



L-Università ta' Malta

Faculty for Social Wellbeing

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Project carried out by: Dr. Claire Azzopardi Lane

Project Manager: Professor Andrew Azzopardi, Dean of the Faculty for Social Wellbeing

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Positive Parenting Project

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1. Literature Review

1.1 Parenting with disability

Raising children in today's society might be seen as an undervalued occupation, but for disabled parents the challenge is to overcome the culture's refusal to recognize them as potential parents and functional family units (Killoran, 1994). This could be due to the fact that disabled people are considered to exist outside the boundaries of reproduction (Waxman & Finger, 1989; Kallianes *et al.* 1997; McDonald *et al.* 2007). The greatest of concerns seems to revolve around their ability to raise a child and their presumed incompetence (Killoran 1994; Lee & Oh 2005; Reinders, 2008; Wade *et al.* 2008). Cases where children are taken away from disabled parents because they are deemed unfit, sometimes with legal procedures starting prenatally, are often reported (Killoran, 1994; Begum, 1992; McConnell and Llewellyn, 2000; Azzopardi, 2017). Furthermore, for disabled persons, parenting tends to be

overshadowed by inter-related problems, such as low income, the risk of more than average health problems, ineffective professional support, and social networks as well as negative public responses (Aunos and Feldman, 2002; McConnell and Llewellyn, 2010). Care and health professionals, as well as the family court system are known to operate from a deficit model of disability aspect. Such model reflects their view of disabled parents as inappropriate and incompetent for the role of parenting (Malcarida, 2020). Disabled parents are seen as offering a not 'good enough' type of parenting, falling short of the ideal parenting benchmarks. Parenting by persons with intellectual disability is perceived even more negatively (Stenfert Kroese *et al.* 2002). Although parenting is supposedly based on a principle of equal citizenship rather than parental competence, people with intellectual disability tend not to have children due to social barriers rather than because of their intellectual impairment (Kallianes *et al.* 1997). Numerous times they find themselves in positions where choices over parenting are decisions that others make for them (Reinders, 2008).

Historical ideas that are still present about disabled people's rights to reproduce and rear children, have strongly influenced the dearth of information, policy and services relating to disabled parenting. The experiences of disabled parents have been unexamined and underserved by boarder policies and supports relating to families and parenthood (Malcarida, 2020). Consequently, the ambivalence related to disabled parents is evident in the lack of mainstream family policies, indicating an unspoken assumption that disabilities and parenting are incompatible.

1.2 Disabled women as mothers

Malcarida (2016) coined the term 'newgenics', to describe subtle, overt, or informal ways in which disabled women's reproductive possibilities continue to be both actively and passively policed. Pressure is often exerted by family members, care, and medical personnel, to undergo sterilisation or take up long term contraception, in order to avoid the possibility for women, with physical, sensorial, psycho-social, or intellectual impairments to become mothers (Steele & Dowse, 2016). Such pressure is often tied to the women's independence, such as freedom from guardianship arrangements or living independently (Malacrida, 2020). While motherhood is an important and natural part of a women's identity, it is a forbidden

issue for disabled women, especially for women with intellectual disability (Rodgers, 2001). These women tend not to be accepted as having an adult status and remain constrained by the community's negative perceptions and assumptions (McCarthy; 2009). They are not expected to become girlfriends or lovers and are often told that marriage is not a possibility and even less motherhood. Since it is still not considered to be culturally normative for disabled women to become mothers, those who do thus doubly transgress social norms. Their status as mothers highlights their sexuality in a society that tends to portray them solely as persons with disability and to place their womanhood as a characteristic that is subservient to their disability (Garland-Thomson, 2002). The message given out by the medical field also suggests that disabled women are not eligible for traditional societal female roles (Killoran, 1994; Kallianes *et al.*, 1997). Disabled women recount the lack of sensitivity health professionals demonstrate towards their rights of having a child, reinforcing beliefs that they are unable to adequately care for their children (Yoshida *et al.*, 1999). It is often the case that disabled women are not given information about sexuality and birth control as it is assumed, they do not require it. Negative attitudes held by healthcare professionals not only affect the way disabled women see themselves, but they also restrict necessary information required by these women, affecting their ability to make choices related to their sexual lives and procreation (Begum, 1996). Disability rights advocates suggest that the politics of eugenics underlines the repression of the sexuality of disabled persons, especially those with intellectual disability and the reproductive rights of women with intellectual disability (Kallianes *et al.* 1997; McCarthy, 2009). Medical choices concerning contraception and surgical irreversible methods such as sterilization have been performed without their consent, with the aim to protect against unwanted pregnancy (Servais *et al.*, 2002). There is also often the concern that disabled women will produce a child with similar conditions (Lee & Oh 2005).

Kallianes and Rubinfeld (1997) claim that women's movements and disability rights movements have given sexuality and reproductive rights of disabled women insufficient importance. Reproductive rights have been interpreted as the right to be free of unwanted pregnancy, to obtain contraception and safe, legal abortion, however disabled women believe it should also include the right to bear and raise children.

