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Erased Desires - Of Disability and Sexuality

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We have come a long way from understanding disability in the bio-medical framework. Disability is part of human diversity. Photo: Shehzad Noorani

Twenty-four-year-old Nayeem, a private university student, has a spinal cord injury. He often talks about his girlfriend, whom he has been dating for more than a year now. They study at the same university. They met on campus when Nayeem was selling coupons for a department picnic, became good friends and eventually started dating. Nayeem says that he loves her “with all his heart”.

He has shared his physical limitations with her. He has to wear a catheter all the time, is unable to have an erection, will not be able to move freely in bed and will need support during sexual intercourse. He tells her of his fear that he might never make her sexually happy. However, his girlfriend, resonating Nayeem's sentiments, thinks love transcends physical connections and that it is also about the emotional bonding and support.

Nayeem is well aware that people are often surprised by his girlfriend being in a relationship with a disabled man. He thinks that it is not just his good fortune as a disabled man to have found her, an able-bodied woman. He thinks that both of them have been fortunate to have found each other and be in each other's lives.

For too long disability has been understood and talked about in a bio-medical framework—that it is something which is internal, a deformity that needs immediate medical attention and fixing. However, understanding disability in this way pathologises the individual. According to social scientists and disability rights scholars and activists, disability is socially constructed. Think of the roads, restaurants or malls in Bangladesh. How many of them have a ramp? The seats at the front of buses are assigned for the disabled, but how will one climb the bus in the first place and get to the seats?

It is in fact the environment that disables an individual by not providing the proper assistance that he or she requires. It can be things like bars around the toilet seat, or barrier-free floors in public spaces. The streets, shops and schools are hence rendered able-bodied spaces, which are not welcoming of disabled bodies. This exclusion of disabled bodies from the public space also adds to the cultural stigma and shame surrounding disability.

However, no matter how many ramps are made, assistive devices bought or societal attitudes changed, there has to be an acknowledgement that disabled people do experience pain, fatigue and different kinds of discomfort. Gender scholar Margrit Shildrik writes about how one experiences body and mind, and how those somatic and cognitive realities in mediation with social obstacles prevent disabled people from accessing and reaching points in life that able bodied people may reach sooner or more conveniently.

Understanding disability critically can help us question the binary of normal and abnormal. Being able-bodied is equated with being normal, beautiful and sexy. The privilege of being “normal”, “proper” or “able-bodied”, and the binary between the disabled and able-bodied has to be marked out, challenged and worked around to bring transformation, equality and equity in society.

Discussions around sex and sexuality are taboo in many countries around the world, including Bangladesh. The topic of sexuality is rife with confusions, paradoxes, and denial in general. And it is more so for disabled people. Disabled people are seen as victims whom society at large either pity or demonise. When it comes to the sexual rights of disabled people, there is ample research work on sexual violence and intimate partner violence that disabled individuals (especially women) experience. However, there is scant work that addresses how disabled individuals experience or want to experience sex and sexuality, and the kinds of resources that are required for disabled people when it comes to dating and being in relationships.



40-year-old Ayesha with post-polio syndrome took a picture of her room—a space of her own to enjoy a sense of privacy. Photo: Ayesha



30-year-old Mintu with diplegic cerebral palsy had commuted a three-hour bus ride from Manikganj, to meet his girlfriend in Dhaka. They only spoke on the phone for three months prior to this meeting. Photos: Mintu



It is pertinent that violence is not overlooked, and that disabled people have access to legal rights. However, the discourse of disability and sexuality has never explored ideas around pleasure, agency and sexual rights, which leads to a limited understanding of the different dimensions of disability. Disability scholar Anita Ghai writes that disabled people are thought to be asexual and lacking in sexual desire, are infantilised and over-protected by family members from exploring one's sexuality. Intellectually disabled people are also often believed to be hypersexual, which leads to the perception that they cannot control their sexual urges and thus pose dangers to society. In both these cases, voices of the disabled individuals are either misrepresented or ignored.

Moreover, the understanding of sex and sexuality gets reformulated and nuanced when disability enters the picture. Sexuality comprises biological, psychological, emotional, social, cultural, spiritual aspects. It expands to notions of intimacy, fantasy, connecting emotionally and physically; it is not just about having sexual intercourse. That sex can be non-penetrative and can still be pleasurable helps us understand that sexual experiences are diverse and that any attempt to standardise ideals around body, desire and sexual acts needs to be questioned so that we reach a deeper understanding of diverse human realities.



