

One Voice: Official Voice of the National Federation for the Disability Sector

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Just a woman



Experiencing womanhood with intellectual disability



Sexuality has been defined by the World Health Organisation (WHO, 2004) as “a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction” (para.7). However, when it relates to persons with disability, sexuality has often been depicted as “freakish”, “abnormal” and “innocent”. Women with intellectual disability have been deprived of their sexuality and reproductive capacity at times leading to sterilisation and institutionalisation. In some instances, they have been conveniently wed to dominant, abusive non-disabled partners, as an alternative means of care as documented by researchers in the UK, mainly Michelle

McCarthy(2010) and Claire Bates (2018). Parental attitudes greatly influence the provision or prevention of opportunities for persons with intellectual disability. Being often seen as vulnerable by both professionals and the general public, it is understandable that parents may view their adult children with intellectual disability at a greater risk of exploitation within intimate relationships. Parents tend to tolerate nonsexual relationships and friendships amongst peers with intellectual disability while withholding those of an intimate nature, as they fear abusive relationships, sexually transmitted diseases and the possibility of having children. Such notions effectively support the notion of paternalism towards persons with intellectual disability.

JUST AN “ANGEL”

For a long time, women with intellectual disability were portrayed as angelic and special, casting them into categories and further excluding them from society. Keeping them in an infantile state, absent from education, community and financial independence, were some of the injustices they had to endure, making them liable to forced sterilisation and domestic violence. Today, the full recognition and participation of women with intellectual disability in society is still lacking and their enjoyment of full social citizenship is still hindered by manifestations of intersectional discrimination, that of being women and having intellectual disability. This is limiting their opportunities to explore their sexuality, engage in intimate relationships, make informed life choices and subsequently be in control of their reproductive rights. Albeit having legal capacity, women with intellectual disability are often obliged to obtain family consent prior to entering into an intimate relationship and making life choices. Even though, gender specific stereotypes attribute social worth to women on becoming wives and mothers, the dominant discourses about marriage, pregnancy and motherhood are rarely representative of women with intellectual disability in Malta. Despite the laws and policies being in place, societal attitudes still marginalise women with intellectual disability with regards to sexuality and child bearing.

On a local level, the Maltese National Policy for the Rights of Persons with Disability (2014, principle 12.2) claims that access to sexual education, services and support must be provided to meet the emotional and sexual needs of persons with disability. This policy suggests the need of a comprehensive national policy on the freedom of sexual expression of persons with disability (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014, measure 12.4), as a counterpart to the National Sexual Health Policy in 2011, which makes minimal reference to the needs of persons with intellectual disability. Despite this sexuality in disability is indeed an issue of concern and taboo.



Biography

MS DAPHNE FARRUGIA is an Occupational Therapist by profession. Her role is to facilitate persons' recovery from physical and cognitive limitations, while empowering them to overcome the barriers, which prevent them from functioning in daily occupations. She aims at maximising the individual's potential to be fully participative within society, while strongly believes in the right for an inclusive society. Her interest in the area, made her pursue a Masters of Arts in Disability Studies within the Faculty of Social Wellbeing. Under the supervision of Dr Claire Azzopardi Lane, her research focused on the perceptions of women with intellectual disability in respect of their sexuality, relationships, marriage and parenting. Concurrently, the views of their respective mothers were also explored. Several recommendations were outlined to possibly elicit discussions for further change in policy and attitudinal barriers to bring sexuality and disability to the forefront and safeguard the freedom of sexual expression.

A WOMAN OR A CHILD

The intersectionality of being both a woman and having a disability positions women at risk of double discrimination. However, as evident in the findings of the research that I carried out, women with intellectual disability displayed similar aspirations to non-disabled individuals in the areas of relationships, marriage and parenting. They identified themselves as independent adults, who have a right for choice and control over their own lives. They considered themselves as sexual beings, with a desire to have or adopt children and considered themselves as having a good sense of judgement. They rejected the overprotection from their mothers claiming that they know when to look for support. However, every woman's account supported the principles of the social model of disability, where their sexuality was often hindered by the societal and matriarchal expectations around them, often ripping them from full social inclusion.