Research has reported (Lee & Oh, 2005; Kallinianes *et al.*, 1994) that disabled women who wanted to have a child believed that this was a possibility with the appropriate social support (Llewellyn, 2002; Aunos, Feldman, & Goupil; 2008). The need for supportive networks for these mothers is underlined by various researchers (Killoran, 1994; Kallinianes *et al.*, 1997; Llewellyn and McConnell, 2002; Lee & Oh, 2005) who maintain that failure to parent lies in inadequate professional support, rather than in the disability itself being an indicator for failure (Wade *et al.* 2008). Moreover, Reinders (2008) affirms that since women and men with intellectual disability will be living on their own in the near future, rather than in institutions, under the control of professionals, more children will be born to people with intellectual disability. He concludes that; *“they do what other people do: find friends, fall in love and make babies”* (Reinders, 2008, pg.312).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006) asserts the rights of persons with disability to a family life. Article 23, Respect for home and the family, includes the following rights among others:

‘to marry and to found a family . . . to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education. . . In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents’.

Based on the UNCRPD, the National Disability Policy (2014) makes direct reference to Sexuality and Parenthood (pg.62). Point 12.1 of the said policy confirms that “persons with disability have the right to form intimate relationships and raise families”. Furthermore, point 12.2 endorses disabled parents’ right to have access to goods, services and other kind of support that would ensure that they could fulfil their role as parents. The measures related to these points made in the National Disability Policy underlined that professionals should be given training to ensure that disabled persons are not discriminated against when it comes to goods, services or any other kind of support that could facilitate as well as maintain their intimate relationships, and/or in fulfilling their roles as parents effectively (point 12.7 pg 64-

65). Point 12.8 concludes that *“supported parenthood schemes should be created and sustained in support of parents with disability”*.

Following the National Disability Policy (2014), the Malta National Disability Strategy was launched for consultation in 2016. Objective 12 of this strategy document further addressed the needs of disabled parents, whilst acknowledging that this subject has been *“considered a taboo for way too long now”*.

According to the latest census held in 2011, 3% of parents with dependent children self-reported a disability and may need extra support. Contrary to public perception, disabled persons are capable of being good parents and tend to show remarkable resilience in finding ways of overcoming impairment-related barriers. Nevertheless, these parents may need extra support. This is often provided by the extended family but state support is also available through Aġenzija Support. Point 3.5.4 of the Positive Parenting National Strategic Policy (2016-2024) refers to Supporting Positive Parenting by state service provider; Aġenzija Support. Aġenzija Support works with disabled persons and their families, providing them with opportunities that enable them to fully participate in community life. Besides supporting parents whose children have a disability, the agency also supports parents who are themselves disabled.

The work force at Aġenzija Support is mainly made up of social workers, allied health professionals, psychology graduates and support workers. The Positive Parenting National Strategic Policy’s Actions suggest that continuous professional development of staff, on a strengths-based approach (Margalit & Kleitman, 2006) and on the social model of disability (Oliver, 2004) is therefore very important. This model is based on constant consultation with parents and children with a disability and would help professionals empower parents in the upbringing of their children.

In light of the above, it is thus crucial to speak to disabled parents themselves about their experiences. Listening to the voices of disabled mothers and fathers exposes gaps in policies and practices that ignore them and impinge upon their parenting experiences. Narratives, taken from the viewpoints and experiences of disabled parents, offer an important

perspective to traditional interpretations of disabled parenting as operating from the deficit model. By connecting personal narratives to broader social structures, we obtain insights into the intersectional aspect of disability.

The Positive Parenting Project was conceived with the following objectives in mind:

1.3 Objective 1a of the Positive Parenting Project

- Form an advisory group of disabled mothers / parents (from a variety of impairment groups) to identify and list the challenges encountered in their experience of pregnancy and motherhood/parenthood and the needs that require being met by both health and disability services.

2. Methodology

Following ethical clearance from the Faculty Research Ethics Committee (FREC), information letters were distributed by the Commission for the Rights of Persons with Disability, and local NGOs. The information letter was also translated into easy to read and converted into a video for sign language users. The information letter outlined the purpose of research, what was required of the participants and the participants' rights if they involved themselves in the research. Interested participants had to contact the researcher if interested in being interviewed or for further information. Due to Covid19 restrictions, one to one interviews were held via zoom with the disabled mothers/parents.

A number of interested participants contacted the researcher. Details of the participants in Table 1.

Role	Age group	No. of children	Impairment group	Congenital or Acquired
Mother	40-45	1	Hidden Disability	Acquired

Mother	30-35	1	Physical & Hidden Impairments	Acquired
Mother	30-25	1	Sensorial	Congenital
Mother	25-30	1	Sensorial	Acquired
Father	60-65	2	Physical	Acquired

Since no parents with intellectual disability came forward to participate in the research, the Ethics and Data Protection Form was altered to include professionals who worked with parents with intellectual disability. Information letters were sent out to professions through the national service provider for disability services, Aġenzija Sapport. Two professionals participated in the research. During the interviews both disabled parents and professionals recounted their experiences and made recommendations on how disability services and mainstream services for disabled parents can improve.

3. Interview Findings: Parents & Professionals

Some of the following findings emerge from interviews carried out with professionals working in disability services. Because no parents with intellectual disability came forward to participate in the research, the call for participation was extended to include professionals who had experienced supporting disabled parents. Because third party consent was not provided by the parents with intellectual disability, the reported findings do not refer to explicit experiences of disabled parents but more to the overarching experience and perspectives of the professionals themselves.

Quotations are translated into English where the interview was carried out in Maltese.

