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Disability as an Existential Challenge: Reading the Body in Sarah Ismail's Poetry

by Amrit Mishra

Disability is a state of the body that has to be understood and accepted as a given. No one plans or wishes for a disability but is nevertheless condemned to live with the disability for life. There are psycho-somatic repercussions of a disability that are long-lasting. The presumption is that a disability affects only the body/mind organ that it impacts adversely. The reality however is that it bends the sense of 'being' a human individual and makes him/her feel out of place, a misfit in society. The debate on disability has often stated that inclusion is the way out. But, the primary step that is often overlooked is one of acceptance. The disabled body must first be accepted for what it is. The gaze of people towards the disabled body is an aspect that needs to be addressed. Anita Ghai in her book *Disability and South Asia: Knowledge and Experience* (2018) talks of the impact of the abled outlook on the disabled mind and mind. In order to do this, it is necessary that we debunk the notions of the normal and open ourselves up for the different states of being that a disabled person experiences. The need here is not to be understood. To say that we understand another person's experience is to appropriate it. The intent here should be to let the other person be and to allow the other enough space for existence. In his talk titled *Violence at Google* in the year 2008, Slavoj Žižek calls for a code of discretion and says that rather than pursuing the futile goal of understanding the other completely, we should only attempt to "avoid each other politely"- in essence letting the other be (during Google Talks *Violence*).

One of the most prominent quotes that gained my attention with regard to the situation of the disabled is a quote from the genius disabled physicist Stephen Hawking wherein he says:

It is a waste of time to be angry about my disability. One has to get on with life and I haven't done badly. People won't have time for you if you are always angry or complaining.

(Disabled World Disability quotes: List of quotations regarding disabilities)

It is in the above sense very well explained by Prof. Hawkins that I intend to think of an ethics of acceptability for disabled life.

In the poem, 'Normal' Sarah Ismail critiques the unipolar idea of normalcy: "Normal to you is a place where it's true / That girls wear pink and boys wear blue." The world has accepted a binary structure that repeatedly others those who fail/ refuse to conform. The disabled body is one such experience. It has to undergo natural othering throughout life to struggle for a respectable self. Sarah Ismail's poetry is against the binaries of life. It is also a questioning of the ideas that are associated with normalcy which in fact are privileged when thought of from the point of view of the disabled individual. The simplest activities of life become difficult for a person with disability. The inability of the disabled person is often blamed on fate and bad luck. But, the disastrous impact that it has on the disabled person cannot be brushed aside. It is very important that the disabled person is able to keep one's persona intact. It need not be compared with the so-called normal and pushed to feel a sense of lack within. It is only when we as a society will be able to inculcate behavioral changes that we will be able to accept disability as a natural state of being. It is only when this normalcy is restored that we can behave equally as individuals and as a society with people with disabilities. The aim should be to get over the sense of patronization that inadvertently enters the psyche of the 'normal' people. There is no scope for excessive sympathy in an exchange between the normal and the disabled subject. This must be done away with in order to ensure that optimal respect and decency is meted out to the disabled subject.

The lack of love in the lives of people with a disability is a persistent and recurring problem from birth. The disabled life is compromised on multiple levels with regard to love. Several times

disabled children feel alienated from their families owing to the distance they feel from their families. Sarah points out the lack of a father, enjoyment, relish, and joy in the lives of the disabled children. Quality education is a great challenge for disabled children. The identity of these children is somewhat distorted due to these limitations. The schools fail to provide ample opportunities for physical involvement for children with disabilities. Every experience is somewhat diluted for the disabled human being. Also, there are consistent judgmental gazes coming from the abled world. The strategy of affirmative political action misses the point because the helplessness that this limitation creates is on a much more immediately tangible personal level. It is, therefore, necessary to realize the differences that a disabled individual experiences and allow the disabled subject to deal with his/ her life on their own rather than intruding their space to make choices for themselves. The logic of inclusion falls defunct because it fails to accept the given differences and tries to force the abled experiences and desires on the disabled body as the ideal.

The gaze of the abled body is a burden on the disabled to fit in. The forced help, the annoyingly irritating uncalled for sympathy, the attempt to subsume, overread or interpret the disabled experience only to be wrong are nothing but interferences in the disabled consciousness. Every time an abled body comments on the experiences and limitations of the disabled or indulges in pitying the disabled- it is an experience of pain for the disabled world as the abled world refuses to look beyond the body. Often, this attitude is seen in the family members of the disabled subject as well:

Do not even bother to look at me

If what you are going to see

Stops at my eyes or at my ears

And if you'll only talk to me to fill my eyes with tears. (Ismail, 4)

Sarah Ismail points out the pain that the disabled body suffers due to the objectifying gaze of the abled. She asks the abled people to not look at them if they are going to look in a limiting way, only at their bodies. She clearly says that such a judgemental patronizing gaze gives immense pain to the disabled self as the sense of othering is accentuated exponentially proportional to the feeling of estrangement of the disabled subject. The existential angst is triggered by feeling out of place and vulnerable. This ennui becomes all the more profound because it enters the day-to-day life of the disabled person. The cause of the angst is the people around the disabled self and Sartre's idea of 'Hell is other people' (Sartre and Chazelle *No exit*) becomes all the more visible in the life of the disabled people. It is therefore impossible to think of a better world unless we change the balance of power and make the disabled subject self-sufficient. It is in this way that we can move towards rediscovering the individual self. It is very important that the disabled body is allowed to accept its own state of being and that its existence is acknowledged for what it is.