The findings demonstrated that gender and sexuality merge into a stereotypical image of women with intellectual disability being vulnerable and in need of protection and control. Elements of contrast between the wishes of women with intellectual disability and those of their mothers were evident in this research. Most parents struggle with the transition of their children into adulthood, where they attempt to equalise independence and protection. The use of imposed contraception, insistence on abstinence from any form of intimacy and viewing sex education negatively, were reported in this study. Reference was made by the women with intellectual disability who participated in the study, to the sex education received, as only targeting the biological aspects of sexuality, including hygiene and menstruation. In addition, unplanned pregnancy, sexually transmitted diseases and the negative consequences of sexual activity were often the fulcrum of such sex education. Any discussion about choice making, assertiveness, pleasure and positive sexual experiences were left out of the equation. Despite the women with intellectual disability being adults, denial of sexual maturity was common by the mothers who still perceived them as perpetual children. Intimacy was repressed and any sign of it was admonished. The methods of over-protection employed varied from encouragement to avoid intimate encounters, going out in groups rather than on one to one dates, going out with the partner's parents or parents joining in during dates.



Marriage was also an area feared by most mothers, as they gave credit to the social prejudices that having a disability makes their daughters ineligible women. Placing their daughters on contraception seemed to rather put the mothers' mind at rest, away from the concern that disability breeds disability. In contrast, the women with intellectual disability voiced the detachment from the overprotecting attitudes of both the family and professionals, as being fundamental. Joining forces and making the personal political may assist in further withdrawal of such perceptions of them being asexual and in need of protection.



THE WAY FORWARD

Whilst acknowledging that disability rights have come a long way, the experiences of these women are significant in our understanding of how the intersection between their gender and impairment still influences their life trajectories. Although the attitudes shown by mothers could be recognised as an altruistic attempt to shelter their daughters, this is resulting in the impediment of their daughters' sexual development and womanhood. Hence, this research sets a social obligation within the Maltese context that women with intellectual disability should be provided with the opportunity to make informed choices about their sexuality, relationships and reproductive rights, while minimising the risk of abuse and exploitation. Thus, education is paramount. Sex education for women with intellectual disability should not merely focus on abuse, sexually transmitted diseases and contraception, but rather on the positive aspects, and the rights, risks and responsibilities related to sexuality. Attention should be drawn to the fact that partner intimacy is part of a natural healthy life and is a pleasurable act, which demands mutual consensus and respect between partners. The choice of sexual orientation and reproductive rights should also be on the agenda of positive sexual education. Hence, the need of a comprehensive sexuality and sexual health policy that targets positive sexuality.

The findings of this research also call for socio-emotional sexual educational programmes to assist women with intellectual disability to pursue their desire for sexual relationships and parenting in an informed manner. Their right to parenthood should be safeguarded, while assistance and skills training for competent parenting should be provided as promised in the National Policy for the Rights of Persons with Disability (2014), The Malta National Disability Strategy (2016) and the Positive Parenting Policy (2016–2024). Hence, the state and responsible stakeholders must ensure that this policy is implemented in an effective way. This also demands for more trained professionals to deliver positive sex

education in schools, services for persons with disability, NGO's and advocacy groups, where they can learn, share and express their sexual experiences in a positive way.

Indeed, Malta has recognised the rights of persons with disability including the right to sexuality and parenthood. It has adopted measures to support their emotional and sexual needs since the launch of the Equal Opportunities Act in 2000 (Article 3.7), the ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2012 (Article 23), the National Policy on the Rights of Persons with Disability in 2014 and the Malta National Disability Strategy in 2015 (Objective 12). Furthermore, the launch of the National Strategic Policy for Positive Parenting in 2016, identified the need of a rights-based person-centred approach. This strategic policy identifies the need for NGO's to work collaboratively with Agenzija Support to further empower parents with a disability in parenting. It promises to enable families to build a peer support network based on their strengths and stories of success. As the policy assures, the provision of psychological and family therapy support, will promote positive parenting and rejects the dominant discourse that persons with disability are not good enough parents. In addition, the National Disability Policy also demands support for parents with disability and housing schemes for accessible accommodation (measures 12.8 and 12.9).

However, further targeted action, inclusion and attitudinal change in this sector is a needed. This revolutionary change can only ensue by raising awareness and changing the perceptions of how sexuality and reproductive rights are portrayed by both the person with disability and the non-disabled, within a given community. Accepting the concept that sexuality is a human right to be enjoyed by all, will possibly instil a more positive outlook on the subject. Education is key! Ongoing tailor made educational programmes on sexuality and intimacy should be provided and information must be readily available in easy read formats. In the UK, mobile application such as 'Be Safe Have fun' (CKUK) and the booklet 'Love, Sex and You' (NHS) offer accessible advice and support to persons with intellectual disability in the areas of sexuality and relationships. Organisations such as Change, Scope and Easyhealth also provide significant guidance to access relationships and sex responsibly. Outlining the sexual needs and wants of women with intellectual disability is not substantial, but it's high time that we should foster such concepts on a local level too.