3.1 Disabled mothers

Although this research was aimed at disabled parents, the respondents were mainly mothers and professionals who had experience at supporting disabled mothers. Malacrida (2020) underlines how reproductive control and parenting support are both highly gendered arenas in which women bear an unequal burden. Furthermore, gendered norms and structures, such as educational and employment opportunities, render disabled women more vulnerable to perceived and actual parenting challenges than disabled men. Saying that, the voice of disabled fathers is missing in disabled parenting research, and recommendations for research focusing on their experiences is highly solicited and addressed in the recommendations section.

Increased pressure felt by disabled mothers is well documented, often as a result of the extensive responsibility they carry (Asch, Rousso, Jefferies, 2001; Malacrida, 2020). An example of such experiences was related by a disabled mother who explained how she felt when she had home visits by the midwife;

“as a mother with disability I used to feel a lot of pressure and used to make sure that [my baby] was clean and that his nappy was in place, god forbid if they (midwives) came and found that I was doing something the wrong way and say that I’m doing it wrong because of my disability and I cannot take care of him, because maybe they would take him away. Because I have a disability so the bar is much higher for me.

“jiena bħala omm b’dizabilità kont inħoss ħafna pressure, I used to make sure li [l-baby] nadif, li għandu n-nappy qiegħda sew, li ma jmurx jigu l-midwives u jsibu li qed nagħmel xi ħaġa ħażina, u jgħiduli li qed nagħmilha ħażin għax jien disabled, u allura ma nistax nieħu ħsiebu, għax forsi joħduhuli. Għax jiena b’dizabilità allura the bar is much higher for me.”

3.2 The sensationalised disabled parent

Disabled parents have often made headlines because they transgress the social expectations that are attributed to disabled persons. A Deaf mother described how since she was the first Deaf Maltese person to ever adopt a child, there were a number of journalists who took interest in her story and articles were written in the local media about her parenting experience. Such reports are telling. On one hand they bring awareness to the general public

about disabled persons and their role as parents or even adoptive parents in this case. At the same time, the mere fact that becoming a parent needs to be reported in local media simply because the parent lives with an impairment and therefore the parental experience becomes a news item, is worrying. A physically disabled mother concluded that this was a result of society not expecting to see disabled women in the role of mothers. She framed this notion of sensationalism by stating;

“it is like something out of this world that a mother has a disability”

“qisha xi ħaġa ta’ barra mid-dinja li għandek omm li għandha dizabilità”

3.3 Provisions for the individual needs of disabled parents/mothers

Although the parental role is seen as a leap forward for disabled people’s rights, and also as mentioned above at times it is reported in the media as an exceptional life event, parents who participated in this research reported that their needs as disabled parents are not met as necessary once they are navigating the parenting world. Society fails to provide mainstream services that are accessible for disabled parents. Physical accessibility has been a mainstream issue for decades, as this mother explained;

“after you have the baby, most of the things you are expected to do as a mother are not accessible for mothers with a disability”.

“wara li jkollok il-baby, ħafna mill-affarijiet li inti mistenija tagħmel bħala omm mhumiex aċċessibli għall-ommijiet b’dizabilità”.

Examples of inaccessible venues and services ranged from privately owned venues used as mother and baby clubs to the venue used for the state run Read with Me early literacy program. This mother again confirmed that this situation arises from the fact that society does not think that disabled women can also be mothers. She also reported how at times she would be told that a venue is accessible when in reality it would not be. She claimed that;

“society’s idea of accessibility is not what real accessibility is, for instance there would be a ramp but it would be very steep”.

“dak li s-soċjetà taħseb li hu aċċessibbli ma jkunx tassew aċċessibbli, eżempju jkun hemm rampa imma tkun wieqfa ħafna”.

The crucial need for a sign language interpreter to accompany a Deaf mother/parents to be to hospital visits was underlined. Without the sign language interpreter, the Deaf mothers said they would not have coped. Health professionals were reported to be initially surprised about the role of the third person accompanying the parents. This further identifies the need for awareness and training amongst health professionals about the support needs of parents from different impairment groups.

Sign language interpreters were also said to be of indispensable support to parents during the state run Parentcraft courses.

“without the interpreter it would have been immensely difficult, I wouldn’t be able to understand, because the teacher explaining the course speaks fast, she does not look at me, and my husband is Deaf too so he couldn’t help me”.

“mingħajr l-interpreter kien ikun diffiċli immens kieku, ma kontx inkun nista’ nifhem, għaliex it teacher li tispjega l-course, titkellem tgħaġġel, ma tħarisx lejja, ir-raġel tiegħi Deaf ukoll u ma setax jgħini”.

Another mother explained how left out she felt during the Parentcraft courses. She described that all the focus was on breast feeding when she could not breast feed due to her hidden disability. She reported that alternatives to breast feeding were perceived negatively and the implications for disabled women, especially those with invisible impairments, were not taken into consideration.

The double discrimination experienced by disabled parents who have a child who also has a disability was highlighted in the experiences of Deaf parents. A Deaf parent who required services for her child from the Child Development Assessment Unit (CDAU), described how she “felt bad” because no one knew how to sign there, therefore she could not communicate with anyone. She recounted questioning how come no one knew how to sign and what would happen if any of the children requiring services were Deaf sign language users. Because of this lack of access, she had to depend on her parents who attended for services with her and her son and acted as an interpreter. This allowed her to communicate with the medical

professionals or therapists, however this arrangement was not always possible and there were times when she had to go on her own. Such lack of access to communication for Deaf persons puts these parents in a position of vulnerability and powerlessness, making them dependent on others, and in the absence of that support network, leaving them stranded.

