removal of their children because of assumed incompetence. However, from the very beginning of the separation process she was adamant that if anyone tried to separate her from her daughter she would retaliate with all her might.

Emma also confessed this reality. With a gloomy expression she explained how difficult it was for her to keep up with the expectations of her daughters' educators. Homework was a nightmare for her children and even more for herself because it took over their life. Her children used to spend hours on end to get it done. Emma who has a visual impairment explained that she was unable to read their diary and follow what was expected of them. If the diary had been presented in an electronic format, her life and that of her family would have been much easier but she faced a lot of resistance from educators to provide this accommodation. Furthermore, Emma could not help her children with their reading and writing exercises, so everything took longer to be completed. Emma confessed that sometimes her children started their homework at eight or nine o'clock when her husband returned from a day's work because she was unable to help them out. Homework was never-ending and used to stretch also on Saturdays and Sundays. To add insult to injury, educators filed a report for negligence and unexpected

home visits from social workers started taking place. Educators insisted that the problem was within the family setting rather than in the education system which was being insensitive towards the individual needs of this family. With a feeling of sadness Emma said,

This experience was devastating for me. I feel like crying just thinking about it. They [the educators] made me feel like having children was a bad choice for me because I was unable to help them with their homework. Homework caused so much stress in our family. It ruled out our happiness. (Emma)

Several years have passed by and this negative experience is still so vivid for Emma that it is impeding her from adopting a child. It is not possible for Emma and her husband to have another biological child because this would be detrimental for Emma's health, so adoption might be an alternative. Her husband is really keen on this, yet coping with the expectations of schooling is terrifying for Emma and is holding her back. Sorrowfully, Emma stated that she feels guilty and selfish about the way she is reacting but she still does not have the courage to embark on this new experience.

According to most of the participants, there is a societal belief that disabled women are unable to engage in a committed relationship and have children. Their parenting abilities are constantly undervalued by those around them, and their impairment is often placed before their womanhood. Consequently, disabled mothers constantly have to prove their parenting abilities. Regrettably, assumed incompetence increases the risk for disabled mothers to experience the removal of their children. This harsh reality was experienced by Beth, Sue, Kate, as well as Emma.

#### **Stereotypes and Prejudices**

Oftentimes, disabled women may be an easy target for stereotypes and prejudices. In fact, Kate referred to the double discrimination that is often experienced by disabled women. She stated, "Just by the fact of being a woman, you are already exposed to stigma. Let alone having a disability and having children at the same time." A recurring theme that was mentioned by participants revolves around eugenic beliefs that are still present in society. Some of the interviewed mothers explained that there is a strong societal belief that disabled women cannot produce healthy offspring and could pass on their disability to their children. Emma said, "There is a myth as well as fear that if a woman is disabled, then her children will genetically and hereditary have the same condition." Beth added to this by explaining that this fear is mostly experienced by the family members of a disabled person. These will assume that their relative's offspring will have the same condition. According to Kate, this stereotype is so engrained in Maltese society that even she, who is very aware that her condition is not hereditary, still felt extremely anxious throughout the pregnancy about having a child with cerebral palsy just like her. Kate stated,

If you have a condition, even though you know that it is not hereditary still you expect it to happen. ... because I do not know any other way. ... Even though cerebral palsy is not hereditary, having a healthy baby for me was a miracle. The moment they [the midwife and her assistants] placed my daughter on me I could not stop crying. All the accumulated anxiety was finally released. (Kate)

Similarly, Amy said that one of her greatest fears while she was pregnant was that her daughter will be hearing impaired like her.

Some participants also referred to overprotection. Beth indicated that oftentimes young disabled women experience overprotection by their parents who try to safeguard them by keeping them at home. They forbid their children from going out and socialising

with others of the same age. Emma confirmed this phenomenon and stated that her mother was extremely overprotective towards her. She claimed, "I did not have the voice ... I could never choose what I want to do." Emma also acknowledged that throughout her pregnancy she felt helpless. She was only 19 years old going on 20 and still lived with her mother. Emma said that this was a really difficult period in her life because both her boyfriend who later became her husband and she had no status. Emma explained that she was treated by her mother as a dependent child. Furthermore, her mother always insisted on attending gynae appointments with her even though her boyfriend was loyal and always present. Emma further recalled how only one person was allowed with the expectant mother in the delivery room and that to her greatest disbelief her mother insisted that she was the one to accompany her. Consequently, her boyfriend retaliated and there were several clashes between her mother and her boyfriend. This situation has caused a lot of distress for Emma who claimed, "I was torn between two people: my mother and my husband. This was heart-breaking." Emma elaborated further on overprotection and acknowledged that even when she got older and had her own family, her mother used to check on her by making unnecessary phone calls, especially when she was out and about. This situation not only irritated Emma but used to expose her to unsafe situations. Emma explained that when she walks around, especially when she is outdoors, it is very dangerous for her to navigate in the streets and at the same time focus on a phone conversation. This scenario increases the risk of bumping against obstacles such as the side mirrors of parked lorries which happen to come to face level for pedestrians. By time, Emma managed to become assertive and had the courage to stop answering phone calls while she is outdoors.

Another aspect that has emerged from the data analysis highlights the two extremes experienced by disabled mothers: either being considered as failures or as "superheroes." Emma actually experienced both sides of the coin and stated,

Some see me as a superhero because even though I do not see yet I manage to take care of my children. People with this belief tend to be very inquisitive and ask questions such as, "Do you clean? Do you cook?" They actually need to hear the answer in order to be convinced that disabled mothers can be competent mothers. These people consider my adaptations as magical powers. (Emma)

This phenomenon was also mentioned by Beth who explained that disabled mothers who lead the same life as any other mother are looked upon with astonishment. Beth added that oftentimes she encounters comments such as, "Oh God how well she copes!" or "She manages her children just like someone without a disability." According to Beth these statements mirror the misconception that it is extraordinary for disabled mothers to cope with the demands of motherhood.

On the other hand, Emma indicated that there are others who belittle her. In fact, heavy-hearted, she recalled quite a few humiliating instances which she experienced while raising her children. Once, a tutor who was helping her daughters with their academic work at home told them, "You must be ashamed of yourselves. You have a blind mother, and you behave this way." Emma explained that she felt perplexed while hearing this but she managed to pluck up her courage and respond, "Do you mind not to refer to me like this in front of my children?" Emma added that similar comments were also made by the social worker during home visits. To make things worse the social worker had also created a timetable which her daughters had to follow rigorously on a daily basis. This timetable was compiled without consulting them, hence, it turned out not to be feasible. It did not cater for their needs and moreover it did not fit with the family's lifestyle. Emma

explained that the social worker had placed her family in a stereotype ideal, and instead of providing support she caused more stress on the entire family.

Regrettably, stereotypes and prejudices negatively affect the emotional and psychological wellbeing of disabled mothers. Most of the participants affirmed that motherhood is not a piece of cake because even the impairment itself can cause distress, let alone if this is topped with false beliefs from those around them. Kate stated that when she was pregnant she had a planned Caesarean section and she used to worry extensively about the epidural. She did not want to be treated like a guinea pig and be the first woman with cerebral palsy to be administered this injection. Consequently, this instability caused Kate a lot of anxiety which kicked in again when her daughter started walking. Kate was perfectly aware that she could not chase her daughter because of her mobility limitations, and this caused a lot of uneasiness. Kate has found the support of a psychotherapist very useful to cope with this daily life stressor. On the other hand, Ann constantly experiences a lot of guilt feelings. She believes that her degenerative condition is causing a lot of pressure on her children who have to clean, cook, and wash up. Ann admitted.

Everything revolves around my guilt, and this has caused a lot of mental depression. ... I just watch the kids and I feel this is not their life. ... Their life has to be happier, so I think guilt and depression are the worst. (Ann)

Guilt feelings were also experienced by Emma who stated that at times she believed that she was placing a lot of additional responsibilities on her daughters because of her visual impairment. Emma explained that she used to get exceptionally angry at them if they left things lying around on the floor.

Some participants also associated psychological distress with removal of children. Beth referred to the removal of her daughter as a "trauma", which was also accompanied by immense fear and great difficulty to trust those around her. Beth used to doubt everyone, even her own mother. She was constantly extremely cautious because she was terrified that she will lose her son as well. This situation brought along various hardships for Beth because she used to refuse any kind of help. With the help of her supportive partner and father of her son she managed to overcome fear and mistrust. However, she admitted that recalling this dark episode in her life still triggers emotional discomfort.

Stereotypes and prejudices portray disabled women as unable to embark on motherhood and set up a family of their own. There is a strong societal belief that disabled women cannot produce healthy offspring and could pass on their disability to their children. Oftentimes, young disabled women also experience overprotection from their parents who deny them socialization with peers of the same age in an attempt to curb their possibilities of building meaningful relationships despite their intention to safeguard them from any possible harm. Overprotection from parents may also stretch for years and continue even when disabled women become parents themselves as in the case of Emma. According to interviewed participants disabled mothers are considered either "superheroes" and in possession of "magical powers" or else failures. These scenarios may negatively influence the emotional and psychological wellbeing of disabled mothers. In fact, interviewed participants acknowledged that quite often they experience distress while coping with the daily life stressors caused either by their impairment, by the unfair and untrue societal beliefs, and by the (potential) removal of their children.

#### **Physical Versus Invisible Disabilities**

The majority of interviewed mothers, irrespective of having a physical or an invisible disability, acknowledged that they receive most support from immediate family members, as well as friends. Kim stated, "My husband helps me continuously. I am blessed to have him in my life. I also receive a lot of help from relatives." Kate added, "I receive most support from family and friends." Meanwhile, Ann admitted,

I have received so much help from my neighbours and from my Maltese friends. ... They would just walk in and wash up the dishes. Like when the children are at school, they come and clean the kitchen, wash the dishes ... Some would come and sweep the house ... Some would bring food. Some bring soups. (Ann)

On the other hand, Emma highlighted a different type of support and indicated that she has received a lot of encouragement from a prayer group that she used to attend together with her husband.

Additionally, several interviewed mothers mentioned the support received from various entities. Emma mentioned the community hours that were offered to her by a post-secondary educational institution. Students attending this setting used to voluntarily help her daughters with their homework in their own home setting. Emma relied heavily on this support because her visual impairment impeded her from helping her children with their academic work. Another mentioned entity was Agenzija Sapport, which is a national agency that provides services to improve the quality of life of disabled persons. Kate referred to the support provided by a helper which she has obtained through the intervention of this agency. This helper assists Kate at home with daily chores that she cannot complete on her own such as washing the floor. This agency has also helped Ann, who has a degenerative condition, to get a car which is more suitable for her needs. She

also got help with the registration for the vehicle road licence exemption scheme, as well as for the tax exemption scheme. In the meantime, Kim mentioned the Blue Badge service which is also provided with the assistance of the above-mentioned agency. This service allows holders to park their vehicles in reserved parking bays. Kim, who has mobility limitations, stated that this service is crucial for her. However, since her limitation is only apparent when she walks, she said that oftentimes she encounters lack of empathy from the general public. Additionally, Kim has to continuously justify her validation for this service – something which really frustrates her. Kim narrated several experiences which substantiate this unfair reality, including an episode which occurred while she was parking her car in the blue bay of a supermarket carpark. A man whom she described as arrogant, shouted at her, "Cannot you see! That space is for the disabled!" Kim responded, "So it means that I have to go round with a label on my forehead indicating that I am disabled?" Meanwhile, she raised her skirt and exposed her impaired leg. The man ended up speechless. Kim explained that the public is still not knowledgeable enough about invisible disabilities. According to her, when someone is good-looking and dressed up, instinctively others assume that it is impossible that this person has an impairment.

Ann has also experienced similar circumstances to those narrated by Kim. At times she was even inspected by local wardens who approached her to issue a parking ticket.

Ann described these incidents as devastating and commented,

You cannot judge persons by their looks. You have no idea what they are going through. I do not walk around saying that I have a disabled spine or something like that. Do not judge a book by its cover. (Ann)

This phenomenon was also confirmed by Amy who has a hearing impairment. She admitted that she encounters people who quite bluntly tell her, "All excuses. You just

choose what you want to hear and ignore the rest." On these instances Amy has to explain with great distress that she truly has a hearing impairment and that she is not fishing around for excuses. Similarly, Sue, who has autism and ADHD which are both invisible disabilities, explained that when she is shopping at the supermarket she has to wear ear plugs because she finds it extremely difficult to tolerate the noise of the ongoing music in the background. This is due to her sensory issues. Consequently, Sue stated that several people stare at her. Furthermore, she receives countless awkward looks from those who happen to walk past her. Contrasting to the experiences mentioned by Kim, Ann, Amy, and Sue, both Kate and Beth, who have visible disabilities, confirmed that help by people around them, sometimes even strangers, is often offered to them instantly and without requesting it. Beth confirmed this phenomenon and said that when she happened to be at the park with her son other parents used to help her lift him up and place him on the swing when they realised that she is unable to use both hands. Even when she used the public bus she always found immediate help with closing her daughter's pushchair and getting it on board. Beth explained that at that time low-floor buses were unavailable, instead buses used to have steps, thus presenting her with more challenges.

