



Disability and Parenting - The Experiences of Four Women with Disability
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Disability and the Family

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Disability and Parenting - The Experiences of Four Women with Disability
Claire Azzopardi-Lane; Anne-Marie Callus

Abstract:

Women with disability are said to experience double discrimination, and their role as mothers augments their experiences of disablement. This qualitative research explores the intertwining and complex factors that emerge from the narratives of four disabled mothers in a Maltese cultural context. Interviews were conducted with four mothers who have different impairments. The findings from the narratives are presented using a life course approach. In the analysis of the data, social factors were found to impinge on the experiences of mothers with disability to a greater extent than impairment-related factors. These social factors comprise the immediate support networks of each mother, as well as wider cultural factors pertaining to being a mother with disability in Malta. The responses of the four mothers to these factors the stigma and misconceptions about the inability of disabled women to be mothers while at the same time, particularly mothering.

Keywords: disability, mothers, motherhood, Malta, stigma

Introduction

Disabled women who become mothers transgress social norms by highlighting their sexuality in a society that tends to put their disability before their womanhood (Traustadottir, 1990). This paper presents research from Malta, an island nation-state where Catholicism, and concomitant family values, exerts a powerful influence on Maltese culture (Borg 2001). Such notions reflect the research by Alesina and Giuliano (2010) and findings on the traditional role of women in southern European countries. Geographical proximity further enhances family ties in Malta, which is made up of two inhabited islands covering an area of just over 300 square kilometres. Family ties, and therefore dependence on the family, are even more pronounced for disabled people. As Callus (2013) observes, the main locus of support for disabled people in Malta is assumed to be within the family.

Disabled women and motherhood

While non-disabled women experience societal pressure to have children, disabled women are excluded from fulfilling traditionally female roles and are often advised to terminate the pregnancy or relinquish the child (Edmonds 2000; Gould and Dodd 2014). News of their pregnancy encounters reactions from concern, nervousness, to outright

dissatisfaction and expectant disabled mothers at times resort to hiding this state till quite late in the pregnancy (Prilleltensky 2003).

In general, mothers more than fathers, especially those with intellectual disability, are prone to criticism related to parenting skills and ability, and are held accountable by professionals for not parenting in prescribed ways (Read 2000; McConnell and Llewellyn 2002; Blum 2007). Such research suggests that women operate within oppressive cultural ideologies of mothering and are likely to experience significant episodes of self-blame (McFarlane, 2004; Blum, 2007). Waxman (1994: 155) argues that 'beneath the asexual stereotype lurks the belief that disabled women's reproductive capacity is a biological, moral and an economic danger'. This is reflected in the underlying concerns that disabled mothers will produce 'defective' babies and dysfunctional children (Prilleltensky 2003: 23; Ryan and Runswick-Cole 2008).

Despite research confirming the importance of social support networks and services in the lives of mothers of disabled children and their families (Llewellyn & McConnell, 2002; Shewan *et al.* 2014), researchers report on the lack of accessible information about parenting (Wade *et al.* 2008) and the lack of parental coaching. Difficulties that disabled parents come across seem to confirm their parental inadequacy, while not taking into account structural issues such as poverty, poor

housing and lack of familial supports (Swain and Cameron 2003). There is also a prevailing assumption that parenting deficiencies cannot improve. Yet research has demonstrated that many parents are competent, can meet the required responsibilities, and can improve their skills with appropriate parent training, information and direct assistance (MacLean and Aunos 2010).

Despite these difficulties, many disabled women do become mothers and raise their children (Rosenblum et al. 2009; Llewellyn 2013). This paper describes the experiences of mothering of four disabled women.

Research methodology

A narrative approach was used to allow for a close study of the intersectionality of existing factors in the lives of four mothers with disabilities. As Creswell (2013: 71) states, narratives can be co-constructed in the interview process 'as the story emerges through the interaction or dialogue of the researcher and the participant(s)'. This is the approach adopted for this study. Moreover, in order to bring various narratives to the fore, four mothers with different impairments were selected. The narratives are presented using a chronological approach from pregnancy to the children's education. The themes brought out in these narratives are then analysed from a sociocultural and feminist perspective. The analysis is in turn informed by the social model of disability, and therefore the focus is on the socially constructed factors that create disabling barriers for these four mothers and their children (Oliver 2006).