“There is no sign language anywhere. There is the need for more awareness about the use of sign language, not only for me, but also for the children who are Deaf”.

“Ma hemm sign language imkien. Hemm bżonn ta’ aktar awareness fuq l-użu tas-sign language, mhux għalija biss, imma anki għat-tfal li huma Deaf”.

Awareness of the needs of Deaf parents was reported to be lacking within the school system, starting from the statementing services. A Deaf parent recounted how after having been referred for statement services by the CDAU, the parents were called for a meeting. The report by CDAU clearly stated that the parent was Deaf, but the services of a Sign Language Interpreter was not provided during the meeting and the mother recalled how she could not understand what was being said during this meeting. In other environments, such as the Child Care Centre, the Deaf parent recounted using written emails to communicate with the service providers, but the grandparent’s support was also required on a regular basis. The parent felt that persons working in these environments were not trained on how to deal with disabled parents.

Once her son started school, the Deaf mother reported that she also found it difficult to have her communicative needs met. Her son’s learning support educator (LSE) happened to be new to the job, untrained and not knowledgeable about the needs of Deaf persons. Many times, the grandparents would go to school and speak with the LSE and then report back to the mother. The mother also explicitly asked the school to use emails to communicate with her when possible, which was something they complied with. During the current home-schooling experience, due to the COVID 19 pandemic, Deaf parents reported specific challenges related to online learning. They explained how they find it hard to understand what is being said since video calls are regularly used as part of online teaching.

3.4 The hierarchy of disability

It is also worth mentioning how not all disabled persons are perceived in the same way by society and what is known as the hierarchy of disability also extends to the parenting role. The hierarchy of disability originates from the stigma associated with disability (Deal, 2003), whereby persons in an impairment group differentiate themselves as being better than those from other impairment groups. This hierarchy is further reflected in non-disabled people's behaviours (Miller, Chen, Glover-Grafand Kranz, 2009; Azzopardi Lane, 2011). When extending to disabled parents, parents with intellectual impairments or psycho-social impairments are seen as the least fit to parent. Moreover, as a disabled parent stated; ***"the less society perceives you as capable (to mother/parent) the higher the expectations are set for your parenting role"***.

Persons with hidden disabilities are known to suffer from this form of double stigma. A mother with a hidden disability reported how because her disability is not visible it is often overlooked, questioned, and at times met with disbelief. She described a situation where she was trying to explain her condition to local authorities and claimed that; ***"I was dismissed without being given the chance to even say a word, and I am an eloquent person but... I just let it go..."***. Such narratives bring up two important points, the first point is the powerlessness and disablement experienced by these parents, the second the double discrimination experienced by minorities within the minority of disabled parents.

3.5 Insensitivity, Invisibility and Disableism

Disabled parents seem to be further disadvantaged by a society where ableism and disableism prevail. Participants recounted experiences that highlighted their realities, amidst insensitivity and being rendered invisible. A Deaf mother recalled her experience while she was delivering her child.

"I had hardly seen him that she took him away to check his hearing. We had long decided that it would have not been a problem [if he was born deaf]. But I wanted to tell her that I knew straight away that this baby could hear, I could see he was very responsive to sound".

“Bil-kemm kont għadni rajtu li ma ħaditux (il-midwife) biex tiċċekjalu s-smiġħ. Aħna konna ilna li ddeċidejna li ma tkunx problema. Imma jiena ridt ngħidilha li jiena kont naf mill-ewwel li dan il-baby kien jisma’. Stajt nara li kien responsive ħafna għall-ħsejjes”

During a medical visit to a paediatric consultant, a Deaf parent recalled how she was told that since her speech was not clear (due to her hearing impairment), she was not a positive influence on her child.

“the doctor told me that my speech is not a positive influence at all to my son. Obviously children learn from their mummies, he had really hurt me when he said this, so I stayed quiet [and didn’t speak much] so my son would not hear me”.

“it-tabib qalli li l-ispeech tiegħi vera mhux ta influwenza tajba fuq it-tifel. Ovvjament it-tfal jitgħallmu mill-mama tagħhom, u vera weġġgħani x’hin qalli hekk, allura kont qadt kwieta biex ma jismagħnix (nitkellem) it-tifel.

The mother further claimed that professionals might have beliefs that do not reflect the truth about their abilities. Assumptions of parental incompetence have been widely reported in literature, together with concepts of ableism, prevalent in many contexts, including professional ones meant to provide support services to disabled persons. This mother reported how she felt that without saying it, medical professionals blamed her, being a Deaf parent, for her son’s developmental issues. She confessed to have felt very stressed because of these things. The parent also recalled how the biological mother of her adopted son had doubts about her parental competence. She explains that the biological mother feared that because she was Deaf, she would not be ***“up to standard”***.

Experiences of insensitivity were reported by a mother with hidden disabilities who reported insensitive behaviour when it came to breast feeding. Her experience at the Breast-Feeding Clinic was recalled as being ***“extremely negative”***, as the professionals did not take into consideration the fact that some mothers might have invisible disabilities that would not allow them to breast feed.

Invisibility is regularly reported by disabled persons when in the presence of non-disabled persons. A disabled mother recounted how she experienced invisibility when she and her son

attended medical visits accompanied by a hearing person. She recalled how when speaking about her son, the medical professionals carrying out her son's visit would address the hearing person accompanying her and not her. She explained;

“They used to address the hearing person, just like I was not there. I am his mother! He is MY son! Why are you addressing his grandfather?”