Participants also referred to lack of empathy from various medical professionals. Sue stated that it is irrelevant for her to disclose her condition with medical professionals, because even if she tells them that she has autism they still do not know how to support her or what accommodations would improve her experience in hospital. Ann, who has acute depression, has experienced similar circumstances. She admitted that she has heard nurses say, "What? She is on so many pills! A whole list of antidepressants." With disappointment Ann indicated,

I feel bad. Should I be on it [her medication]? But then, I cannot be off it because it is too much on the mind. I mean, a nurse is supposed to help you and not berate you like that. This affects my guilt feelings ... I think nurses should be more empathetic. (Ann)

In a dreadful tone of voice Ann narrated another experience where a particular doctor suggested that she could be used as an experimental case. Ann had the courage to answer back and reply that she was not an experiment but a patient. Contrastingly, Kate, who has cerebral palsy which is a visible disability, acknowledged that medical professionals were always understanding and responsive to her individual needs.

Lack of empathy towards individuals who have invisible disabilities was also identified among educational professionals. Even though Sue has disclosed her condition to educators as well as administrators, they still make no accommodations which can make her life as a mother a little bit easier. Instead, they continue to shame her in front of the other parents, thus disseminating the message that disabled mothers are incompetent. Furthermore, Sue explained that educators as well as school administrators do not listen to her and also dismiss what she says. Sue said, "They only talk about what their perceptions of disabilities are. They just shut me down." Additionally, Sue added that society in general and not just educators should be more empathetic. She acknowledged,

People on the outside, they do not see how hard it is for me as a mother ... my colleagues do not understand how hard it is for me to run my life and how hard it is for me to mother my kids ... The only people who understand what it is like are the other people like me. The other mums with ADHD. (Sue)

Sue attends an ADHD support group. According to her, living with ADHD can be isolating at times and going to a support group is the right place to meet people who are dealing with the same challenges. Moreover, sharing coping strategies can be supportive, as well as motivating. Sue also elaborated further on the lack of empathy from colleagues, and

explained that one fine day the assistant director decided to change the layout of their office even though he was aware that two employees including herself have autism. Sue stated that sudden, unexplained changes disturb her a lot and negatively impact her overall performance. She said that she needs time to adapt to change. To sum up, Sue, as well as Emma, emphasized that society should focus more on providing services and adaptations that cater for the needs of disabled persons, such as the provision of more community services and the availability of parentcraft courses tailored for disabled mothers and their partners. According to Emma these courses empower disabled mothers.

Almost all the interviewed mothers admitted that they receive most support from immediate family members and friends. Ann also referred to the support offered by her neighbours. On the other hand, Emma mentioned a different type of support and elaborated on the encouragement she used to receive from attending a prayer group. Additionally, Emma, Kate, Kim, and Ann referred to the support provided by various entities, namely community hours offered by an educational entity and Agenzija Sapport. Meanwhile, several participants, including Kim, acknowledged that oftentimes the public highly lacks knowledge about invisible disabilities. This is reflected in the unique experiences that she openly narrated. Several times both Kim and Ann were judged and criticized for making use of the blue parking bays and they had to repeatedly justify their validation for this accommodation. Similar experiences were also narrated by Ann, where her hearing impairment was not acknowledged. Lack of empathy from the general public, as well as from medical professionals and educators, were common themes that emerged in this research study. Sue also added that most often her perceptions are ignored.

Contrastingly, both Beth and Kate, who have physical disabilities, confirmed that those around them, even strangers, are mostly helpful. Kate also affirmed that medical professionals are sensitive and responsive to her individual needs. To sum up, both Sue and Emma pointed out that society should focus more on providing services and adaptations.

#### Conclusion

The unique experiences of seven disabled mothers and their perception about disability and motherhood in a Maltese context were presented in this chapter. Individual experiences and perceptions were categorized under four themes: the joy of motherhood, assumed incompetence, stereotypes and prejudices, and physical versus invisible disabilities. An in-depth discussion of these findings will be presented in the chapter that follows.

### **Discussion**

#### Introduction

This chapter will discuss the findings on the lived experiences of disabled women pursuing motherhood in a Maltese context and their perceptions about disability and motherhood. A critical disability analysis within a Foucauldian framework will be adopted. In the first section discussion will revolve around disabling discourses, ableist assumptions, and normalisation. This will be followed by a discussion on the medical gaze, power-knowledge, and eugenics. Discussion in the third section will be based on the panopticon and disciplinary-power, which will be followed by resistance and the power of motherhood in the last section of this chapter.

## Disabling Discourses, Ableist Assumptions and Normalisation

As clearly outlined in the findings of this research study and also as presented in the literature review, an undercurrent of ableism prevails in the arena of disability, sexuality, and motherhood both locally and remotely (Azzopardi-Lane & Callus, 2016; Daniels, 2019; Debattista, 2015; Frohmader & Ortoleva, 2012). The ideology of motherhood rules out disabled women because more often than not they are considered as nonconforming with the ideal standards of nurturing. Disabling discourses are many times directed towards disability, sexuality, and motherhood. Discourses are systems of thought and knowledge that construct our experience of the world. They are a form of control of how the world is perceived; hence, discourses act as a window into power (Foucault, 1969). According to Tremain (2017), discourses "construct social reality" (p. 33). From the findings of this research study, I can argue that the experiences of disabled mothers are generally shaped by the cultural and social discourses that define disability

and motherhood rather than by the impairment itself. Disabling discourses about disability, sexuality, and motherhood suppress and marginalise disabled women. Ableist assumptions stemming from internalised traditional views of disability and motherhood portray disabled women as non-sexual, in need of care, dependent on others, and unable to assume family and care roles (Vaidya, 2015; Wolowicz-Ruszkowska, 2016). Findings in this research study are in accordance with this. Beth elaborated on disabled women being considered non-sexual, while Emma mentioned the assumption of dependency on others. Meanwhile, Beth, Emma, Kate, and Sue all remarked on the inability to assume care roles.

It can be argued that this ingrained social imagery about disability, sexuality, and motherhood also operates at the unconscious level of society and is frequently manifested in the lack of provision of adequate support, services, and goods that are needed by disabled women pursuing motherhood (Daniels, 2019). This is evident in the findings of this research study mainly in the form of lack of reasonable accommodations in the healthcare sector, as well as limited empathy from healthcare professionals, in particular towards women who have invisible disabilities, as indicated by both Sue and Ann. This phenomenon greatly reflects the dominant medical discourse associated with disability where many times healthcare professionals focus their intervention on correcting biological and cognitive characteristics. Consequently, abnormality is generally given the limelight by healthcare professionals and womanhood is ignored. Additionally, the body of a disabled woman is frequently considered to be defective and unfit to have babies. From her own experience of pregnancy and early motherhood, Daniels (2019) who became disabled in her teenage years through a road traffic accident leaving her with brain injury, permanent loss of feeling and movement in her right arm, and a paralysed

vocal cord, adds on to this scenario and reports that oftentimes doctors are unaware how to properly attend to pregnant disabled women. Therefore, they frequently end up handling the pregnancy with disproportionate panic. This may be generated from the side-lining and disengagement with disability issues, as well as lack of training in the area of disability. In fact, Sue elaborated on limited training of healthcare professionals and stated that it is useless for her to disclose the fact that she has autism to them, because even if she does, they still do not know how to support her or what accommodations are needed to improve her experience in hospital.

In order for women to be considered valid mothers they have to possess several valued characteristics, including physical ability, limitless energy, and emotional, mental, and physical stability. Furthermore, they have to be independent and self-sufficient (Daniels, 2019). Ableist normativity pigeonholes disabled women as deviant from these norms, separates them, and treats them as others. According to Foucault, normalisation secures "membership in a homogeneous population and serve[s] to distinguish subjects, divide them from each other, classify them, categorize them in a number of ways and rank them in a host of hierarchies" (Tremain, 2018, p. 496). Hence, as illustrated in the findings of this research study by Kate, Emma, Beth, and Ann, and as presented in the literature review, disabled women pursuing motherhood are persistently being judged against the above-mentioned criteria of normality and ruled out from the status of a mother. It can be argued that ableist normativity may be further reinforced by media representation of disability, especially in a small island like Malta where most people know each other. Speaking about the local context it may be concluded that sometimes media acts as a source of conservation of disabling discourses. This is particularly evident in articles about disabled persons who challenge ableist assumptions, and instead have intimate relationships, cohabitate with partners, get married, as well as have children. Being an exceptionality, they end up making headlines (Azzopardi, 2014; Calleja, 2013a; Calleja, 2013b; Camilleri Clarke, 2020; Castillo; 2016). Their common life trajectory is depicted by media as something exclusive, thus arousing social interest and sensationalism whilst fostering disabling discourses. Nevertheless, looking at the media from a positive perspective, it can also be said that more awareness about the fact that the impairment itself does not inflict any kind of limitation is created. Rather than the impairment, media may be emphasising the fact that it is society that continues to impose barriers on disabled persons. Media holds a very powerful role because it may greatly influence our perceptions of disability, sexuality, and motherhood.

### The Medical Gaze, Power-Knowledge, Bio-Power and Eugenics

Several research studies explore the assumption that disabled women are likely to produce disabled offspring (Azzopardi-Lane & Callus, 2016; Streur et al., 2020; Walsh-Gallagher et al., 2012). It is still widely believed that disabled women will give birth to disabled babies, even though the reality is that most disabilities are non-hereditary (Peta, 2017). This phenomenon has repeatedly emerged in this research study, particularly in the accounts provided by Emma, Beth, Kate, and Ann. Both Kate and Ann also elaborated on the fact that the thought of passing on their disability to their child has fed their anxiety during pregnancy. Kate also stated that even though she was fully aware that her disability is not hereditary, she was still not able to stop thinking about the possibility of having a child who has the same disability as hers. This scenario may indicate how challenging it may be to deconstruct dominant discourses that are deep-seated in society. Additionally,

in light of this assumption, oftentimes pregnant disabled women are portrayed as weak. Consequently, they "are expected to give their trust" to medical experts (Daniels, 2019, p. 117). This situation has historical roots and, according to Nielson (2013), during the nineteenth century scientists and medical professionals replaced religion as the authority on disability. This prestigious position has been secured because of their competence in defining and curing illnesses and healing injuries. Medical professionals started to be seen as the cognitive authority (Brittain, 2004; Humpage, 2007), a situation which conforms to Foucault's (1978) concept of "power-knowledge" (p. 99). Foucault explains that knowledge generates power "by constituting people as subjects and then governing these subjects with the knowledge" (Ritzer, 2010, p. 615); hence, power is grounded on knowledge and makes use of knowledge.

Prenatal tests which were once carried out for pregnancies that develop complications are now performed regularly. The foetus is more likely to become a subject of judgement and is classified either as healthy or else as defective. The great advancements in prenatal testing have positioned certain foetuses "as being less worthy of the privileges of citizenship than other foetuses, and as liabilities to society" (Lupton, 2012, p. 336). The presumed need to carry out prenatal testing in itself points towards hegemonic practices that classify the life of disabled persons as not as good, worthy, and productive as that of their non-disabled counterparts. Foucault (1978) refers to this phenomenon as "biopower" (p. 140). Biopower controls subjects through the implementation of standardization practices and ensures the production of subjects who are efficient and productive (Tremain, 2005). Additionally, Tremain (2005) explains that biopower is not exerted through the implementation of laws but is rather offered as a

choice, hence "guiding the possibilities of conduct and putting in order the possible outcomes" (p. 8). In view of this and as stated in the literature review, oftentimes disabled women may face opposition to their pregnancy both from relatives, as well as from healthcare professionals. Subsequently, they may also experience pressure to terminate their pregnancy (Streur et al., 2020; Walsh-Gallagher et al., 2012). Frequently, the right to personal autonomy and physical integrity of disabled women pursuing motherhood is violated. Oftentimes, relatives and healthcare professionals engage in substituted decision-making and urge disabled women to terminate their pregnancy, or else direct them towards forced contraception, claiming that they are taking these decisions in their best interest (Gould & Dodd, 2014; Malacrida, 2020; McCarthy, 2009). However, in actual fact, these decisions may be based on stereotypes revolving around the capacity of disabled women to be mothers. The provision of comprehensive sex education that is disability-sensitive as well as provided through accessible formats may empower disabled women and help them become autonomous and able to make free and informed decisions about their sexual and reproductive health.