Four narratives cannot be representative of the experiences of disabled mothers in Malta. However, the themes that emerge clearly show how the sociocultural environment impinges on the personal lives of these mothers in ways which can be extended to the experiences of other mothers with disability living in the same environment. All four women who participated in the research are personally known to either or both of the researchers. Throughout this paper we shall call them

Josette, Doreen, Carmen and Marthese. After we obtained the required clearance from the University Research Ethics Committee, we approached the four mothers who gave their consent for the interview to be conducted. The fact that we knew them meant that there was already a relationship of trust between us. Nonetheless, we made it clear to each participant that they could withhold their consent or choose not to answer specific questions. Purposive sampling was used to ensure a representation of as wide a variety of experiences as possible. The next section presents an analysis of the narratives of the four women, starting with their different social and family situations and how these impinge on their experience of motherhood.

Presentation of findings:

The four mothers' socioeconomic situations

The four women interviewed have a mobility, intellectual, hearing and visual impairment respectively and have different support needs. But these impairments only tell a small part of their stories. The table below summarises the main points regarding these four women's socioeconomic situation.

Table 1

Name	Impairment	Marital status	Living with	Level of Education	Employment status
Josette	Severe mobility impairment	Single	Two disabled persons in supported accommodation (has visiting rights over three and a half year old son and has regular contact with the father)	Secondary school education	Full-time employment
Doreen	Moderate intellectual disability	Single	Brother and sister-in-law and a niece and two nephews and 2 year and a half old daughter. (There is no contact with the father)	Secondary and tertiary education in a special school	Full-time employment
Carmen	Profound hearing loss	Married	Husband and four-year old son and (second child born since the interview took place)	Post-secondary level	Full-time employment

Marthese	Severe visual impairment	Married	Husband and fourteen-year old twin daughters	Post-secondary level	Part-time on a disabled persons' employment scheme
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Two mothers, Carmen and Marthese, followed the traditional route of getting married and then starting a family. Carmen and her husband are both Deaf¹. Their children do not have a disability. Marthese's severe visual impairment resulted from her pregnancy. Doreen, who has an intellectual disability, had a child with a long-time partner, who also has an intellectual disability. Their daughter too has a significant developmental delay. Doreen's pregnancy was unplanned and pressures resulting from this brought her relationship with the father of her child to an end. Doreen lives with her brother, his wife and their three children. Josette, who has a congenital severe mobility impairment, had wanted a child for a long time and became pregnant from her long-time partner.

¹ The term 'Deaf' with a capital 'D' is here being used to refer to those persons born with a hearing profound who recognise themselves as speakers of sign language and as being part of a separate Deaf culture (Padden and Humphries 2005).

Due to lack of support services Josette had to give up her son to fostering from birth, maintaining weekly contact with him.

The socioeconomic factors in the four women's lives, presented in the table above, impinge on their experiences. The next sections of the paper present the salient aspects of these experiences from pregnancy to the children's early years, through to their education where relevant.

The women's experience during pregnancy

Medical issues played a varying degree of importance in the pregnancy of the four women. Two of the mothers, Josette and Doreen, described the negative experiences surrounding their motherhood. Although their child gave both mothers joy, they described how the situation they were or are still in has also brought them sadness, anger or anxiety.

Josette planned to have a child with her partner:

...in a few words I wanted to have children. When I was going out with him [partner], not at the very beginning though, I used to ask him to have a baby and to bring him up together. In my mind I imagined I'd bring him up myself.

Josette, who lives in a residential setting, did not reveal her pregnancy till she was seven months pregnant, for fear of the reactions of the staff at the home where she lives. When she did reveal this the staff and the management of the home were supportive and took her to hospital for the required tests. On the other hand, Josette recalls how her family could not accept her pregnancy and did not support her during this period or after the child was born: 'My family couldn't accept, they gave me no support...my father was telling me... "you can't keep him, it's impossible"'.

Josette encountered disbelief by the medical professionals. She concludes that their problem with her pregnancy was rooted in fear.