“Kienu jindirizzaw lil persuna li tisma’, bħallikieku jiena ma kontx hemm. Jiena ommu it-tifel! Dak it-tifel TIEGħI! Għalxiex qed tkellem lin-nannu?”

The mother concluded that she felt she had a duty to know how her son was progressing, therefore she wished to know the professionals' feedback. She stated that such behaviour just proved that these professionals do not have awareness about how to behave with disabled parents.

3.6 Examples of good practise

Although some medical professionals were reported to lack sensitivity and awareness when working with disabled parents, some examples of good practice also emerged. Such as that of a disabled mother who explained how it had been her long-term medical consultants who encouraged her to have a child. Another mother recalled how when all resources to get pregnant were exhausted, her consultant suggested that the couple should look into adopting a child, with none of the stereotypical reservations about the Deaf mother. During the process of adoption, the mother also reported not having any problems related to her impairment, something which she had feared to encounter. She also made reference to allied health professionals who were very supportive and encouraging, and who did their best to communicate with the mother.

A Deaf mother further praised the midwife who had delivered her baby for her ability to communicate through the difficult delivery process. She described how the midwife did not know sign language however, by using a lot of facial expressions and focusing her communicative efforts directly on the mother managed to support her fully. The mother explained how; ***“she was looking at me... sometime people don't look at me when they talk to me”***.

3.7 Referral to Child Protection Services

Disabled parents are referred to Child Protection Services for a number of reasons, including emotional, educational, physical neglect. At times they are referred for lack of hygiene in the home, personal hygiene on the children themselves and their school items.

Professionals reported that;

“The physical neglect is what was most visible, and the most evident. These ring the alarm bells first.”

Educational neglect was at times also an issue. Professionals reported that disabled parents might not have had a positive experience within the education system. Therefore, they do not always have awareness on how important it is to make sure their children are accessing education.

“Possibly because they were brought up at a time where schooling was not relevant for persons with disability, they would not worry if their children missed school for a week or a semester”.

Emotional neglect was also named as one of the reasons for referral. Professionals described how parents would not be able to explain certain things to their children, were not knowledgeable about how to process certain emotions and how to deal with certain behaviours. Professionals claimed;

“They often lack parenting skills. I used to notice this even in people who did not have a diagnoses of intellectual disability”.

Reports of lack of boundaries and sexual abuse were also at times received. The situations that lead to such a referral often involved parents who would be isolated and who would find affection in people who would potentially put them and their children at risk.

3.8 Vulnerable persons or persons in a position of vulnerability?

Situations of vulnerability arise from the environment, negative attitudes and practices. Certain persons may be more at risk of being in situations of vulnerability than others and disabled persons are no exception. Nonetheless disabled persons are conceived, especially by non-disabled persons, as intrinsically vulnerable rather than finding themselves in positions of vulnerability due to contextual implications.

Persons with intellectual disability are reported as often falling victim to abusive situations. Family, friends and neighbours are described as possibly being the ones taking advantage of them, using them for their own objectives and in turn putting their children at risk. Examples of such situations would be using them for pushing drugs, prostitution or using their homes for illegal activities.

“They used to find this vulnerable person, who is afraid to refuse and say no”.

Disabled mothers are often seen by professionals as completely responsible for the safety of their children. They are also regarded of as being responsible for choosing safe partners and for regulating their partner’s behaviour. Ultimately mothers are held culpable when any type of family violence or breakdowns occur, even when they themselves are the victims (Knowles 1996; Roberts 1999). This responsibility is particularly onerous when we consider that disabled women are far more likely than other groups of women to be victims of sexual, psychological, economic and physical violence (McCarthy, 2009). Professionals reported that the mothers they worked with were held responsible and faced the consequences when concerns involving their children arose.

3.9 An official diagnosis of intellectual disability

It is often the case that an official diagnoses of disability is not present even though the intellectual impairment is evident to the professionals. The latter explained how this extensively limited them in how much they could support these parents.

“...because it was the elephant in the room, everyone knows but there no proof.”

Wider literature reports that disabled parents are very aware of the treat of a diagnoses (Malacrida, 2020). Professionals agreed that;

“if there is proof that there are an amount of limitations, unfortunately it can work against them (parents)”.

Numerous disabled parents decline an official diagnosis, and subsequent support services, for fear of being judged as inadequate, and being disqualified from keeping custody of their children. This pushes disabled parents to preferring to rely on their own resources rather than run these risks. These reports were echoed by a professional participating in the study who asserted;

“To administer psychological tests, you need the parents to cooperate. Now if they were being investigated they would be very paranoid about anything you do to them, as it may be interpreted as a means to lose custody of their children”.

Nonetheless, the lack of an official disability diagnoses can be a major deterrent. Professionals reported that it was very concerning that without a diagnosis they could not refer a parent for support services such as parenting skills support. They claimed that this would only contribute to the situation escalating. Such cases, professionals claimed were not isolated.

“I can think of a number of clients looking back, who had intellectual limitations, that it was quite clear, that they had an intellectual disability, but there was never a follow up to be seen by a doctor and even for themselves it would not be clear”.

The extent to which disability is still seen from a medical model perspective rather than from a human rights model is evident here. This situation creates a lacuna in disability services and in parental service provision. Furthermore, the professionals recounted how the disability many times would not be the main concern, because other present social issues, such as domestic violence and abuse, would be more problematic. This intersectionality, where the disability identity and the parental identity intersect with other variables is explained by Feldman’s (2002, 2020) contextual model of parenting. The contextual model of parenting, rather than putting the emphasis on intellectual impairment as the sole determinant of

parenting competence, takes into consideration economic and psychosocial hardships amongst other variables, affecting parent, child, and family outcomes.