It is important to highlight the fact that participants in this research study did not mention any instances where they were urged to terminate their pregnancy. However, both Beth and Emma stated that they have experienced disapproval about their pregnancy from relatives, who told them that they will not be able to look after their child because they are disabled and hence, they will place an additional burden on them. It can be argued that abortion may not have been mentioned by participants in this research study because this subject is still considered taboo in Malta. Being a predominantly Roman Catholic country, Malta is the only European Union member state where abortion

is completely banned even in cases of fatal foetal abnormalities, rape or incest, or when there is risk of life of the pregnant person. Presently, if doctors terminate a pregnancy they are subject to imprisonment that can last for up to four years. The same sentence applies to pregnant persons who choose to terminate their pregnancy (Euronews, 2022; Gravino & Caruana-Finkel, 2019). Very recently an amendment to this existing law was proposed with the intention to ease its strictness and allow the termination of a pregnancy if the pregnant person's life is at risk (Carlo, 2022). This reform was instigated by an episode where an American woman who was on holiday in Malta was refused termination of her pregnancy even though it was alleged that this was not viable and was presenting a threat to her life. Ms. Prudente lost all the amniotic fluid in her uterus, which presented a risk of infection which could be fatal. In light of the Maltese law her pregnancy could not be terminated because the foetus's heart was still beating. Eventually, this mother was evacuated to Spain, where an abortion was performed (Brincat, 2023; Carlo, 2022). This scenario instigated a lot of debate and protests in the country. On one side the pro-choice movement was in favour of recognising women's reproductive rights and civil liberties, while on the other end, the pro-life movement claimed that life starts at conception, and terminating a pregnancy at any stage and situation is a murder. The pro-life movement was all along greatly backed up by the Church.

Despite all this commotion, ironically, every year a substantial number of Maltese women travel abroad to have an abortion (Askew, 2022). The rate of abortions in countries with strict laws like Malta appear to be comparable to those where abortion is broadly legalised. Between 2011 and 2017 an average of 57 Maltese women per year

week. It is worth nothing that this figure excludes women who travel to other European countries to obtain abortion (Gravino & Caruana-Finkel, 2019). Furthermore, results obtained from a research study carried out with Maltese women by Fenech Conti (2022) indicate a total of 41 abortions per 1000 live births. Women also purchase medical abortion pills online. Women on Web, which is an online organisation, has received 488 requests from Malta alone since its establishment in 2009 up to August 2018 (Gravino & Caruana-Finkel, 2019). Dibben et al. (2023) also investigated this phenomenon and examined the number of women and pregnant persons seeking at-home medical abortion via online telemedicine in Malta from 2017 to 2021. Over the five-year period analysed there was a substantial increase in the number of persons who received medical pills, with 1090 requests made through Women on Web and 658 persons being granted their request. The primary reasons for ordering abortion pills were legal restrictions and lack of access to abortion pills in Malta (Dibben et al., 2023).

# The Panopticon and Disciplinary-Power

Participants in this research study, including Kate, Beth, Emma, and Sue, referred to assumed incompetence and stated that their parental skills are constantly being monitored, judged, and criticized by those around them such as their relatives and inlaws, teachers and assistant heads from the schools their children attend, social workers, and the public in general. This situation sits very well within Foucault's (1991) notion of "panopticism" (p. 208). The panopticon is a design for a prison produced by Jeremy Bentham in the late eighteenth century, which consists of a central observation tower that is encircled by a round building divided into individual cells. The guard stays in the central

tower and constantly observes each prisoner within their separate cells. Meanwhile, prisoners cannot see the guard in the central tower (Roberts, 2005). Each and every prisoner "is seen, but does not see" (Foucault, 1991, p. 200). Any recklessness displayed by prisoners will be followed by a period of "corrective training" (Foucault, 1991, p. 202); hence, knowing that at any moment they are being observed, prisoners instinctively begin to regulate their own behaviour (Roberts, 2005). Foucault (1977) identifies this phenomenon as disciplinary-power. Bentham's panopticon was never built, but his idea was used as a model for several institutions, including prisons. Foucault uses Bentham's idea as a metaphor to represent the operation of surveillance and power in contemporary society (Foucault, 1977; O'Farrell, 2005). Foucault argues that discipline is just one way in which power can be exerted. Furthermore, discipline controls the behaviour of persons and it is enforced by intricate systems of surveillance (Foucault, 1977; O'Farrell, 2005).

This scenario can be correlated to the findings in this research study. Beth stated that she was being monitored by those around her, who eventually labelled her as an incompetent mother because of her disability. Consequently, her daughter was taken away from her. Sue also experienced a similar situation. Her performance was constantly being scrutinized and she was portrayed by her son's teacher and assistant head of school as an incompetent mother and unable to keep up with the required responsibilities of motherhood. In light of these accusations Sue's ex-husband threatened her with taking full custody of her children. Emma also experienced this ordeal. Her daughters' teacher filed a report for negligence, and unexpected regular home visits by social workers started occurring. Similar to the prisoners in the panopticon, Beth, knowing that she was constantly being monitored by those around her, instinctively began to regulate her

behaviour. When she had her second child she was afraid that she will lose him as well; consequently, she used to refuse any kind of help in order not to attract attention. This may indicate that a disabled mother will go extra miles in order to be seen as a competent mother who can do it all by herself and without the help of others (Fritsch, 2017). It can also be argued that because Beth felt vulnerable, she did not seek the support she needed. These situations may be devastating, because disabled mothers who do not seek help can easily become physically and emotionally drained. They do not only have to deal with the issues that are faced by parents in general but also with the negative consequences that derive from false allegations and assumptions, not to mention impairment-related issues, as seen in the findings of this research study. Amongst others, impairment-related issues were mentioned by both Kim and Ann who from time-to-time experience severe pain resulting from their physical impairment. Consequently, because of the pain, their daily plans as well as those of their family are oftentimes jeopardized.

Additionally, from the participants' accounts in this research study it can be argued that when compared to their non-disabled counterparts, disabled mothers experience increased pressure when it comes to parenting ability. This phenomenon was mentioned by both Kate and Emma, and from what they said it may be concluded that the less they are perceived by society as capable to parent, the higher the expectations are set for their parenting role. This phenomenon was mentioned in the literature review and as stated by Azzopardi-Lane (2021), disabled mothers generally experience higher parenting benchmarks. They have to perform much better than non-disabled mothers in order to fall within the ideal standards of parenting, and they also have to struggle to prove their validity as mothers (Gould & Dodd, 2014; Theodore et al., 2018). Additionally, from their

experience, Emma and Beth stated that disabled women pursuing motherhood are either considered a complete failure or else they are regarded as superheroes. There seems to be nothing in between. Similarly, Davis (2013) reports that disabled mothers are never placed within the normal category. Instead, in one way or another they are always placed outside the boundaries of normalcy. In light of this scenario it can also be pointed out that parenting discourses generally give the impression that parental caring is mainly of a physical nature and revolves around nappy changing, feeding, cleanliness, and safety. This narrow mind frame only looks at a small fraction of motherhood and gives little credence, if any at all, to the unconditional love, constant guidance, support, acceptance, and encouragement provided by disabled mothers to their children throughout their life.

Dealing with nappy changing and feeding is only a very short-lived stage of motherhood.

Parenting goes way beyond this.

The fact that most disabled mothers constantly feel undermined and threatened may generate several repercussions, one of which is assumed parental incompetence.

Beth stated that her ex-husband's accusations of not being a good mother were so embedded in her mind that there were instances in her life where she actually believed that she was not a good mother even though she was doing her utmost. Ann went through a similar experience, and she started believing that she was putting too much responsibility on her children. Consequently, both Beth and Ann explained that these situations were negatively affecting their emotional and psychological wellbeing so much that Ann was going through a depression. It can be argued that these repercussions might have been minimised or even avoided if appropriate and effective services and supports were in place. Parenting with an impairment may be challenging but, if well supported,

then disabled mothers will most likely be able to embrace this journey with satisfaction.

Research shows that services and supports empower disabled mothers to increase their confidence, as well as their competence in parenting (Aunos & Pacheco, 2013; Darbyshire & Stenfert Kroese, 2012; Lightfoot et al., 2018).

#### Resistance and the Power of Motherhood

Foucault presented the persuasive argument that resistance is an essential component of power. Power and resistance are linked in a complex manner and cannot be separated from one another (Tremain, 2008). In accordance with this, although disabled women are oftentimes viewed as deviating from societal expectations about motherhood, an increasing number of them are still choosing to become mothers (Malouf et al., 2017). Thus, they are challenging assumptions about what social roles they can fill. In doing so, they are resisting established social constructs and placing themselves within alternative discourses, in this case the discourse of motherhood. Some may believe that children who are raised by disabled parents may face more significant challenges in their development because their parents may find it difficult to provide adequate care and guidance. However, research shows that, contrary to common perceptions, having an impairment may sometimes enhance rather than reduce a person's capability to nurture and bring up children (Cureton, 2016; Kirshbaum & Olkin, 2002; Olkin et al., 2006). Cureton (2016) explains that when it comes to meeting their children's basic needs, disabled parents frequently need to be particularly mindful of them, remain in close proximity, and devote considerable time and effort to them, which can result in a closer relationship, more trust, and increased communication between them and their child. Additionally, several parenting approaches adopted by disabled parents take longer to be implemented when

compared to their non-disabled counterparts. Consequently, this promotes the development of patience in their children (Cureton, 2016). Generally, disabled parents strive to establish successful parenting techniques, sometimes through trial and error; hence, children are more likely to also develop flexibility and resilience. In addition, they can acquire a greater perception of their environment, enhance their cognitive capacities and other senses, and learn to adjust to errors. Furthermore, disabled parents may request their children to assist them with daily chores such as meal preparation, laundry, and house cleaning at an earlier age than usual. This fosters a sense of responsibility and self-worth, while it also promotes the development of problem-solving skills and selfresilience. As children get older, they may also be asked to support their parents, which teaches them about interdependence, how to help in a respectful manner, and how to accept help without feeling ashamed and humiliated. Gradually, children tend to become more aware of their parents' increased sensitivity towards them. Consequently, they are motivated to reciprocate and respond with empathy and kindness towards them. Eventually, these positive qualities may also expand to encompass others beyond their own family (Cureton, 2016).

From another perspective it can also be argued that disabled persons themselves can also benefit from raising children in unique ways. For many disabled women motherhood brings a feeling of achievement, contentment, and joy, as confirmed by the vast majority of participants in this research study. As stated by Gould and Dodd (2014), disabled women may find that being a mother is an essential role in their life because it may help them overcome being predominantly identified by their impairment. In addition, disabled women often demonstrate eagerness and enthusiasm to prove their

commitment and capability to care for their children (Gould & Dodd, 2014). Cureton (2016) also states that social stigma associated with having a disability may result in social isolation, making it harder for disabled women to form close personal relationships.

However, raising a child can provide an opportunity to develop a strong bond that might not otherwise be possible. This phenomenon emerged in the findings of this research study and was mentioned by Kate who said that her relationship with her daughter is exceptionally strong. Additionally, parenting can foster the development of new adaptive strategies (Cureton, 2016), as stated by Kate, Kim, Emma, and Sue. To mention a few, Kim explained that she used to climb down the stairs on her rear while holding the baby in order to avoid falling or tripping over. Similarly, Emma, who has a visual impairment, narrated how she used to mark the ounces on the bottle with a thick, dark marker so that she will be able to prepare her daughters' feeds independently. Successfully raising a child can also boost self-esteem and provide a sense of achievement, which can have a positive impact on the children's development too (Cureton, 2016).

### Conclusion

In Malta, in the past decade, there has been an increased recognition of the sexuality of disabled persons (Azzopardi-Lane, 2019). This has been demonstrated by Malta's ratification of the UNCRPD in 2012, with a particular focus on Article 23 which acknowledges the right of disabled persons to express their sexuality, form intimate relationships, marry, have children, and raise families. Additionally, Article 6 emphasizes that the human rights and fundamental freedoms of disabled women should not be discriminated against (UNCRPD, 2006). The principles of Article 23 have also been adopted as a foundation for Malta's National Disability Policy, which was implemented in

2014 (Azzopardi-Lane, 2019). Furthermore, recently Malta developed its first National Strategy on the Rights of Disabled Persons 2021-2030, titled Freedom to Live. This strategy lays out 13 objectives, some of which focus on areas such as relationships, family, sexuality, and parenthood for disabled persons (Ministry for Inclusion and Social Wellbeing, 2021). Despite the progress made in recognizing the sexuality and family rights of disabled persons in Malta, there remains significant suppression of their expression in these areas as outlined in the findings of this research study. As discussed in this chapter, prevailing discourses surrounding disability and ableist assumptions continue to exist. Services and supports for disabled women pursuing motherhood are generally limited and not disability-sensitive. Social and cultural factors still play a significant role in determining their inclusion and discrimination in the area of sexuality and reproduction. The process of achieving sexual citizenship, marriage, and parenting requires confronting the "power of the gaze and the social ordering process" (McFarlane, 2004, p. 29), since these statuses are still exclusively positioned for non-disabled women. The chapter that follows will present the conclusions from this research study.