The doctors wouldn't believe [that I was pregnant], and they had a problem, not a real problem, fear, not a real problem it was fear, whether the baby would be born alive or dead, or disabled like me.

She had anticipated that she would be given support to raise her child, and was surprised by the reaction of service providers at the residential service:

They told me 'with your condition, how can you take care of a baby'? And I told them 'then you need to find me support!' They told me that there isn't any....

The mother, who had a non-disabled son, explained further:

They didn't want [to find me support], they told me; 'No we will give him to a family. He will go to a family'. I told them that he would not know that I am his mother but then they told me that the foster parent will tell him that she is not his real mother.

Josette also reported that a medical professional suggested that she is 'sewn up', especially since she ran the risk of having children with her own

genetic condition. Defiant of this medical advice, Josette claims 'but if I had to do it again I would, even if I am the one to suffer.'

On her part, Doreen's negative experiences started within the relationship itself, since her partner played the male dominant figure: 'My experience wasn't pleasant. When I didn't give him [her partner] what he wanted [i.e. sex] he used to get very upset'. In Doreen's case the pregnancy was unplanned and she recalls:

My friend told me that he most probably abused of me, he took what he wanted and got me pregnant. I didn't know what would happen. He told me he would be careful and I believed him. I didn't want to have children, but that is what I got now from my mistake.

Doreen also felt guilty that she had put such a burden on her family, especially by giving birth to a disabled child: 'If you are like me [disabled] you shouldn't have children. As the child will be born the same as the mother.' This negativity is compounded by her former boyfriend's reaction:

He [child's father] told him [common friend] that if I didn't have the girl, if she died, he would go out with me again. And when he told me I started to cry, she is my blood, she is part of me, God forbid something happens to her.

Doreen recounts her experience with medical professionals while she was pregnant and later on when her daughter was born. She relied extensively on her sister-in-law Marija. Medical professionals addressed her sister-in-law and made no attempt to explain to her in a way she could understand. Instead Marija would explain what had been said later at home: 'they used to talk to Marija, but I wouldn't know what they would be saying. Marija used to understand and then she would explain to me later.'

In the case of Marthese, her experience was different in yet another way since it was the pregnancy itself that caused her visual impairment. However, this only emerged clearly after her twins were born and, aside from regular health check-ups and the fact that her babies were born prematurely, there were no specific medical issues during the pregnancy itself.

For Carmen, apart from the fact that she and her husband requested a hearing screening test for their baby (which returned negative), there were no medical impairment-related issues. On the other hand, Carmen, whose husband is also Deaf, flagged the issue of communication:

The problem is that at hospital you don't know what they're saying to you. I didn't have any problem because my mum was with me. But if I'm on my own, I don't know when it's my turn when they call me. So if

I'm on my own, I tell the midwife. . . . they give me priority. But it's not easy when you're on your own.

Carmen is most comfortable communicating in sign language and could not be sure that she would understand completely what the doctors and other healthcare professionals were telling her, so her mother usually accompanied her. For the birth itself, she contacted a midwife friend of hers who ensured that she would be present to provide her the support in communication that she needed.

The children's early years

The issue of support in the early years of raising their children, whose ages, at the time of the interviews, ranged from two to fourteen years emerges as a salient one for all four women, although to varying degrees.

Carmen explains how she and her husband shared childcare:

The first year, my husband and I were both on reduced hours. I used to work mornings and he afternoons. And we stay with our son. Like that we still had one salary. I earn more than my husband and that way our income was better. My husband could have stopped working for five years. But men don't like stopping working. They don't like staying at home. A woman doesn't mind it that much.

For Carmen, a more important issue in the early years of her son was his language development. Since she and her husband communicate mainly in sign language with each other and with their son (who has normal hearing), they took steps to ensure that he would develop good spoken language skills, such as sending him to a play school 'so that he could get used to speech' and making sure he spends time with his grandparents. Carmen recounts a rather endearing anecdote that highlights the issues that may be encountered in a Deaf household.

And he got a lot from my mother too. So sometimes he says a word . . . Tom and Jerry, the cartoons. And my son said 'Terry' instead of 'Jerry'. And his grandmother, my mother, told him 'No, it's Jerry.' He told her 'No. That's how mum says it.'