3.10 Attitudes towards parents with intellectual disability

Parents with intellectual disability are described as inherently incapable of adequate parenting and unable to benefit from parent education, because of their intellectual impairment (Feldman; 2002). The overshadowing of intellectual impairment over other factors that may better predict parenting abilities, such as parent history of trauma, parental mental health, and social support is reported to have contributed to discriminatory child protection decision-making and legal outcomes regarding child custody when parents have an intellectual disability (Feldman, 2020). This was similarly described by professionals in this research who reported that *“certain biases towards parents with intellectual disability are quite clear”*. Furthermore, participants admitted that some professionals might assume parental incompetence without investigating and taking things at face value.

Feldman (2002, 2020) consistently cites contextual models of parenting that take into consideration economic and psychosocial hardships amongst other variables, rather than the current emphasis on intellectual impairments evaluations, as a proxy for direct measures of parenting competence. Furthermore, Feldman recommends that professions involved in parenting capacity assessments are trained to adapting assessments for parents who have intellectual disability, using a comprehensive, contextual approach, rather than the current emphasis on the intellectual impairment itself as a direct measure of parenting competence. A contextualized assessment identifies the needs and supports for the parent to be successful and may make service and support suggestions beyond parent education, such as building a support network, be more socially engaged, and participate in activities that promote parent, child, and family wellbeing.

Professionals in the field of disability services, who have experience supporting mothers with intellectual disability, identified the lack of autonomy these mothers have, and how decisions are taken by non- disabled others. It is widely acknowledged that disabled mothers are not

involved in decision making, their voices are not heard, and they are not asked for their opinions.

“they [professionals] decided whether she was able to continue supporting her child considering the support that she had”.

These participants also felt that professionals from Child Protection Services look at the best interest of the child without considering the rights of the disabled mother. They claimed that what they wanted to see, both through their professional capacity and through the service provided by Disability Services, was for disabled parents to be given their rights. One professional put this in a very simple manner by saying;

“... what we wanted to see was that she was being given more opportunities to spend time with her child and to be the mother she wanted to be.”

3.11 Resources and Support

Professionals explained how parents did not always understand why support and parenting skills training was being offered. In cases when the child/children had been removed from their custody, it was not uncommon that they did not understand that they could work towards improving on their parenting skills and regain access to their child/children. The obstacles encountered by professionals ranged from the parent/s not understanding the need for support and the consequences of not accepting support, to seeing support and parental training as a treat. Parents were described as resistant at times;

“Especially if you tell them that if the situation continues in this way the children might be taken away”.

However, unfortunately there is not always enough support available for disabled parents to avoid losing custody of their children. Nor are there sufficient resources to reintegrate the children when they are taken into custody and help disabled parents regain their custody. Professional reported that they would offer the parents a number of options, depending on the resources available, such as the support available from the extended family, the amount of pressure involved and the willingness of the parents to improve the situation.

“Without the adequate resources you are setting them up to fail. You are just allowing them more time to prove your case.”

Referring parents with intellectual disability to a mainstream parenting skills programme was regarded by professionals as useless, in line with wider studies carried out in Canada (Llewellyn and McConnell, 2010). However, professionals claimed that;

“the problem was to find a person who can help that parent with parenting skills at her level”.

The introduction and maintenance of a home-based parental skills training services by local service providers was instrumental in supporting parents with intellectual disability. The latter were reported to be more compliant, engage better and feel more at ease in this situation rather than being in a classroom with other (non-disabled) parents. Nonetheless, the training of professionals working in such parental skills training services about disability issues is imperative.

There are instances where paid support, in the form of physical help, is provided to disabled parents as a way of mitigating the removal of the child/ren. This form of support is expected to support the parents whilst teaching them skills and allowing them to practice skills learnt. Many times this form of support is outsourced and professionals found that it was not always adequate for disabled parents, especially for parents with intellectual disability.

“We continued to emphasise with the care agency, because unfortunately this is something we see with every client who has a carer, that they take full responsibility, they take over, even simple things that the mother was capable of doing, like making tea, the carer started doing, she was losing skills rather than gaining them”.

Professionals reported that although the support workers employed with the Agency are trained by the Agency itself and understand well what is required of them, the number of such support personnel is limited. When support is outsourced to third agencies, most of the time these carers are foreign and have worked in their countries as teachers, nurses or carers for the elderly. However, they would have never worked with disabled persons, neither with physical nor intellectual impairments. They very often have a medicalised understanding of disability, and do not see these parents from a competence-based rights model.

The need for professionals working within Child Protection Services to also be trained in disability issues so as to understand the individual needs of disabled parents, especially those

with intellectual disability, was also flagged. This was also crucial especially for those parents who live with an undiagnosed intellectual disability and are not eligible for services from Agenzija Sapport.

“One of the hesitations of mainstream service providers when linking up with us is that our clients have disabilities, and unfortunately a lot of their workers are not trained to work with persons with disability”.

There also still seems to be a rift when it comes to placing children with high support needs into care, even though this is viewed as the last resort. If this is required, professionals claimed to be concerned about the lack of availability of mainstream placements. They claimed that children with disability do not usually find a placement in mainstream settings or in the foster system either.