### Conclusion

#### Introduction

The final chapter of this study presents a summary of the main findings, which align with the research questions outlined in Chapter 1:

- What are the experiences of disabled women pursuing motherhood?
- How do the experiences of disabled women impact their perceptions about disability and motherhood in a Maltese context?

Additionally, recommendations outlined from this research study will be presented with the aim to foster advancements in the field of sexuality, reproduction, and motherhood for disabled women. Subsequently, the strengths and limitations of this research study, as well as implications for future research, will also be explained.

#### **Main Findings**

#### **Experiences of Disabled Women Pursuing Motherhood**

This research study explored the lived experiences of seven disabled women pursuing motherhood in a Maltese context. Findings suggest that the persistence of stereotypes and prejudices related to disability, sexuality, and reproduction is still evident today. In particular, disabled women are often portrayed as incapable of becoming mothers and navigating family life. This societal perception is oftentimes rooted in the belief that disabled women are unable to produce un-disabled offspring and may pass on their disability to their children. As a result, young disabled women may experience overprotection from their parents who may prevent them from socializing with peers in an effort to prevent them from forming meaningful relationships. Unfortunately, this overprotection may continue even after disabled women become parents themselves in

the form of their parents constantly monitoring them. Additionally, society generally holds the belief that disabled women are incapable of pursuing committed relationships and parenthood, and their parenting abilities are often undervalued. Many times, disabled mothers may be seen as either heroic figures or as failures, which can have a negative impact on their emotional and psychological wellbeing. The focus is placed on their impairment, resulting in disabled mothers having to constantly prove their abilities as parents. Unfortunately, this perceived incompetence also increases the likelihood of disabled mothers having their children taken away from them. Coping with the daily stressors caused by their impairment, societal beliefs, as well as removal of their children, can cause significant distress for disabled mothers.

## Perceptions of Disabled Women About Disability and Motherhood in a Maltese Context

From the findings of this research study, it can be concluded that most participants felt that their impairment is frequently placed before their womanhood. One of the participants perceived her intersectional identities of being both woman and disabled as an additional attribute that increases the likelihood of encountering stigma. Hence, she considered herself more vulnerable to experiencing double discrimination. Another participant thought that her viewpoints are oftentimes disregarded. She felt that many times she is not given attention, she is not listened to, and her opinions are devalued. Most participants in this research study also believed that healthcare professionals, educators, and the general public often lack understanding about invisible disabilities. Despite society being more compassionate towards those who have visible physical conditions, they believed that there is often insensitivity towards those with hidden disabilities. As a result, persons with invisible disabilities frequently have to prove their

eligibility for using services and support, thus suffering needless frustration and distress.

Some participants also acknowledged the importance of prioritizing the delivery of useful services and adjustments that cater for the needs of disabled women pursuing motherhood, such as the provision of more community services, as well as parentcraft courses that are specifically tailored for disabled mothers and their partners. These courses were viewed by participants as a tool for empowering mothers who have different impairments.

Despite facing numerous challenges, including societal assumptions related to their disabilities as outlined in the findings chapter, most participants in this research study regarded motherhood as a deeply fulfilling and rewarding experience. Regardless of the uphill battle they constantly face during the journey of motherhood, they found a sense of purpose in caring for their children and often viewed them as their motivation to persevere. In fact, many participants considered motherhood as an opportunity to embrace their impairment and adapt to their new role as caregivers. Participants acknowledged that in spite of the challenges caused by their impairment, they were able to find alternative ways how to effectively care for their children, and consequently they found great satisfaction in doing so. Most participants also highlighted the importance of social support networks. They highly valued the support they received from family, friends, and neighbours, and acknowledged that they would have had a much harder time without them. In addition to this, other participants believed that they received significant encouragement and support from other networks such as a prayer group or a support group. Being part of such networks was seen as particularly beneficial because it provided an opportunity to meet others who were facing similar challenges. Sharing coping

strategies has been viewed as a supportive and motivating experience. One participant believed that only other disabled mothers who have the same impairment as herself could fully understand her. She found comfort in being able to connect with others who could relate to her unique experiences.

#### Recommendations

Based on the findings of this research study, it may be concluded that there is a crucial need to confront the pervasive negative discourses, prejudices, and stigma surrounding disability, sexuality, relationships, marriage, and reproduction. One effective way to address these issues may be through the Personal, Social, and Career Development curriculum in schools. This curriculum should challenge misconceptions related to disability, sexuality, and reproduction, and encourage positive attitudes. Both sexuality and reproduction should be portrayed as fundamental aspects of daily life, as well as human rights which should be accessible to everyone, including disabled persons. Through this curriculum students should learn to appreciate diversity, acknowledge the rights of disabled persons to enjoy intimate relationships and experience parenthood, and break down barriers that prevent them from accessing these rights. By promoting education that challenges stereotypes and misconceptions, the Personal, Social, and Career Development curriculum can play a vital role in creating a more just and equitable society that supports the rights and dignity of all individuals, including those with disabilities.

It is also essential that formal education on disability, sexuality, and reproduction is provided by trained educators who are proficient in these areas. These educators should be able to deliver the lessons effectively to all students, including those with disabilities. It

is crucial to treat disabled students equally and provide them with the same opportunities as their peers. To ensure that all students have equal access to the information, the delivery of lessons, and the disseminated material, these should be available in various formats ranging from visual representations, electronic documents, easy-to-read versions, and the use of Braille among others, as stated in the National Disability Policy of 2014 (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014). By providing education on disability, sexuality, and reproduction to everyone we can increase awareness and understanding among non-disabled students, as well as empower and develop advocacy among disabled students, enabling them to express their needs and assert their rights (Shah, 2017). When disabled students are included in these lessons, they can develop a positive self-image, improved self-esteem, and self-confidence (Shah, 2017). Overall, providing formal education on disability, sexuality, and reproduction by trained educators and in various accessible formats can promote inclusivity. This approach can help foster a more tolerant and accepting society where diversity is celebrated and everyone has the opportunity to reach their full potential and aspirations, including motherhood.

Improving awareness about disability, sexuality, and reproduction can also be achieved through the active participation of disabled persons in media. Media can be a powerful tool that can reach a vast audience; therefore, there should be support for innovative use of media that conveys the message of disabled persons as whole human beings. Media representations should refrain from sensationalizing the lives of disabled persons, as explained in the previous chapter, and instead adopt the positive affirmative model of disability; for instance, showcasing successful disabled mothers without

sensationalizing them. More involvement of disabled persons in local television programs is also necessary. Programs that focus on disability should have disabled persons as protagonists, since they are the experts in the area. By involving disabled persons in the media, we can break down negative stereotypes and promote inclusivity. It is crucial to portray disabled persons, including disabled mothers, as valuable members of society who can contribute in meaningful ways. By focusing on their strengths and capabilities we can help change public perceptions and foster a more accepting society.

This research study also revealed that professionals such as those working in the healthcare sector and educators in schools oftentimes lack professionalism when interacting with disabled women pursuing motherhood. To address this issue, Disability Equality Training should be conducted on a regular basis for the mentioned professionals, as well as others working in both private and public organisations that offer services and support to disabled persons. This training should focus on various aspects such as the use of appropriate language, behaviour, and etiquette when providing services and support to disabled women. In addition, this training should provide an overview of reasonable accommodations required by women from various impairment groups. Such provision can significantly improve the quality and effectiveness of services and support provided to disabled women pursuing motherhood. This training should also offer a platform for discussions and provide insights into the lives of disabled women. It is crucial to understand that disability is not a homogeneous condition and that each person has unique needs and challenges. Providing adequate support and services requires an understanding of the diversity within the disabled community. Additionally, the Disability Equality Training should be viewed as an ongoing process rather than a one-time event.

Professionals in healthcare and education sectors, among others, should be committed to continuous learning and improvement to better serve their clients. This training should also be participatory, where participants can share their experiences and learn from each other.

It is also crucial to provide disabled women who wish to become mothers with tailored home-based parental skills training that addresses their specific needs. This is because disabled women may encounter physical, social, and economic obstacles that can affect their ability to effectively care for their children. The training should be evidence-based and delivered by professionals who have expertise in working with disabled persons (Azzopardi & Azzopardi-Lane, 2021). Through this parental-skills training disabled mothers can acquire the necessary knowledge and skills to overcome barriers and manage additional challenges they may face. This can also boost their confidence and sense of empowerment in navigating the demands of parenting (Azzopardi & Azzopardi-Lane, 2021). The increased availability of parental skills training for disabled women pursuing motherhood can help them become successful mothers and improve outcomes not only for them but also for their children (Macbeth et al., 2015; Tarleton, 2014).

From the findings of this research study, it has also been acknowledged that there is a fundamental need for the setting up of a women's group to increase awareness about the challenges that disabled women face when pursuing motherhood. By forming this group, disabled women who aspire to be mothers or who are mothers can come together and convert their personal struggles into a political movement. They can then advocate for the government to provide more assistance during their parenting journey. This group can also exert pressure on the state and other responsible stakeholders to effectively

implement policies and strategies. This will ensure that disabled women receive the necessary support and resources they need to achieve their maternal goals. Furthermore, in order not to work in silos, members in this group can filter into mainstream activist groups to extend their reach and impact. By working together with other mainstream movements, disabled women pursuing motherhood can amplify their voices, draw attention to their needs, and create meaningful change in society. Ultimately this will result in a more inclusive and supportive environment for all women who face challenges in pursuing their maternal aspirations.

#### Strengths and Limitations

This research study has delved into an aspect of disability studies which is rather under-researched in the Maltese context. Disabled women pursuing motherhood are often marginalised in society and their voices are not heard. In addition to the strengths discussed in Chapter 3, this research study has provided a platform for participants to voice their experiences, the barriers they face, and their aspirations. By giving these women a voice, this research study aims to understand better their unique experiences. Moreover, by valuing their lived experiences, it may have the potential to lead to a greater understanding of their needs. This approach recognizes the capacity of disabled women to be competent mothers. It also acknowledges their ability to act as policy advisors and to provide consultations for improving existing services and developing new ones.

This research study can act as a catalyst for disability rights activism in Malta with a focus on prioritizing the issues of sexuality, reproduction, and motherhood. By shedding light on the experiences of disabled women pursuing motherhood, this research study can encourage action to improve access to and the effectiveness of services and support. It

can motivate the relevant authorities to dedicate more effort and resources towards developing, implementing, and updating policies and practices that are informed by the perspectives of disabled women. Collaborating with disabled mothers in this process can lead to more effective and sustainable solutions that better meet their needs. In addition, this research study may also serve as a valuable resource for disability advocacy groups who are working towards advancing inclusion and the sexual and reproduction rights of disabled women. By providing insights and recommendations on the experiences of disabled women, this research study can inform and guide their efforts in creating a more just and equitable society for all.

In Chapter 3 of this research study several limitations were also presented. Despite my commitment to prioritize the voices of disabled women pursuing motherhood, it is also very important to note that this research study does not fully meet the criteria of emancipatory disability research. This is because participants were not involved in every stage of the research process, as recommended by Barnes (2008). Conducting research entirely with disabled persons can result in a more authentic and meaningful outcome (Barnes, 2003; Oliver, 1997); however, it can also be a time-consuming process due to the extensive support and different accommodations required along the way (Callus, 2017). Unfortunately, given the constraints of time, it was not possible to involve participants in every stage of this research study. This was a missed opportunity, as disabled persons bring valuable expertise and experiences to the table. Their involvement in the research production can lead to the generation of more reliable data, better research findings, and a greater potential for real change (Barnes, 2003; Oliver, 1997). While this research study did not fully implement all the core principles that characterise emancipatory disability

research, efforts were made to promote the involvement and empowerment of all participants. Additionally, following the completion of this research study, a copy will be distributed to CRPD, who acted as gatekeepers and are responsible for safeguarding both Article 23 and Article 6 of the UNCRPD.