Carmen and her husband therefore sought to normalise their son's linguistic development in a culture that is bilingual in Maltese and English by ensuring that he speaks these two languages clearly. However, they have also asserted their own identity as Deaf persons and are raising him to also be a fluent speaker of Maltese Sign Language.

For Marthese, the first years of raising her children coincided with her struggles to regain her vision fully before eventually accepting herself as a disabled person. Not surprisingly, Marthese describes this as a very difficult time, compounded by the fact that she did not receive the support that she needed.

I was just sent home. . . . And no sort of help, counselling, nothing. . . . Nothing. So for the first three or four years or so, eh, I had to cope on my own. . . . So, I was a survivor. And unfortunately when a person has a disability, you have to have a certain determination and be a fighter if you have children.

While Marthese did find support from her husband and parents, in the interview she laments the lack of crucial support from social services and

other agencies who, she feels, could have guided her better about the services available. For Marthese, the mother plays a special role within the family:

The mother, even in Maltese culture, there are huge expectations on the woman. She's the one to rear the children. She takes care of them, keeps them clean, feeds them, takes them out.

Josette's negative experience related to child care started from the moment her son was born. She spent three months in hospital due to serious health issues and recalls signing fostering documents whilst in hospital as she had no alternative.

Everything was done in a hurry. I signed the documents to allow him to be fostered while I was still in hospital, so they would be sure I sign. But I had agreed with them that he could be with the foster parents till the age of five and then I could probably have him back. But do you know what the social worker told me? 'You'll have to do what needs to be done'.

Josette argues that had she committed some type of abuse on her son, she would understand why her visits would be limited to two hours a week. But, she claims that since she has only given him life, she does not

see why she has to be denied the right to spend more time with him

(Baum and Burns, 2007).

When I came out of hospital and came around, I again spoke to my son's social worker. I asked her if I could see him at least twice a week. She told me that his foster parents couldn't make it. I told her 'excuse me, he is my son after all!'

In Doreen's case, her situation is more settled after the negative experiences during the pregnancy itself. She has found part-time employment, while her sister-in-law Marija takes care of her daughter, who has also a developmental disability. Doreen helps financially by working. When not at work, she spends all her time with her daughter. She can feed her and give her to drink and play with her. Marija is seen as the one able to take informed and reliable decisions to be pursued by the whole family.

Just as most mothers do, Doreen has aspirations for her child. She wants her child to do better than her and to have more opportunities than her:

I wish that when she grows up she is like other people, that she has her own friends, that she goes out and so on, and that she hangs around with the right people, and not with the people that are worse than her, like I did.

The children's education

At the time of the interview, Josette and Doreen's children were too young to be in the education system. Marthese's children were midway through their secondary schooling. She describes the early years of her daughters' schooling as particularly stressful as the teachers were expecting her, as their mother, to give them the necessary support at home.

I found support from the school. But not at first. At first, they expected a lot from me, the school. . . . The school, the plans and aims. . . they put all the ideals on me and whether I could or not, I had to stick to them.

These expectations are reflected in the wider society as well. As a member of a disabled persons' organisation, Marthese is quite often on the media. She says that when people see her with her guide dog and learn she has two children, their reaction is to cast her as a very strong woman. The consequence, she argues, is that 'you can't have your bad moments. You have to be smart all the time, laugh, help others. Nobody asks you if you need help yourself.' But she also gets the opposite reaction from some people:

'What was she thinking of, having children?' I've heard that. 'What were you thinking of?' They don't understand that a disabled person who takes on the

responsibility of becoming a parent would have thought about it over and over because there are many things that a disabled person has to think about. So it's something that she really wants and makes an effort to achieve.

Marthese's own way of coping with the demands made by her children's education included finding volunteers to help her daughters after school. She expresses satisfaction with the way she has raised her children.

You pass through many struggles in life, and it's very fulfilling for you for example. So these are beautiful things. For example they wrote an essay 'The person I admire most is my mum'. And I'm really pleased. I'm pleased. You know? For instance they're really happy about me, they say 'our mum looks young. Our mum is beautiful'.

Carmen's son has just embarked on his educational career. The main issues that Carmen raises are related to her profound hearing impairment. Like Marthese, she mentions the need to show the staff at her son's school how to adapt to her impairment-related requirements. In her case, these centre on how best to communicate with her.