“Unfortunately, mainstream service providers feel that people with such high needs, like people with severe autism cannot fit within their homes”.

Professionals reiterated the importance of having social workers supporting and advocating for disabled parents when Child Protection Services are involved. In the case when children are taken into care the professionals sounded the concerns about the rights of the mothers, and how much these are taken into consideration by the Child Protection Services.

“With care orders we do see a lot of the time that the rights of the mother are not taken into consideration especially when they have a disability”

They felt that it was often the case that disabled parents were failed by the system, starting from the point where they are never given knowledge and information. At times the system would fail them by not even being given a chance to be a parent.

“Again it is the lack of resources that are failing these people.... no matter what we tried there was always some kind of wall that we were faced with, whether it would be lack of resources in regard to carers, whether it would be lack of resources in regard to where she is going to live”.

They also highlighted how imperative it is for parents to understand and learn about their parental rights. The overbearing recommendation, however, is for quality proactive sex

education and parental skill training to avoid children being taken into care and separated from their families.

3.12 Parental Skills Training

It is common for the support networks, both those consisting of relatives and paid support, to take over the mother's role. This possibly stems from predominant notions of overprotection but also extending to perspectives originating from a deficit model (McConnell & Llewellyn, 2002), whereby disabled parents are seen to operate from a position of inadequacy (Theodore, Foulds, Wilshaw, Colborne, Nga Yu Lee, Mallagha, Cooper and Skelton, 2018). Therefore, the non-disabled support tends to takeover rather than support the mother to gain parenting skills.

Professionals recommend that mothers are ***“given the main role in the child's life rather than the back end role”***. They further claimed that if a mother was ***“trained from the get-go, when she was pregnant, or even before she was pregnant things would work out very differently for the family”***. Being reactive to these situations, where a mother is already experiencing a crisis, might not allow enough time for skills to be learnt. Moreover, a reactive approach is likely not to be successful when there are ongoing issues, and little time to change things, especially if the child's safety is at stake. Professionals also reported that although the Child Protection Services do understand that many times the parents are the best person for the child/ren to be with, if the child's safety is compromised the probability is for the child to be removed and taken into custody.

A pro-active approach to sex education and parenting skills training can be implemented using a number of resources. In the 1980 [Professor Maurice Feldman](#) developed a competence based intervention programme that tackled practical skills, this is known as the [Step by Step](#) Parenting Programme. He also developed the Step by Step Family Game that targets older children (2 -10 years), and focuses on increasing the parent child rapport and cooperation. These programmes are tailor made for persons with intellectual disability and have been evaluated and re-evaluated in a number of contexts and are therefore evidence

based. Currently in the United States the Department of Justice has issued a ruling where child protection agencies have to provide evidence-based interventions to parents with intellectual disability before they seek permanent removal of a child. The two programmes mentioned above, can be used proactively with parents with intellectual disability, they have also been used reactively with parents who are involved with Child Protection Services. Both programmes have yielded positive gains and helped parents not to lose custody of their children in a number of context (Llewellyn and McConnell, 2010).

[The Real Care Baby](#) is an infant simulator widely used with adolescents in Scandinavian countries. The latter can complement the Step by Step Parenting Programme. Another proactive way of addressing parenting skills is the use of Real Care Baby together with the [ASVZ Curriculum](#); ‘Children do I know what that involves?’ designed and implemented in Sweden with persons with intellectual disability as documented in their article entitled; An intervention using the Parenting Toolkit “Children—What does it involve?” and the Real-Care-Baby simulator among students with intellectual disability—A feasibility study ([Janeslatt, Larsson, Wikstrom, Springer and Hoglund, 2017](#)). Objective 1c of the Positive Parenting Project explores the parenting skills resources mentioned above and implements a training programme with professionals working in the field.

Furthermore, [sex education](#) resources focusing on boundaries, public and private behaviour, appropriate and inappropriate behaviour and recognising domestic violence and abuse (McCarthy and Thompson, 2016) are known to help recognising, avoiding or overcoming situations of vulnerability and abuse (Frawley and Wilson, 2016).

3.13 Recommendations

Following the interviews with disabled parents and professionals working in Disability Services a list of recommendations was drawn up to inform policy and practise. The recommendations as follows:

Research

- Wider research that captures experiences of parents from **extensive impairment groups**.

- Research that focuses on the experiences of **disabled fathers**.

Training

- **Disability equality and sensitivity training for professionals working in the medical field.** Ideally this training would be incorporated in the initial professional training of such professionals, however it can also be delivered as continuous professional development or in-house training.

“There were things that they said or did, that without them knowing used to hurt me, and that used to make me feel bad and worry that I am not a mother as I should be for my son”.

- Disability specific training for professionals involved in the design and delivery of the **Parent Craft courses**.
- Basic **sign language skills training for CDAU staff** together with an ongoing service of **Sign Language Interpreters** seen as a holistic part of the service, rather than as an additional accommodation.
- Training more Sign Language Interpreters by the University of Malta and increasing the services of **Sign Language Interpreters** by Disability Services to ensure comprehensive service provision.
- Training of professionals within disability services to deliver comprehensive, **competence-based parenting capacity assessments** based on Feldman’s contextual [assessment](#) model.
- Liaison with the Aġenzija Appoġġ and the Incredible Years Programme for **training of professionals working in Child Protection Services** in disability specific issues.
- Home based **parenting skills training services offered by Disability Services**, where said training is tailor made for the individual needs of the disabled parents using evidence based parent training programmes (such as [Step](#) by Step), and delivered by professionals knowledgeable at working with persons with intellectual disability.