### **Implications for Further Studies**

This research study provided a unique insight into the experiences and perspectives of disabled women pursuing motherhood in a Maltese context. However, a complete understanding of this phenomenon can only be obtained if the views of disabled men regarding reproduction and parenthood are examined as well. Apart from this, it would also be highly valuable to have similar research conducted entirely within an emancipatory disability framework, where disabled persons pursuing parenthood are not merely research subjects, but actively participate as researchers throughout the entire process. Amongst other activities, they would conduct interviews, analyse data, and disseminate findings. By involving them in the research process, the study can provide a more accurate representation of their experiences regarding sexuality, reproduction, and parenthood. Their participation can help to reduce power dynamics, promote open communication, and resonate emergent themes with their experiences. The involvement of disabled persons also helps to reduce bias or discrimination that may be present in the research process. Overall, emancipatory disability research can enhance the quality of the study and lead to a more comprehensive understanding of disability (Theodore et al., 2018).

#### Conclusion

This study has given a platform for disabled women pursuing motherhood to share experiences and perspectives. Although there have been some improvements in the rights of disabled women, as mentioned in the introduction chapter of this research study, there are still significant challenges. While policies recognizing disabled women's rights exist, their sexuality, reproductive rights, and motherhood are still being regulated and enforced. As revealed by this research study, most disabled women in Malta encounter various barriers when they come to form relationships, get married, or have children.

Thus, this study cannot be considered conclusive; instead, more discussions with disabled women need to be conducted to raise awareness about disability, sexuality, and reproduction. This can help to shift societal attitudes towards disabled women who express their reproductive choices and want to become mothers. Furthermore, disabled women can use self-advocacy and empowerment to influence policy, hence leading to a more fulfilling life for themselves and others in the disabled community.

According to Foucault (1984, p. 8), "There are times in life when the question of knowing if one can think differently than one thinks, and perceive differently than one sees, is absolutely necessary if one is to go on looking and reflecting at all." In this statement Foucault is emphasizing the importance of questioning our own perceptions and ways of thinking in order to gain new insights and continue learning. Foucault also suggests that sometimes we must challenge our current way of thinking and seeing the world in order to move forward in our understanding. In the context of this research study, this interpretation is significant because it suggests that we have to challenge our assumptions and ways of thinking about disabled women pursuing motherhood. This

research study has helped me to expand my thinking and gain new perspectives. Above all, I have come to realize that disabled women pursuing motherhood have unique experiences and challenges that may not be immediately apparent to those who do not share those experiences. This realization is important because I am now better prepared to recognize that disabled women experience life differently and I have to step out of my comfort zone and be more open-minded and empathetic towards them. This way of thinking is also refreshing because now I am certain that with adequate support disabled women can achieve their maternal aspirations just like anyone else.

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# **Appendices**

## **Appendix A: Research Ethics Application Approval**

8/11/23, 6:25 PM

University of Malta Mail - Research Ethics Application - Approved by FREC, no UREC decision needed



Charmaine Muscat <charmaine.muscat.03@um.edu.mt>

#### Research Ethics Application - Approved by FREC, no UREC decision needed

3 messages

SWB FREC <research-ethics.fsw@um.edu.mt>
To: charmaine.muscat.03@um.edu.mt
Cc: Dr Claire Lucille Azzopardi Lane <claire.azzopardi-lane@um.edu.mt>

5 April 2022 at 15:17

Unique Form ID: SWB-2022-00095

Dear Charmaine Muscat,

Your ethics application regarding your research titled Motherhood: Listening to Disabled Women has been approved.

Faculty Research Ethics Committees are authorised to review and approve research ethics applications on behalf of the University of Malta, except in the case of sensitive personal data. In this regard, your ethics proposal does not need to be sent to UREC-DP. Hence, you may now start your research.

Regards,



Faculty Research Ethics Committee

Faculty for Social Wellbeing Room 113, Humanities A Building +356 2340 2237



### **Appendix B: Email to Gatekeepers**

Date:

Name of Organisation: Commission for the Rights of Persons with Disability

Dear Mr/Ms,

My name is Charmaine Muscat and I am currently a student reading for a Master of Arts in Disability Studies degree at the University of Malta. As part of my course requirements, I am in the process of writing a dissertation, entitled "Motherhood: Listening to Disabled Women."

I am therefore writing for your consideration in acting as gatekeepers and assisting me in the recruitment of participants, by distributing the information letters and consent forms to potential participants.

Subject to approval by the University of Malta Research Ethics Committee, women from various impairment groups who are aspiring to be mothers, are actively planning to be mothers, are expectant mothers or are disabled mothers will be invited to participate. Age bracket is 18 years and above. This study will seek to unravel the opportunities and barriers that they face in their reproductive lives as well as to explore their perceptions about disability and motherhood in a Maltese context.

This research which will be set on a number of emancipatory principles, will be seeking to carry out a one-time interview with six disabled women on a one-to-one basis for an approximate duration of one hour. All measures will be taken into account to ensure participants anonymity as far as possible.

Whilst thanking you in advance, please do not hesitate to contact me.

Yours truly,

Charmaine Muscat

Email: <a href="mailto:charmaine.muscat.03@um.edu.mt">charmaine.muscat.03@um.edu.mt</a>

## **Appendix C: Blurb for Social Media Platforms**

### **Motherhood: Listening to Disabled Women**

Are you a disabled woman of age 18 and above? Are you aspiring or actively planning to be a mother? Are you a disabled mother or an expectant disabled mother?

As part of my research for the Master of Arts in Disability Studies, I am exploring the experiences of disabled women pursuing motherhood and their perceptions about disability and motherhood in a Maltese context.

Could you help by participating in an interview which will take about an hour? Online interviewing is also possible.

Kindly contact me on <a href="maine.muscat.03@um.edu.mt">charmaine.muscat.03@um.edu.mt</a>

Thanks in advance.

## Appendix D: Blurb for Social Media Platforms (Maltese Version)

Motherhood: Listening to Disabled Women

Inti mara b'diżabilta` u għandek tmintax-il sena jew aktar? Qed taspira jew tippjana biex issir omm? Inti diġa` omm jew qed tistenna tarbija?

Fir-riċerka tiegħi għall-*Master of Arts in Disability Studies* ser nesplora l-esperjenzi tan-nisa b'diżabilta` li jixtiequ jsiru ommijiet jew huma diġa` ommijiet. Ser nesplora wkoll, x'jaħsbu dawn in-nisa dwar id-diżabilta` u l-fatt li tkun omm f'Malta.

Tixtieq tgħini? Tista' tagħmel dan billi tieħu sehem f'intervista li tieħu madwar siegħa. L-intervista tista' wkoll issir b'mod virtwali.

Jekk jogħġbok ikkuntatjani fuq <u>charmaine.muscat.03@um.edu.mt</u> Grazzi bil-quddiem. **Appendix E: Information Letter** 

1<sup>st</sup> June 2022

Dear Madam,

My name is Charmaine Muscat, and I am a student at the University of Malta, presently reading for a Master of Arts in Disability Studies. I am presently conducting a research study for my dissertation entitled **Motherhood: Listening to Disabled Women.** This is being supervised by Dr Claire Lucille Azzopardi-Lane and Professor Gillian Martin. 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 aims of my study are:

- to explore the opportunities and barriers that disabled women face in their reproductive lives and
- to explore disabled women's perceptions about disability and motherhood in a Maltese context.

Your participation in this study would help contribute towards adding to the limited knowledge available about this topic. Additionally, it would help contribute towards more inclusive policies and practices which will potentially lead to positive change in social attitudes towards disabled women expressing reproductive choices and being mothers in contemporary society. Any data collected from this research will be used solely for purposes of this study.

Should you choose to participate in this qualitative research study, you will be asked to participate in a one-time interview. Duration of interview will be approximately an hour and the interview will occur in a place of your choice and upon agreement with the researcher. Online interviewing will also be another possible alternative. Zoom will be used as a platform. Upon consent the physical interview will be audio recorded and transcribed as it is recorded. In the case of an online interview, it will be recorded by means of the Zoom audio recording function and protected by end-to-end encryption. This recording will be stored on the researcher's computer and not on the cloud. Recording will be also transcribed as it is recorded. Only the researcher, supervisor and in exceptional cases the examiners will have access to transcripts. Additionally, you will be given a copy of your transcript to read and approve before it is used by the researcher. You will be assigned a pseudonym and your identity will not be noted on transcripts or notes from the interview, but instead a code/made-up name will be assigned. The codes/made-up names that link data to identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer, and only the researcher will have access to this information. Other data will be stored in an external USB which will be stored and locked in a cupboard only accessible to the researcher and deleted upon a year of completion of the study in June 2024. Any hardcopy materials will be placed in a locked cupboard. Any identifiable material will be stored securely upon one year of completion of this study.

Participation in this study is entirely voluntary, in other words, you are free to accept or refuse to participate without the need to give a reason. You are also free to withdraw from the study at any time without the need to provide any explanation and without any

negative repercussions for you. Should you choose to withdraw, any data collected from your interview will be deleted.

If you choose to participate, you will be given a small token as an appreciation for your participation. Please note that there are no direct benefits to you. Your participation may entail emotional and psychosocial harm, and experience social stigma and harm, even if these are unlikely occurrences. However, in the event that you feel distressed due to participation in the interview, you will be able to access professionals listed here to assist you at no financial cost on your part.

List:

#### Richmond Foundation

#### Support line 179

#### Kellimni.com

Further information about these support services will be provided in a separate document.

Please also note that as a participant, you have the right under the General Data Protection Regulation (GDPR) and national legislation to access, rectify and where applicable ask for the data concerning you to be erased. The data shall be erased for as long as this is technically possible unless erasure of data would render impossible or seriously impair achievement of the research objectives. The latter directly reflects the exemptions provided for in the GDPR Article 17(3)(d). All data collected will be deleted upon one year of completion of the study in June 2024.

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

Thank you for your time and consideration. Should you have any questions or concerns, please do not hesitate to contact me via e-mail at <a href="mailto:charmaine.muscat.03@um">charmaine.muscat.03@um</a>.edu.mt or you can also contact my supervisor at <a href="mailto:claire.azzopardi-lane@um.edu.mt">claire.azzopardi-lane@um.edu.mt</a>.

### Appendix F: Ittra ta' Taghrif

1 ta' Ġunju, 2022

Għażiża Sinjorina/Sinjura,

Jiena Charmaine Muscat studenta fl-Università ta' Malta. Bħalissa qed insegwi kors fil-*Master of Arts in Disability Studies*. Ir-riċerka għat-teżi tiegħi jisimha: *Motherhood: Listening to Disabled Women*. It-tuturi tiegħi huma Dr Claire Lucille Azzopardi-Lane u

Professor Gillian Martin. B'din l-ittra nixtieq nistiednek tipparteċipa fir-riċerka. Hawn taħt issib aktar informazzjoni fuq l-istudju li qed nagħmel u fuq xi jkun l-involviment tiegħek jekk tiddeċiedi li tieħu sehem.

L-għanijiet tal-istudju huma:

- li niskopri l-opportunitajiet u d-diffikultajiet li jiltaqgħu magħhom nisa b'diżabilta` filħajja riproduttiva tagħhom u
- li niskopri x'jaħsbu dwar id-diżabilta` u l-process li issir omm f'Malta.

Sehmek jgħin u jista' jservi ta' għajnuna biex ikun hawn aktar tagħrif dwar dan is-suġġett. Sehmek jgħin u jista' wkoll iservi ta' għajnuna biex ikun hawn aktar strateġiji u prattiċi inklussivi li potenzjalment jistgħu iwasslu għal aktar attitudni soċjali pożittiva dwar l-għażliet riproduttivi tan-nisa b'diżabilta`u l-fattur li jsiru ommijiet. L-informazzjoni kollha li tinġabar fir-riċerka tintuża biss għall-fini ta' dan l-istudju.

Jekk taqbel li tippartecipa, tintalab tieħu sehem f'intervista waħda li tieħu bejn wieħed u ieħor siegħa. Din l-intervista ser issir f'post tal-għażla tiegħek u bi qbil mar-ricerkatrici. Bil-kunsens tiegħek l-intervista ser tiġi rrekordjata bl-awdjo. L-intervista tista' ssir ukoll *online* bil-pjattaforma *Zoom*. Din ukoll ser tiġi irrekordjata bl-użu tal-funzjoni provduta f'*Zoom*. Il-kontenut irrekordjat ser jinżamm fuq il-kompjuter tar-ricerkatrici u mhux fuq *cloud*. Il-

kontenut irrekordjat ser jiĝi tradott kelma b'kelma kif inhu. Ir-riċerkatriċi, it-tutur u f'kas eċċezzjonali l-eżaminaturi biss se jkollhom aċċess għat-traskrizzjonijiet. Inti ser tingħata kopja tat-traskrizzjoni bies taqra u tapprova qabel ma din tintuża mir-riċerkatriċi.

Ser nkun qed nieħu l-miżuri kollha biex niżgura li inti tibqa' anonima. L-identita` tiegħek mhux se titniżżel fit-transkrizzjonijiet u l-anqas fin-noti li jittieħdu waqt l-intervista.