A physically disabled woman also transgresses femininity or the concept of the “proper” feminine look. A bent leg, a bent body or a bent back is seen as unattractive and renders the woman ineligible for dating or marriage. Due to the patriarchal realities in Bangladesh, a disabled woman is also far more likely than a disabled man to experience socio-cultural barriers when it comes to exploring dating options or simply expressing herself on her own terms.

Disabled men experience oppression and exclusion in terms of societal and individual expectations of masculinity. Expectations to earn, take care and protect one's family, sexually perform are all believed to be markers of masculinity. Men's sexual prowess is expressed either through their bodily strength, or their erections. Often times, disabled men are not able to live up to these ideals and are consequently seen as “less of a man”.



26-year-old Sonia with spinal cord injury, fell in love and got married with her physiotherapist. Sonia mentions that the partner should be positive and supportive when it comes to engaging in sex. Photo: Sonia

The Persons with Disability Welfare Act 2001 of the Government of Bangladesh listed 10 specific priority areas: disability prevention, identification, curative treatment, education, healthcare, rehabilitation employment, transport and communication, culture, social security and self-help organisations. Information on sexual and reproductive health and rights (SRHR) was however absent. The government of Bangladesh in 2013 sanctioned a revised rule—Rights and Protection of Persons with Disabilities Act, Act no. 39 of 2013—which brought hope in terms of talking about rights, dignity, discrimination and participation of disabled people in public and private lives. However, several aspects of the Act need addressing, such as contradictions with the Labour Act 2006 of Bangladesh, which states that any person who becomes disabled due to workplace injury will be terminated from work, although being entitled to full compensation.

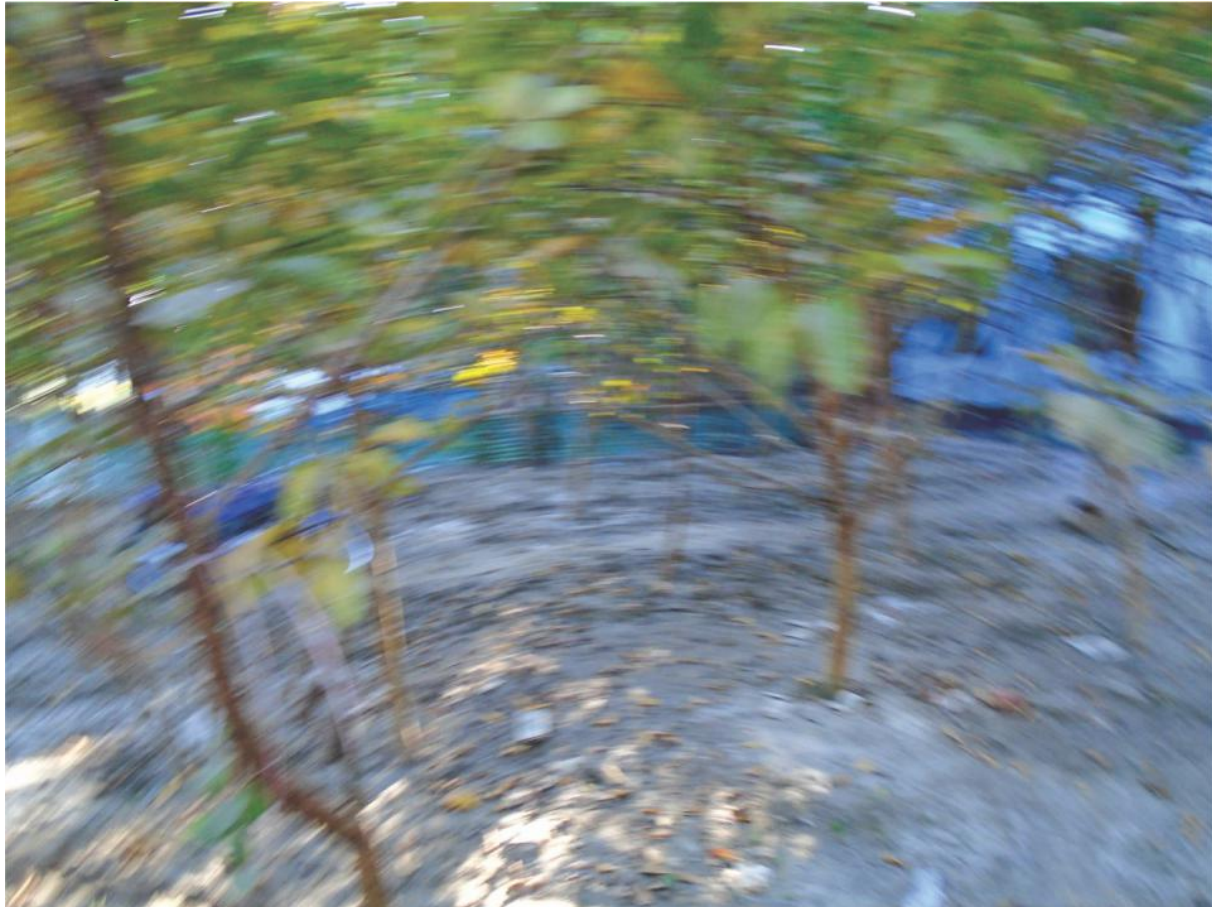
The Disabilities Act says that workplaces need to accommodate disabled individuals, and hence contradicts the Labour Act. Moreover, the committees that are mentioned in the Disabilities Act, and are supposed to work at different national, district and town levels are yet to materialise. The 2013 Act also does not mention anything specific to sexual and reproductive health and rights (SRHR).