But then I tell them, for example at school, I tell them text messages only. The school. If something happens to my son, I tell them send me a text message. And I gave them my dad's phone number just in case. . . . Because you know how people are a lot of the time. They don't take any notice. They phone all the same,

many times. I write 'SMS only' but to no avail. They still phone.

As can be seen from these findings, the situations and experiences of these four mothers have common characteristics. At the same time, they had all their own personal issues to deal with. The next sections of the paper analyse these characteristics and issues from a sociocultural and feminist perspective.

Analysis of findings:

Sociocultural issues

As pointed out earlier, family ties are very strong in Malta. Carmen, Doreen and Marthese all rely, to various extents and in various ways, on family members to provide them with support in rearing their children.

Marthese emphasizes the importance of the support that her husband and her own mother gave her, especially in the twins' early years. Her mother did not help her only with the child care, but also with coming to terms with her new status as a disabled person. As Camilleri (1999) notes, it is not unusual for disabled people not to automatically define themselves as disabled, but to do so gradually. In Marthese's case, this process was aided by her mother encouraging her to make use of available services.

Doreen requires support in taking care and bringing up her daughter, who was 2 years 6 months at the time of the research. She herself identifies the need for support (Gould and Dodd, 2014), and recognizes the fact that she would have had to give up her daughter if her family had not supported her (Booth and Booth, 1997). In Doreen's case, having lost both her parents earlier, her brother and sister-in-law remain her sole support network.

Carmen mentions how Deaf couples in Malta rely on their own parents not only for child care needs but also to ensure that their hearing children are exposed to spoken language. Carmen mentions that some Deaf parents move in with the mother's or the father's parents for the first year or so of their child's life. Here, the parents' hearing impairment creates an additional support need.

Josette's experience is very different from that of the three other mothers. It is significant that she is the only one who had to give the baby up for fostering and also the only one not to receive any support in looking after her son from her family (or from the residential services in which she lives). She recounts how she faces negativity from a society that traditionally sees the family as composed of mother and father and does not give equal value to alternative family arrangements (Utrata, 2015). This position is also in line with the teachings of the Catholic Church, whose influence on Maltese culture is still strong (Harwood 2015). Josette identifies as a single mother and feels further stigmatized due to her visible mobility impairments. Such social scepticism is encountered in the attitudes of those who see her unfit to carry out this role due to her physical limitations (Grue and Tafjord, 2002; Malacrida, 2009).

Josette further strained her ties with her family when she became pregnant. She believes that the fact that the father of her child is of

African origin and that he has refugee status escalated her family's rejection of the child. Josette transgressed many cultural norms, as do women who merge the role of motherhood with the realities of disability (Malacrida, 2009). Because she did not have support, she had to put her child into foster care. Josette believed that she should have received State support to avoid this happening. Disabling views are entertained because people with disability are still seen as dependent on other people rather than as carers, thus still struggling to achieve equal rights and full participation in society. There is still a long way to go before women with disability like Josette "can live their motherhood within a discourse of motherhood and not primarily within a discourse of disability" (Grue and Tafjrod, 2002, 681).

Another issue related to societal perceptions is the assumption that disabled people necessarily have disabled children. Carmen and Josette refer to this misconception, while Doreen, whose daughter has a disability, deals with it directly. In her interview, Doreen first expresses a sense of guilt at having given birth to a disabled child, and then is upset with her ex-boyfriend's negative reaction, asserting her love for her daughter. That love, which also comes through when she expresses the wish for a bright future for her daughter, is however tainted by the stigma which she recognizes all too well.

Such stigmatisation makes parents aware of the devalued bodily capital of disabled children (McKeever and Miller 2004). As Gregory (1991, cited in Ryan and Runswick-Cole 2008, 203) points out, baby care manuals and pregnancy books present the overall message that 'disability is unlikely, undesirable and to be avoided at all costs'. It is also worth considering whether her doubly stigmatised status as a disabled single mother also contributed to the professionals' conclusion that she is unfit to mother any more children (Gould and Dodd, 2014).