Minflok ser tingħata kodiċi jew isem fittizju. Il-lista ta' kodiċi jew ismijiet fittizji mqabbla ma' dawk propji ser tiżamm separatament ġo fajl protett fil-kompjuter tar-riċerkatriċi fejn l-aċċess huwa protett b' password lir-riċerkatriċi biss taf. Informazzjoni oħra ser tinżamm fuq external USB li se jitqiegħed f'armarju msakkar u r-riċerkatriċi biss se jkollha aċċess.

Dokumenti oħra ser jinżammu wkoll imsakkrin ġo armarju u kollox ser jiġi meqrud wara sena li jintemm dan l-istudju, jiġifieri f'Ġunju 2024.

Madankollu xorta waħda jista' jkun hemm ir-riskju li tiġi identifikata fil-publikazzjonijiet, preżentazzjonijiet jew mit-tweġibiet diretti jew indiretti li ser jintużaw f'dan l-istudju. Għalhekk, il-parteċipazzjoni tiegħek hija waħda voluntarja, u fi kliem ieħor, inti libera li taċċetta jew tirrifjuta li tieħu sehem mingħajr ma tagħti raġuni. Inti wkoll libera li twaqqaf il-parteċipazzjoni tiegħek fl-istudju meta tixtieq mingħajr ma jkollok tagħti spjegazzjoni u mingħajr ebda riperkussjoni. Jekk tagħżel li ma tkomplix tipparteċipa, l-informazzjoni li tkun laħqet ittieħdet fl-intervista miegħek titħassar.

Jekk tagħżel li tipparteċipa ser tingħata rigal żgħir t'apprezzament. Jekk jogħġbok innota li m'hemm l-ebda benefiċċju dirett għalik. Il-parteċipazzjoni tiegħek tista' twassal għal skumdita` emozzjonali jew psikoloġika għalkemm dan ir-riskju mhux magħruf jew mistenni. Imma jekk tiġri xi ħaġa li ddejqek, inkun nista' ngħinek u jekk ikollok bżonn tkellem lil xi ħadd professjonali dwar dak li jkun ġara inkun nista' ngħaddilek lista' ta'

servizzi ta' sapport. Ma jkunx hemm għalfejn tħallas. Dawn is-servizzi ta' sapport huma Richmond Foudation, Support line 179 u kellimni.com. Għandek issib aktar informazzjoni dwar dawn is-servizzi f'dokument separat.

Bħala parteċipanta għandek id-dritt, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali li taċċessa, tikkoreġi u fejn hu applikabbli, titlob li l-informazzjoni li tikkonċernak titħassar. L-informazzjoni tista' titħassar sakemm dan ikun teknikament possibli u sakemm dan ma jagħmilhiex impossibli jew itellef serjament l-għanijiet tar-riċerka. Dan huwa rifless fl-eżenzjonijiet provduti fil-GDPR Artiklu 17(3)(d). L-informazzjoni kollha li tinġabar fl-istudju titħassar sena wara li jintemm l-istudju jiġifieri f'Ġunju 2024.

Qed ngħaddilek kopja ta' din l-ittra biex iżżommha bħala referenza.

Grazzi tal-ħin u l-kunsiderazzjoni tiegħek. Jekk ikollok xi mistoqsija, tiddejjaqx tikkuntattjani fuq charmaine.muscat.03@um.edu.mt Tista' tikkuntattja wkoll lit-tutur tiegħi elettronikament fuq claire.azzopardi-lane@um.edu.mt

## Appendix G: Easy-Read Information Letter

1<sup>st</sup> June 2022

#### Information Letter to Take Part in a Study



I am Charmaine Muscat, and I am a student at the
University of Malta. I am writing to invite you to
take part in a study that I am doing. In this letter,
you will find all the information about the study and
about how you can take part.



The study is about the experiences of disabled women pursing motherhood. I am doing this study to learn more about the opportunities and barriers that disabled women face in their reproductive lives. I am doing this study also to learn about what participants think about disability and motherhood in a Maltese context.



To do this study, I would like to interview 6 women from various impairment groups.



The interview will be an hour long.



After we do the interview, I will send you a copy of what you said so that you can see if you want to change, add, or remove anything.



When I write about the study, I will use parts of what you said but will not use your real name.

However, there can be a chance that someone reading my study may still recognize you.



You do not have to take part in this study if you do not want to. If you apply to take part and then you change your mind, it will not be a problem. You can stop any time. You do not have to give reasons for stopping.



I will act according to what Maltese law says on how the information that I have about you should be stored. This means that I will keep the information in a secure place. I will also destroy all the information from the interviews, including recordings, a year after the study has been completed in June 2024.



If you take part, you will have a chance to talk about your reproductive life as a disabled woman. You will also be helping by providing more information about this topic which can lead to more inclusive policies and practices. It can also contribute towards more social positive attitudes.



I do not think that there will be any problems for you if you take part. But if something happens that upsets you, I can help you out. If you need to speak to someone else about what happened, I can help you do this. You can get free help from Richmond Foundation, Support line 179 or kellimni.com. More information will be provided in a separate document.



This letter of information is for you to keep.

?	If you want to take part or if you have any questions, you can contact me on charmaine.muscat.03@um.edu.mt. You can also speak to my supervisor Dr Claire Lucille Azzopardi-Lane on claire.azzopardi-lane@um.edu.mt
	Please let me know by 30 <sup>th</sup> June if you would like to take part.

## Appendix H: Ittra ta' Informazzjoni (Easy-Read)

1 ta' Ġunju, 2022

# Ittra ta' Informazzjoni Biex Tiehu Sehem fi Studju



Jien Charmaine Muscat u jien studenta fl- Università ta'
Malta. Qed nikteb biex nistiednek tiehu sehem fi studju
li qed naghmel. F'din l-ittra ssib l-informazzjoni dwar
dan l-istudju u dwar kif tista' tiehu sehem.



Dan l-istudju hu dwar l-esperjenzi ta' nisa b'diżabilta` li jixtiequ jsiru ommijiet jew huma ommijiet. Jien qed nagħmel dan l-istudju biex niskopri l-opportunitajiet u d-diffikultajiet li jiltaqgħu magħhom nisa b'diżabilta` fil-ħajja riproduttiva tagħhom, kif ukoll biex niskopri x'jaħsbu n-nisa b'diżabilta` dwar id-diżabilta` u l-proċess li ssir omm f'Malta.



Biex nagħmel dan l-istudju, jien nixtieq nagħmel intervisti ma' 6 nisa b'diżabilitajiet varji.

10 12 1 10 12 1 2 8 7 6 5 4	L-intervista bejn wieħed u ieħor iddum siegħa.
• REC	Jien nixtieq li nirrekordja l-intervista fuq awdjo għax ikun diffiċli għalija li niftakar kull ma tgħidli. Jien u s-supervisor tiegħi biss se nkunu nistgħu naċċessaw dak li jiġi rikordjat u f'każijiet speċjali l-eżaminaturi.
	Wara li nagħmlu l-intervista, jien nibgħatlek kopja ta' dak li tkun għidt inti biex tara jekk tixtieqx tbiddel, iżżid jew tneħħi xi ħaġa.
	Meta nikteb dwar l-istudju, se nuża partijiet minn dak li għidt inti, imma mhux se nuża ismek ta' veru. Imma xorta waħda jista' jkun hemm xi ħadd li jaqra l-istudju tiegħi jagħrfek.
	Ma hemmx ghalfejn tiehu sehem f'dan l-istudju jekk ma tridx. Jekk tapplika biex tiehu sehem u wara jerġa' jibdielek, ma jkunx jimporta. Tista' tieqaf meta trid. Ma jkunx hemm ghalfejn tghid ghaliex trid tieqaf.



Jien se nimxi skont ma tgħid il-liġi Maltija dwar kif għandi nżomm l-informazzjoni li għandi dwarek. Dan ifisser li nżomm l-informazzjoni f'post sigur. Ifisser ukoll li neqred l-informazzjoni mill-intervisti, inkluż dak li nkun irrikordjajt sena wara li l-istudju jkun lest jiġifieri f'Ġunju 2024.



Jekk tieħu sehem, inti jkollok iċ-ċans titkellem fuq dak li hu importanti għalik dwar il-ħajja riproduttiva. Tkun qegħda wkoll tgħin biex ikun hawn aktar għarfien dwar dan is-suġġett li jista' jwassal għal aktar strateġiji u attitudnijiet inklussivi fost il-pubbliku.



Jien ma naħsibx li se jkun hemm problemi għalik jekk int tieħu sehem. Imma jekk tiġri xi ħaġa li ddejqek, inkun nista' ngħinek. Jekk ikollok bżonn tkellem lil xi ħadd dwar dak li jkun ġara, inkun nista' ngħinek tagħmel dan. Ma jkunx hemm għalfejn tħallas. Tkun tista' tikkuntatja lil Richmond Foundation, Support line 179 jew kellimni.com.



Din l-ittra ta' informazzjoni hi għalik biex iżżommha.

?	Jekk tixtieq tieħu sehem, jew jekk għandek xi mistoqsijiet, tista' tikkuntatjani fuq charmaine.muscat.03@um.edu.mt. Tista' wkoll tkellem lis-supervisor tiegħi Dr Claire Lucille Azzopardi-Lane fuq claire.azzopardi-lane@um.edu.mt
	Jekk jogħġbok għidli sat-30 ta' Ġunju jekk tixtieq tieħu sehem.

## Appendix I: Participant's Consent Form

Motherhood: Listening to Disabled Women

I, the undersigned, give my consent to take part in the study conducted by Charmaine

Muscat. This consent form specifies the terms of my participation in this research study.

- 1. I have been given written and/or 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 stop participation at any time 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, any data collected from me will be deleted.
- 3. I understand that I have been invited to participate in a qualitative research study in which the researcher will interview me to explore the opportunities and barriers that disabled women face in their reproductive lives and, to explore disabled women's perceptions about disability and motherhood in a Maltese context. I am aware that the onetime interview will take approximately one hour. I understand that the interview is to be conducted in a place and at a time that is convenient for me and upon agreement with the researcher. Online interviewing will be another possible alternative. Zoom will be used as a platform.
- 4. I understand that my participation may entail emotional and psychosocial harm, and experience of social stigma and harm, even if these are unlikely occurrence. I understand that I can pause or stop the interview at any time and have also been

- provided with a list of services that can provide support. I can seek free professional support from Richmond Foundation, Support line 179 or kellimni.com.
- 5. I understand that there are no direct benefits to me from participating in this study. I also understand that this research may contribute towards adding to the limited knowledge available about this topic. Additionally, it may contribute towards more inclusive policies and practices which will potentially contribute to positive change in social attitudes towards disabled women expressing reproductive choices and being mothers in contemporary society. Any data collected from this research will be used solely for purposes of this study.
- 6. I understand that, under the General Data Protection Regulation (GDPR) and national legislation, I have the right to access, rectify, and where applicable, ask for the data concerning me to be erased. The data shall be erased for as long as this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives. The latter directly reflects the exemptions provided for in the GDPR Article 17(3)(d).
- 7. I understand that all data collected will be stored in a pseudonymised form and deleted upon one (1) year of completion of the study in June 2024.
- 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.
- 9. I am aware that, if I give my consent, the interview will be audio recorded in case of a physical interview and converted to text as it has been recorded (transcribed).
  In case of an online interview, it will be recorded by means of the Zoom audio

- recording function and protected by end-to-end encryption. Recording will be stored on the researcher's computer and not on the cloud. Recording will be converted to text as it has been recorded. Only the researcher, supervisor and in exceptional cases the examiners will have access to transcripts.
- am aware that, if I give my consent, extracts from my interview may be reproduced in these outputs using a pseudonym (code/ made-up name).
- 11. I am aware that my data will be pseudonymized i.e., my identity will not be noted on transcripts or notes from my interview, but instead, a code/made-up name will be assigned. Codes/made-up names that link my data to my identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer, and only the researcher will have access to this information. Other data will be stored in an external USB which will be stored and locked in a cupboard only accessible to the researcher and deleted upon a year of completion of the study in June 2024. 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 upon one year of completion of this study.
- 12. I am aware that, if I give my consent, my identity may be revealed in publications, reports or presentations arising from this research, and responses I provide may be quoted directly or indirectly.
- 13. I am aware that I will be given the opportunity to review the transcript of my interview before it will be used by the researcher. I am also aware that I may ask for changes to be made if I consider this to be necessary.

14. If I feel that the interview has distressed me in any way, I will be able to access professionals listed here to assist me at no financial cost on my part:

List:

#### **Richmond Foundation**

# Support line 179

#### Kellimni.com

Further information about these support services have been provided in a separate document.