To initiate discussions on disability and sexuality, BRAC James P Grant School of Public Health, BRAC University, conducted a scoping study that brought out photo-narratives of disabled individuals between the ages of 20 and 40, about their perceptions of desire, intimacy, love and romance. By taking pictures and sharing narratives, disabled individuals expressed stories of expectations, hurt, excitement and joy when it came to matters of sexuality. Disabilities such as a spinal cord injury, cerebral palsy, post-polio syndrome, clubfoot and amputation informed the narratives. Their stories speak of a range of diverse embodiments and views.



24-year-old Nayeem is well-aware of how people get surprised at his girlfriend for being in a relationship with a disabled man. He thinks that both of them have been fortunate to have found each other and be in each other's lives. Photo: Shehzad Noorani

For instance, 23-year-old Hosna has a spinal cord injury, but she has extra-sensitive erogenous zones in her upper body and thinks she does not need sexual intercourse to be pleased. Or 40-year-old Romel, who masturbated with his feet in his adolescence, because he was born without arms. Or 40-year-old Ayesha with post-polio syndrome, who thinks that men in general need to understand more about sexual intimacy and believes that a disabled woman should never go the extra mile to please a man. These specific narratives of negations and agency are not meant to be representative of the larger disabled demography. It was about looking at these specific lived realities, understanding that disabled individuals are sexual beings, and highlighting the importance of talking about something that is never spoken of. The narratives are also about how aspects of disability, body, sexuality can be multifaceted. The photographs give glimpses of the realities of the participants that humanise, and make their stories visible for further dialogue and advocacy work on disability and sexuality.



A blurry picture of Runa, whose hands shake constantly. A shift in able-bodied lens is required to understand diverse representations and narratives. Photo: Runa

Disability cannot be understood in just a monolithic way as there are different kinds of disabilities: visible, invisible, learning and intellectual, and experiences of disability and sexuality vary and are diverse. Disability rights activist Malini Chib aptly points out: “The point is not whether we get sex or not. The point is that we are prevented from even thinking or talking about it. It's like we suddenly become untouchables and despicable creatures just because we think, talk and demand sexual intimacy.”



We need to look at disability with a critical lens, to challenge the binary of able bodies being normal, and disabled bodies being abnormal. Photo: Shehzad Noorani

Thinking of one's sexuality, and sexual health, is central to ensuring one's wellbeing—both emotional and physical. Knowing about SRHR and experiencing sexual agency is of paramount importance when it comes to ensuring rights of disabled people so that they can make informed choices and better decisions about their body and

sexuality. Instead of pitying the disabled, we should see how their lived realities have the potential to transform normative perceptions around gender, sex, sexuality and body, by talking about sexuality in ways that are validating.

The scoping study project was conducted by researchers Saad Adnan Khan and Farhana Alam at BRAC James P Grant school of Public Health, BRAC University in partnership with Niketan. The photographs are from the project.