As can be seen, these four disabled mothers do not only deal with the issues and challenges faced by most parents. They also have to deal with impairment-related issues: Doreen's need for support in taking care of her daughter; Carmen's need to have her communication needs met; Marthese's need to have printed information made accessible to her; and Josette's need for support due to her lack of mobility. The persons who come into regular contact with these four disabled mothers, for example health professionals and educators, do eventually learn how to cater for their impairment-related needs. However, as Carmen points out, they have to start all over again once their children move on to their next phase in life. She describes how the staff at the childcare centre eventually got used to the system of texting her, and how she now has to get the staff at the new school to use this system.

The actions and experiences of these four disabled mothers challenge sociocultural stereotypes about disabled people, and especially disabled women. However, they also conform to other stereotypes, most notably those related to women. These are explored in the next section.

Feminist issues

The quotations from the interview with Marthese, presented above, encapsulate cultural expectations where the responsibility of child-rearing is placed squarely on the mother. This comes out, for example, when she talks of her pride of seeing her daughters on stage, an occasion which crystallizes the success she has achieved in raising her children. She is also happy that her daughters comment on her youthful and good looks. It can be said that here Marthese puts her femininity at the forefront, rather than her status as a disabled person.

Furthermore, it is interesting to note that, while as a disabled person Marthese challenges sociocultural expectations by having become a mother, as a woman she conforms to the expectations by accepting the main responsibility for child-rearing and for being a 'good mother' (Thurer 1995). Marthese refers to three typical attitudes that she encounters in this regard: disabled mothers being seen as irresponsible, being pitied or being seen as superheroes. While these attitudes appear contradictory in fact, they also have much in common especially in terms of placing

disabled persons, and in this case disabled mothers in particular, outside the boundaries of what Davis (2013) calls normalcy. Marthese's emphasis on being a good-looking good mother can thus be seen as her way of placing herself *within* these boundaries.

Like Marthese, Carmen confounds stereotypical expectations, by getting to another Deaf person and having two children. However, the childcare arrangements that she and her husband chose shows an intriguing mix of challenging and going along with gender-based stereotypes. As shown above, they shared the child-rearing responsibilities by *both* working on reduced hours. This decision was at least partly motivated by the fact that Carmen's salary is higher than that of her husband – which itself does not reflect social expectations. But her husband did not stay at home so that they would get her higher salary in full. The reason that Carmen presents is based on the sociocultural expectations that men don't stay at home full-time to take care of the children.

Doreen reflects on her motherhood and explains how she came to terms with the related practical and financial responsibilities. This is reflected in Edmonds' (2000) discussion of the identity shift from the role of a person with intellectual disability to that of a mother. Doreen was the sole breadwinner in the family at one point. She thus transgresses not

only the boundaries faced by disabled persons and cultural norms by having a child out of marriage, but also the traditional societal roles of women within the family. On the other hand, she, rather than her former boyfriend, is the one who is left holding the baby (Read, 2000; Green, 2001, Gould and Dodd, 2014).

Because she felt vulnerable, Josette took the precaution of not legally connecting her son to his biological father. Josette claims that she would not be able to stop the father if one day he wanted to take her son away with him, thus she used her power as the biological mother to safeguard her rights over the child. She who does not depend in any way on her partner also transgresses the stereotype of people with disability as persons in emotional, financial and physical need. Josette presents herself as self-sufficient and self-reliant, being able to see to her personal care needs independently and being in full time employment.

Conclusion

The four interviews presented in this paper highlight the different experiences and stories of disabled mothers and the uniqueness of each of their situation, with a multiplicity of factors contributing to that uniqueness. On the other hand, there are similarities which can help us draw certain conclusions which are more generalisable. First of all, the analysis of these four disabled mothers' stories shows how social factors impinge on the experiences of women with disability who become mothers to a greater extent than impairment-related factors. This relates especially to the crucial role played by the provision of support, especially from family members, for these disabled mothers to bring up their children. Furthermore, these four mothers have in various ways conformed to certain stereotypes while challenging others. Significantly, their stories challenge the misconceptions about the inability of disabled women to be mothers. In this regard, they did not conform to sociocultural expectations and it is society that is found to be lagging behind in its perceptions of what disabled women negotiate as their status as mothers.

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