I have read and understood the above statements and agree to participate in this study.
Name of participant:
Signature:
Date:

lo Muscat

Researcher

Charmaine Muscat

charmaine.muscat.03@um.edu.mt

Supervisor

Dr Claire Lucille Azzopardi-Lane

claire.azzopardi-lane@um.edu.mt

#### Appendix J: Formola tal-Kunsens tal-Partecipanta

#### **Motherhood: Listening to Disabled Women**

Jiena, hawn taħt iffirmata, nagħti l-kunsens tiegħi li nieħu sehem fl-istudju ta' Charmaine
Muscat. Din il-formola tal-kunsens tispjega t-termini tas-sehem tiegħi f'din ir-riċerka.

- 1. Ingħatajt l-informazzjoni bil-miktub dwar l-iskop tar-riċerka; kelli l-opportunità nagħmel il-mistoqsijiet, u kull mistoqsija ngħatajt tweġiba għaliha b'mod sħiħ u sodisfaċenti.
- 2. Nifhem ukoll li jiena libera li naċċetta li nieħu sehem, jew li nirrifjuta, jew li nwaqqaf il-parteċipazzjoni tiegħi meta nixtieq mingħajr ma nagħti spjegazzjoni jew mingħajr ma niġi penalizzata. Jekk nagħżel li nipparteċipa, jaf niddeċiedi li ma nweġibx kull mistoqsija li ssirli. F'każ li nagħżel li ma nkomplix nieħu sehem flistudju, l-informazzjoni miġbura mingħandi se titħassar.
- 3. Nifhem li ģejt mistiedna nipparteċipa f'intervista u l-persuna li qed tagħmel irriċerka se tistaqsini xi mistoqsijiet biex tiskopri l-opportunitajiet u d-diffikultajiet li jiltaqgħu magħhom nisa b'diżabilta` fil-ħajja riproduttiva tagħhom, u li tiskopri wkoll x'jaħsbu n-nisa b'diżabilta` dwar id-diżabilta` u l-fattur li ssir omm f'Malta. Jiena konxja li l-intervista se ddum bejn wieħed u ieħor siegħa. Nifhem li l-intervista se ssir f'post u f'ħin li huma komdi għalija u bi qbil mar-riċerkatriċi. L-intervista tista' issir ukoll b'mod *online* fuq il-pjattaforma *Zoom*.
- 4. Nifhem li l-partecipazzjoni tiegħi f'dan l-istudju tista' twassal għal skumdita` emozzjonali jew psikoloġika għalkemm dan ir-riskju mhux magħruf jew mistenni. Imma jekk jiġri dan, inkun nista' nkellem lil xi ħadd professjonali dwar dak li jkun ġara. Ma jkunx hemm għalfejn inħallas. Ingħatajt lista ta' servizzi ta' sapport kif

- ukoll informazzjoni dwarhom. Dawn is-servizzi ta' sapport huma Richmond Foudation, Support line 179 u Kellimni.com
- 5. Nifhem li bil-parteċipazzjoni tiegħi f'dan l-istudju, m'hemm l-ebda benefiċċju dirett għalija. Nifhem ukoll li din ir-riċerka jaf isservi ta' għajnuna biex ikun hawn aktar tagħrif dwar dan is-suġġett, kif ukoll ikun hawn aktar strateġiji u prattiċi inklussivi li potenzjalment jistgħu iwasslu għal aktar attitudni soċjali pożittiva dwar l-għażliet riproduttivi tan-nisa b'diżabilta` u l-fattur li jsiru ommijiet.
- 6. Nifhem li, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leģiżlazzjoni nazzjonali, għandi dritt naċċessa, nikkoreġi u fejn hu applikabbli, nitlob li l-informazzjoni li tikkonċernani titħassar.L-informazzjoni tista' titħassar sakemm dan ikun teknikament possibli u sakemm dan ma jagħmilhiex impossibli jew itellef serjament l-għanijiet tar-riċerka. Dan huwa rifless fl-eżenzjonijiet provduti fil-GDPR Artiklu 17(3)(d).
- Nifhem li l-informazzjoni kollha migbura se tithassar sena wara li jitlesta dan listudju jigifieri f'Gunju 2024.
- Ingħatajt kopja tal-ittra ta' tagħrif biex inżommha u nifhem li se ningħata wkoll kopja ta' din il-formola tal-kunsens.
- 9. Konxja li jekk nagħti l-kunsens tiegħi, l-intervista kemm jekk issir wiċċ imb'wiċċ kif ukoll b'mod *online* se tkun rekordjat bl-awdjo u maqluba fi kliem kif irrekordjata (traskrizzjoni). Intervista *online* ser tkun protetta bil-funzjoni *end-to-end encryption* li tipprovdi l-pjattaforma *Zoom* u miżmuma fuq il-kompjuter tar-riċerkatriċi u mhux fuq *cloud*. Ir-riċerkatriċi, it-tutur u f'każ eċċezzjonali l-eżaminaturi biss jistgħu jaċċessaw it-traskrizzjonijiet.

- 10. Konxja li jekk nagħti l-kunsens tiegħi, siltiet mill-intervista tiegħi jistgħu jiġu riprodotti f'format anonimu bl-użu ta' kodiċi jew isem fittizju.
- 11. Jiena konxja li l-informazzjoni tiegħi se tkun anonima, jiġifieri l-identità tiegħi mhix se titniżżel fit-traskrizzjonijiet jew fin-noti tal-intervista, imma minflok se niġi assenjata kodiċi jew isem fittizju. Il-lista ta' kodiċi jew ismijiet fittizji mqabbla ma' dawk propji ser tinżamm separatament ġo fajl protett fil-kompjuter tar-riċerkatriċi fejn l-aċċess huwa protett b' password lir-riċerkatriċi biss taf. Informazzjoni oħra ser tinżamm fuq external USB li se jitqiegħed f'armarju msakkar u r-riċerkatriċi biss se jkollha aċċess. Dokumenti oħra ser jinżammu wkoll imsakkrin ġo armarju u kollox ser jiġi meqrud wara sena li jintemm dan l-istudju, jiġifieri f'Ġunju 2024.
- 12. Konxja li l-identità tiegħi u d-dettalji personali tiegħi mhux se jiġu żvelati f'xi pubblikazzjoni, rapport, preżentazzjoni jew risposta diretta jew indiretta li se joħorġu minn dan l-istudju madankollu, xorta waħda hemm ir-riskju li nista' niġi identifikata.
- 13. Konxja li ser ningħata l-opportunità biex niċċekkja t-traskrizzjoni tal-intervista tiegħi qabel ma din tintuża mir-riċerkatriċi. Konxja wkoll li nista' nistaqsi biex isir xi tibdil jekk nara li jkun meħtieġ.
- 14. Jekk inhoss li l-intervista b'xi mod tkiddni jew tiddisturbani, ir-riċerkatriċi tagħtini informazzjoni dwar servizzi ta' sapport relatata ma' saħħa mentali jew saħħa psikosoċjali. Nista' naċċessa bla ħlas lil:

**Richmond Foundation** 

Support line 179

Kellimni.com

Isem il-parteċipanta:	
Firma:	
Data:	-
lo Musad	
Riċerkatriċi	Tutur
Charmaine Muscat	Dr Claire Lucille Azzopardi-Lane
Email: charmaine.muscat.03@um.edu.mt	claire.azzopardi-lane@um.edu.mt

## **Appendix K: Consent Form**

'Consent' means that you agree with everything that is written below.

If you agree with everything that is written, sign in the last part.





I know that Charmaine Muscat will record the interview on audio. I also know that only Charmaine Muscat and the supervisor will have access to the recordings and in exceptional cases the examiners.



I know that after we do the interview, I will have a copy of what I said so that I can see if I want to change, add or remove anything.



I know that when Charmaine Muscat writes about the study, she will use parts of what I said but will not use my real name. However, there can be a chance that someone reading the study may recognize me.



I know that I do not have to take part in this study if I do not want to. If I take part and I want to stop, it will not be a problem. I can stop any time. I do not have to give reasons for stopping.



I know that Charmaine Muscat will act according to what Maltese law says about how to store information about me. This means that the information will be in a secure place. Charmaine Muscat will also destroy all the information from the interviews, including recordings, a year after the study is finished in June 2024.



I know that if I take part, I will have a chance to talk about what is important to me about motherhood and disability.

I will also be helping others learn more about this topic and this will potentially contribute towards more inclusive policies, practices and positive attitudes in society.



I know that there should not be a problem if I take part.

But if something happens that upsets me, I can talk about it. If I need to speak to someone else, I can get help from Richmond Foundation, Support line 179 or kellimni.com. I will not have to pay anything for the help I receive.



I have received the information letter about the study and I will also have a copy of this consent form.

I have understood everything that is written here and if I had any questions, they have been answered. I would like to take part in this study.

Name and surname:	
Signature:	
Date:	

## Appendix L: Formola tal-Kunsens (Easy-Read)

'Kunsens' ifisser li inti taqbel ma' dak li hawn miktub hawn taħt.

Jekk taqbel ma' dak kollu li hawn miktub iffirma fl-aħħar parti.



Jiena qed napplika għax nixtieq li nieħu sehem f'dan ilproġett li se jsir minn Charmaine Muscat.



Jiena għandi l-informazzjoni dwar l-istudju u kelli ċans insaqsi mistoqsijet dwar l-istudju u kelli risposta.



Jien naf li se jkolli intervista.



Jien naf li l-intervista se ddum madwar siegħa.



Jien naf li Charmaine Muscat se tirrekordja l-intervista fuq awdjo. Jien naf ukoll li Charmaine Muscat u s-supervisor biss se jkollhom aċċess għal dak li ġie rrikordjat u f'każ speċjali l-eżaminaturi wkoll.



Jien naf li wara li nagħmlu l-intervista, se jkolli kopja ta' dak li nkun għidt biex nara jekk nixtieqx inbiddel, inżid jew inneħħi xi ħaġa.



Jien naf li meta Charmaine Muscat tikteb dwar l-istudju, se tuża partijiet minn dak li għidt jien, imma mhux se tuża ismi ta' veru. Imma xorta waħda jista' jkun hemm xi ħadd li jaqra l-istudju u jagħrafni.



Jien naf li m'hemmx għalfejn nieħu sehem f'dan l-istudju jekk ma rridx. Jekk napplika biex nieħu sehem u wara jerġa' jibdieli, ma jkunx jimporta. Nista' nieqaf meta rrid. Ma jkunx hemm għalfejn ngħid għaliex irrid nieqaf.



Jien naf li Charmaine Muscat se timxi skont ma tgħid il-liġi Maltija dwar kif għandha tinżamm l-informazzjoni dwari.

Dan ifisser li l-informazzjoni tkun f'post sigur. Ifisser ukoll li Charmaine Muscat se teqred l-informazzjoni mill-intervisti, inkluż dak li tkun irrikordjat sena wara li jintemm l-istudju f'Ġunju 2024.



Jien naf li jekk nieħu sehem, ikolli ċ-ċans nitkellem fuq dak li hu importanti għalija dwar il-ħajja riproduttiva tan-nisa b'diżabilta`. Inkun qegħda wkoll ngħin biex ikun hawn aktar għarfien dwar dan is-suġġett li jista' jwassal għal aktar strateġiji u attitudnijiet inklussivi fost il-pubbliku.



Jien naf li mhux suppost ikun hemm problemi għalija jekk nieħu sehem. Imma jekk tiġri xi ħaġa li ddejaqni, se nkun nista' nkellem lil xi ħadd dwar dak li jkun ġara. Se nkun nista' nkellem lil Richmond Foundation, Support line 179 jew kellimni.com u ma jkunx hemm għalfejn inħallas.



Jien irċevejt ittra t'informazzjoni dwar dan l-istudju u se jkolli wkoll kopja ta' din il-formola tal-kunsens.

nixtieq nieħu sehem f'dan l-istudju.	
Isem u kunjom:	
Firma:	-
Data:	-

Jiena fhimt dak kollu li hawn miktub, u jekk kelli xi mistoqsijiet dawn ġew imwieġba. Jien

### **Appendix M: Interview Guide**

- 1. Please indicate:
  - your age
  - your impairment
  - your position regarding your reproductive life. Are you aspiring or actively planning to be a mother? Are you a disabled mother or an expectant disabled mother?
  - (in the case of a disabled mother) How many children do you have and what is their age?
  - Are you in a relationship or single?
- 2. Does the way disabled women perceive themselves affect their decisions regarding motherhood, and how?
- 3. How does Maltese society perceive disabled women pursuing motherhood?
- 4. What does motherhood mean to you?
- 5. What is your experience regarding your reproductive life?
- 6. What was helpful in this experience?
- 7. What challenged this experience?
- 8. Would you change anything in this experience?
- 9. What motivates/motivated you in pursuing motherhood?
- 10. How does the fact that you decided to pursue motherhood affect you?
- 11. (In the case of women aspiring to be mothers) How would you feel about yourself being a mother?
- 12. What factors influence disabled women in pursuing motherhood, and why?