Other recommendations:

- Competence based quality **community support services** for disabled parents, where support workers are trained at working with persons with intellectual disability.
- Resources for disabled parents, or parents to be, who require community-based **accommodation and personal assistance** for themselves and their child.
- A **re-evaluation of the provision** of Community Services (max. 13 hours) and Direct Payment schemes (especially if parent is not able to find support independently) to disabled parents or parents to be.
- **Communication policy** directed towards Deaf or hard of hearing persons, with procedures in line with Articles 9 and 21 of the UNCRPD, in education and health services.

“In the end it would be better on the system. When you calculate how many children are going into care, and see the emotional toll on them, and what is being spent on the resources to keep them in care, because once they are taken into custody, it is very rare that there is work for their re-integration. The work mostly happens with the children, to equip them with skills rather than with the parents to get their children back. So this would be an investment”.

4. Objectives of the Study 1.b

- Form a transdisciplinary team made up of physiotherapists, occupational therapists, nurses and midwives, social workers and support workers amongst other possible professionals, to identify the specific needs of mothers and mothers to be from a variety of impairment groups and outline a programme to address the needs identified.

A group of professions met online and discussed the requirements of disabled parents and parents to be from their professional lens. The following recommendations were made:

- **Community services** that address the needs of disabled parents. Such services would need to be flexible (not fixed hours) and provide **active support**.
- **Supported accommodation in the community** providing for the needs of disabled parents and their children.
- A **holistic approach** when addressing the needs of disabled families.
- **Integration of services with interlinked service provision**.
- **Multi-disciplinary team approach** addressing the learning and support needs of disabled parents, especially those who have children with disability. For instance, the support of Speech Language Pathologists (SLP) with feeding difficulties.
- **Pro-active environmental assessments** to determine adaptations for parents with mobility impairments in their living environments.
- **Physical handling assessments** and required adaptations or practical support intervention.
- **Psycho-social support services** offering counselling services.

5. Objectives of the Study 1c

- Identify and train a number (10-12) social workers working in the field of disability who will receive training in the use of Parenting Skills Programme for parents with intellectual disability.

The Parenting Skills Programme will follow 3 parenting skills programmes pioneered and used in several other contexts. The programs are:

- 1) Maurice Feldman's Step by Step Parenting Program, which is divided in the following 3 Stages.

Stage 1 – Teaching childcare and interaction skills to parents of new-borns, infants, toddlers and pre-schoolers. This program’s manual consists of task analysis checklists and picture books, illustrating the step-by-step parenting skills.

Stage 2 – Teaching parents of children between the age of 2 and 10 years how to promote positive parent- child relationships and prosocial child behaviour.

Stage 3 – Is a comprehensive competence based parenting capacity assessment for parents with intellectual disability, which provides an alternative parenting assessment specific for parents with intellectual disability.

2) The RealCare® Program will also be used. Two parts of the Real Care Program will be used in the training;

- The Parenting: A Guide to Parenting Skills for Life curriculum

- Basic Infant Care, which covers knowledge and skills for caring for young infants and toddlers.

- The Real Care Baby® Simulator 3 will be used for practical training with parents with intellectual disability. The Real Care Baby® Simulator 3 is the world’s most advanced infant simulator. Educators around the world use this unique learning aid to teach early childhood, parenting, infant health lessons, and sex education. This smart baby adds meaning and accountability by using wireless programming to track and report on caregiver behaviours. Tracked behaviours include care events, mishandling actions, time in a seat as well as clothing changes. By using the Real Care Baby Simulator professionals/instructors can create relevant and career-driven learning experiences.

3) ASVZ’s - The Toolkit, ‘Children, what does that involve?’

ASVZ has acquired a great deal of knowledge and experience regarding the topic of a desire to have a child by people with intellectual disabilities. In 2008-2009, they compiled their knowledge and experience in The Toolkit, ‘Children, what does that involve?’. This is a toolkit with games, instructions, and recommendations for how to engage clients, parents and fellow professional care workers in discussions about this topic. With this toolkit, ASVZ won the Dutch Disability Care award for the best Product

for Actual Practice in 2010, an award set up by the Dutch Association of Health Care Providers for People with Disabilities (VGN).

Objective 1c was completed in February 2020. In all 8 social workers employed with Aġenzija Sapport received 20 hours of training. The three curriculums were explored, the ASVZ is available online for free and was given to the social workers for future use.

The Step by Step Programme and the Family Game was donated for free to the researcher by Prof. Feldman as an act of collegiality. They were forwarded to the social workers for future use. Prof. Feldman also delivered a 50-minute presentation to the social worker's team via zoom. This was also delivered at no financial cost.

The Real Care Baby (RCB) curriculum was purchased by Aġenzija Sapport, together with the infant simulator and is available for future use from the Agency's administrators. An image of the RCB can be found here:

<https://drive.google.com/file/d/1kco4h1FqcfkUjQZIWDrSFkVeJmgZnLdg/view?usp=sharing>

Resources that can be used to further explain the stages of pregnancy and the process of childbirth were also purchased by Aġenzija Sapport. These can be used to supplement the ASVZ curriculum. Images of the resources can be found here:

<https://drive.google.com/drive/folders/1VLKsrku2jlpKw4pU3dUG8oIpNrBX6Jyc?usp=sharing>

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