13. What recommendations would you make that could support disabled women pursuing motherhood within the context of Maltese society?

#### Appendix N: Gwida għall-Intervista

- 1. Jekk joghġbok tista' tgħidli:
  - I-eta` tiegħek?
  - id-diżabilta` li għandek?
  - x'inhi l-pożizzjoni tiegħek fejn tidħol il-ħajja riproduttiva? Qed taspira li ssir
     omm, qed tippjana biex issir omm, qed tistenna tarbija jew diġa inti omm?
  - (f'każ li l-partecipanta hija diga omm) Kemm għandek tfal u x'inhi l-eta` tagħhom?
  - tinsab f'relazzjoni jew single?
- 2. Il-mod li bih nisa b'diżabilta` jħarsu lejhom infushom, jaffetwa d-deċiżjoniet tagħhom dwar il-possibilta` li jsiru ommijiet? Kif jaffetwa?
- 3. Kif taħseb lis-soċjeta` Maltija tħares lejn nisa b'diżabilta` li qed jaspiraw/jippjanaw biex isiru ommijiet u lejn dawk li huma ommijiet?
- 4. Xi tfisser għalik li tkun omm?
- 5. X'inhi l-esperjenza tieghek dwar il-hajja riproduttiva?
- 6. X'sibt ta' għajnuna f'din l-esperjenza?
- 7. X'sibt ta' xkiel?
- 8. Tbiddel xi ħaġa f'din l-esperjenza?
- 9. X'jimmotivak/immotivak biex issir omm?
- 10. Il-fatt li ddeċidejt li ssir omm, kif jaffetwak?
- 11. (għan-nisa li qed jaspiraw biex isiru ommijiet) Kif taħseb li tħossok jekk ssir omm?
- 12. Liema huma dawk il-fatturi li jinfluwenzaw nisa b'diżabilta` milli jsiru ommijiet?

  Għaliex?

13. X'tissuġġerixxi li għandu jsir f'Malta biex jgħin nisa b'diżabilta` li qed jaspiraw/jippjanaw biex isiru ommijiet? U x'jista' jgħin lil dawk li huma ommijiet?

#### **Appendix O: Sample of Thematic Analysis**

First Coding Sample

Li tkun mara anke' jekk ma jkollox diżabilta' ukoll hemm čertu stigma. Aħseb u ara jekk ikollok diżabilta' u mbagħad ikollok it-tfal. Li Itaqjt magħha anke' xi ħadd li ma tkunx tafu jekk per eżempju tiltaqa' miegħu kif jarak bil-krozzi u tgħidlu li għandek it-tfal, tarhom, tkun qed ittihom informazzjoni li ma jkunux qed jistennew għax mhux fin-normalita' li jkun hekk. Li m'għandux ikun fil-verita' imma specjalment Malta l-aktar li tiġri din.

Aħna niġu ġġudikati ħafna u l-kapaċitajiet tagħna jiġu ddubitati. Kemm jiena bħala persuna b'diżabilta' u kemm nies oħrajn qisna irridu nagħmlu effort akbar għax we have to show the world li aħna nistgħu nagħmluha l-ħaġa. Per eżempju jekk jiena għajjejt, jekk xi ħadd li m'għandux diżabilta'jaqbad u jgħidlek jiena għajjejt, imma jiena biex nuri li jiena kapaċi lis-soċjeta' irrid nagħmel extra effort anke' jekk inkun għajjejt. Ma rridx li jgħidu li jiena noqgħod lura, li ma nagħmilx dak li hu dmiri jew li jien miniex responsabbli. Trid turi lid-dinja li inti abbli.

Qabel dan kollu kien aktar jaffetwani mil-lum. Qisek maż-żmien ma tibqax tagħti każ dak li jaħsbu jew jgħidu n-nies kemm tista' għax xi ftit jew wisq jaffetwak. Imma ma nħallihomx jinfluwenzawni b'mod ħażin għax imbagħad inkun qed nagħmel ħażin lis-saħħa mentali tiegħi u ma nkunx kapaċi naffronta dak li ħa jkun se jiġi quddiemi jekk noqgħod nagħti każ ta' dak li jaħsbu n-nies. Imma ehe xi kummenti niltaqgħu magħhom diversi drabi minn diversi tipi ta' nies. Imma ma nħallihomx jinfluwenzawni jiena.

Per eżempju meta kelli t-tifla inti kif ħa tkun tista' tagħmel hekk, din il-ħaġa per eżempju. Kif ħa tkun tista' tlibbisha? Kont insib il-metodu tiegħi, naddatta għas-sitwazzjoni u għaċcirkostanza u ehe nlibbisha jien. Kont insibha difficli fil-bidu. Ma nistax nghid li kollox kien plain sailing fil-verita' għax per eżempju meta telget timxi. Meta kellha xi sena ma kinitx tifhimni li jiena peress li kont nuża l-krozzi, kont nagħtiha subajja u żżomm miegħu biex naqsmu t-triq jew xi ħaġa. Imma meta kellha sena kont insibha diffiċli għax ta' sena mhux ħa jifhmu t-tfal. Pero' jiena bħala persuna ma kontx noggħod lura mill-affarijiet għax dik ilħaġa ma nistax nagħmilha. Jiġifieri kont noħodha l-bandli u kont per eżempju nqabbad linnies biex jerfgħuha. Ma kontx inkun nafhom u tipo kont ngħidilhom tista' terfqħuhieli qħal fuq il-bandla? U dejjem sibt għajnuna jiġifieri. Ħafna drabi trid tkun ukoll mill-persuna minna li fejn ghandna bżonn l-ghajnuna nistaqsu ghaliha bil-prudenza ovvjament imma fejn nafu li hemm limitazzjoni li mhux thallina nilhqu dak li nixtiegu nsagsu ghallgħajnuna u nieħduha. Jien gatt ma kelli problema biex nirċievi l-għajnuna li tlabt. Għalija sodisfazzjon kbir li jiena omm. Anke' meta twieldet, jien ċesarja wellidtha t-tifla u jitfgħuhielek fuqek hekk, feeling li ma tistax tispjegah. Anke' per eżempju gabel ma kelli ttifla meta kont pregnant jekk ha naqa', ghax jien naqa' hafna ovvjament, nibża' li ha naqa' għax tista' tkunli taf int ta' ħsara u hekk. Kien hemm mumenti li kienu stressful għalija aktar minn min m'għandux diżabilta', imma ovvjament nipprova naddatta maċ-ċirkostanza li tiģi. Ma nimmaģinax hajti minghajra t-tifla. Illum saret tifhem, ir-relazzjoni għandna ħafna bonding bejnietna. Għalkemm għadha żgħira d-diżabilta' tiegħi għaliha normali. Tara lili bil-krozzi kuljum u għaliha qisu xejn mhu xejn.

Jiena bħala persuna ma nippruvax nagħti każ ta' dak li jgħidu n-nies. Dak li jkolli bħala goal inkun nixtieq li nilħqu għalkemm ikun hemm ħafna diffikultajiet xi kultant, imma jekk ma jirnexxiliex waħdi nipprova nsib il-mezzi u l-għajnuna. Illum hawn ħafna jiġifieri fejn tista' tirrikorri għall-għajnuna u nipprova mmexxi.

**Table N1: Thematic Analysis Colour Coding Chart** 

Themes		
First Coding	Second Coding	Third Coding
the joy of		
motherhood		
assumed incompetence	relationships	
	removal of children	
	inadequate parenting	
stereotypes and prejudices	eugenic beliefs	
	over-protection	psychological effects
	from zero to hero	
physical versus invisible	support	family
disabilities		services
		society

**Appendix P: Support Services** 

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Dr Claire Lucille Azzopardi-Lane

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Motherhood: Listening to disabled women

Dear Participant,

I hope this email finds you well.

I would like to take this opportunity to thank you for your participation in this study. I appreciate your involvement and cooperation throughout this entire process.

I would like to remind you of the aims of this study which were:

- to explore the opportunities and barriers that disabled women face in their reproductive lives and
- to explore disabled women's perceptions about disability and motherhood in a Maltese context.

This study was not anticipated to cause distress and the interview questions were formed in as sensitive a manner as possible however, if your participation has led you to experience any distress or discomfort for whatever reason, then below I have included some information about services that offer free professional support that you might find helpful.

If you require any additional information or wish to report any concerns about this study, please do not hesitate to contact either myself or my research supervisor as indicated above.

This list is related to psycho-social or mental health and well-being services. The last two services are generic support services which can be accessed 24/7.



#### **Richmond Foundation**

info@richmond.org.mt

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Supports both individuals who are experiencing mental health problems as well as those around them. Apart from supporting individuals by offering therapeutic help, Richmond Foundation also guides individuals by teaching the necessary skills to live and work independently. Their services include support groups, assisted living solutions, educational programmes, as well as counselling services.



## Support line 179

This is Malta's national helpline acting to provide support, information about local social welfare and other agencies, as well as a referral service to individuals who require support. It is also a national service to individuals facing difficult times or a

crisis. Their primary mission is to provide immediate and unbiased help to whoever requires it.



## 21244123/21335097

<u>kellimni.com</u> is an online support service in which trained staff and volunteers are available for support 24/7 via email, chat and smart messaging. This service is managed by SOS Malta.

Appendix Q: Servizzi ta' Sapport

**Charmaine Muscat** 

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**Dr Claire Lucille Azzopardi-Lane** 

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Motherhood: Listening to Disabled Women

Għażiża Parteċipanta,

Nittama li dan l-imejl isibek tajba.

Nixtieq nieħu din l-opportunità biex nirringrazzjak tal-parteċipazzjoni tiegħek f'dan l-istudju. Napprezza l-involviment u l-kooperazzjoni tiegħek matul dan il-proċess kollu. Nixtieq infakrek li l-għanijiet ta' dan l-istudju kienu:

- li niskopri l-opportunitajiet u d-diffikultajiet li jiltaqgħu magħhom nisa b'diżabilta` filħajja riproduttiva tagħhom u
- li niskopri x'jaħsbu n-nisa b'diżabilta` dwar id-diżabilta` u l-fattur li ssir omm f'Malta.

Dan l-istudju ma kienx anticipat li jikkawża diffikultà u l-mistoqsijiet tal-intervista ġew magħmula bl-iktar mod sensittiv possibbli, madankollu jekk id-diskussjoni wasslitek biex tesperjenza kwalunkwe tbatija jew skumdità għal kwalunkwe raġuni, hawn taħt jien inkludejt xi informazzjoni dwar servizzi li joffru appoġġ professjonali b'xejn li tista' ssib utli.

Jekk teħtieġ xi informazzjoni addizzjonali jew tixtieq tirrapporta kwalunkwe tħassib dwar dan l-istudju, jekk jogħġbok toqgħodx lura milli tikkuntattja kemm lili stess kif ukoll littutur tar-riċerka tiegħi kif indikat fuq nett ta' din l-ittra.

Din hija lista ta' servizzi ta' sapport relatata ma' servizzi ta' saħħa mentali jew saħħa psikosoċjali. L-aħħar żewġ servizzi huma servizzi ġeneriċi li huma aċċessibli 24/7.



#### **Richmond Foundation**

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Jappoġġa kemm individwi li qed jesperjenzaw problemi ta 'saħħa mentali kif ukoll dawk ta' madwarhom. Minbarra li tappoġġja individwi billi toffri għajnuna terapewtika, Richmond Foundation tiggwida wkoll individwi billi tgħallem il-ħiliet meħtieġa biex jgħixu u jaħdmu b'mod indipendenti. Is-servizzi tagħhom jinkludu gruppi ta 'appoġġ, soluzzjonijiet ta' għajxien assistit, programmi edukattivi, kif ukoll servizzi ta 'pariri.



## Linja ta'Appoġġ 179

Din hija l-linja ta 'għajnuna nazzjonali ta' Malta li taġixxi biex tipprovdi appoġġ, informazzjoni dwar il-benesseri soċjali lokali u aġenziji oħra, kif ukoll servizz ta 'riferiment għal individwi li jeħtieġu appoġġ. Huwa wkoll servizz nazzjonali għal individwi li qed

jiffaċċjaw żminijiet diffiċli jew kriżi. Il-missjoni primarja tagħhom hija li jipprovdu għajnuna immedjata u imparzjali lil kull min ikun jeħtieġa.



Kellimni .com

http://kellimni.com/

21244123/21335097

kellimni.com huwa servizz ta 'appoġġ online li fih persunal imħarreġ u voluntiera huma disponibbli għall-appoġġ 24/7 permezz ta' email, chat u messaġġi intelliġenti. Dan isservizz huwa amministrat minn SOS Malta.