A forced show of pity for the disabled is more hurtful than it is supportive. It is, therefore, necessary to make sure that the disabled individual is protected from the wordplay of the politically correct vocabulary. Disability is an immediately tangible reality that affects the life of people with disabilities. It hampers the social life of the people to the extent that meaning is lost. The rupture that the internalization of a disability causes is incomparable to the other pains of life. It shakes something on the inside and tampers it permanently. Disability gets imprinted on the psyche of the sufferer and yet is the only authentic way to accept the hard reality. It is, therefore, necessary that we create a situation where it becomes possible for the disabled individual to come to terms with the reality and then make the best out of the reality. This in my understanding is the best way for disabled people to experience authenticity. I am not trying to suggest a one-size-fits-all strategy- this is rather one of the alternatives to look at the experience of disability.

The abled body is too enmeshed in the material world to make space for accepting the disabled people on a level plain. There is a huge gap between the experiential world of the abled and the disabled body. The effort therefore should be towards a respectful acceptance instead of a patronizing normalization. The silencing is natural to the disabled experience. The inability is a constant presence. The need of the moment is to acknowledge the limitations instead of attempting to gloss over them. Once this is done we can create the individual and the social space to understand the experience of disability more closely. Yes, compassion is necessary, but there is a very thin line between compassion and a burdening softness-an unnecessary condescended of the abled body. It is therefore an uncompromisable reality that the essential self of the disabled body must be accepted for what it is.

In her *Pastoral Poem: A Girl's Reply to a Marriage Proposal*, Sarah writes of the helplessness of a disabled girl who is unable to fit into the general expectations from marriage.

Can't marry you, can't give you love

For I am no gift from above

I can not sing, I can not talk

I can not move, I can not walk (Ismail, 6)

The disabled self is always helpless, trapped within its body when it comes to relationships from an abled viewpoint. The lack of a physical appeal is a major factor in the interaction between the disabled-abled interaction. This gap cannot be fulfilled in a situation where we look at love from the point of view of the abled self only. The ways of expression of love are different in the different being of a disabled individual. It is wrong to impose the abled standards of expression of love on the disabled body. The silencing of the disabled self is immensely harmful to the psycho-somatic peace of the disabled individual. Love and marriage are so vital to the life of a human individual that they can have an existential impact on the mind of the human individual.

The lack of romance and warmth is so vital that it cannot be undone. For a lot of disabled individuals failed love and marriages can have a traumatic impact which is way more harmful than the disability itself. In her poem “Free Verse: Thinking I can Read Your Mind”, the real problem that the poet deals intricately with is the behavior of the family members with disabled family members on a rehab visit. There is a coldness that emerges out of a close understanding of this interaction. The disabled family member has become a mere burden, a responsibility on the visitor who actually wishes to rest at peace on the weekend. This is a state of social inauthenticity within the immediate circle of the disabled individual. S/He is unable to experience the real self of their own loved ones. But the sensitivity of the disabled self of Sarah Ismail is able to look through the inauthentic pretense of the visitor. A few lines from the poem will speak for themselves:

It is a sunny Saturday afternoon in Southall

I am trying to tell you that I am right next to you

But you do not answer... not even in the only way you can.

But I look at you and I only feel sad, because I wish you could answer all the time as You once did, if only with a smile... (Ismail, 7)

There is a clear gap in communication but on closer reading, it appears that this gap in communication has arisen not only due to the disability but also due to the emotional gap that is an existential problem. It is a silencing of the disabled self that happens because of the alienation with his/her own surroundings. This vacuum that is created rarely has a solution because people have failed the disabled community both on the individual and the societal level. The lack of the freedom of movement/ self that the disabled body experiences reduces the choices available to a disabled person to the level of a subhuman existence. Beyond a point, the Beings of the abled and the disabled individual start existing on different planes. Thus, applying the abled standards of inclusion fails as a method because it fails to offer an uncompromised space for self-expression—

a 'freedom' that is necessary for the disabled individual for self-expression. In her *Acrostic poem-Inclusion*, Ismail writes about the plight of the disabled school children who are discriminated against even in the developed and developing nations. The poem "Inclusion" comes out as an assertion of the repressed right of the disabled individual to study at a non-special school.

One of the major discriminatory experiences that disabled children undergo is that they are not considered 'cool' enough.

I have every right to be here in this school

Not according to the mainstream, though, they just don't think I'm

Cool. I wish I could set them straight somehow and let them see

Let them see just how much knowledge is trapped inside of me.

Until they can see that, none of us have a chance

So please, can't you show them, tell them to give us all a second glance? (Ismail, 12-14)

Sarah is pleading the mainstream here to let the disabled have a space within mainstream educational institutions. Social and educational exclusion is one of the major triggers for existential angst. But the poet does not stop at mere pleading, she also firmly asserts her individual human right to self-expression by voicing the concerns of the disabled community and asking for a world without special education. This shows the stark contrast between the expectations of the disabled community and the redressal measures taken by the mainstream abled community.

The gap in understanding is so large that global policies have been designed as per the worldview of the abled population. It is my contention that we need to go beyond concessional inclusion of the disabled community to a complete as is acceptance of the disabled state of being. This kind of authentic inclusivity will lead to the true amalgamation of the disabled self within the community.

It is also very important to understand that the gaze of the abled body on the disabled body is a major issue that has the potential to create a situation of perpetual angst in the mind of the disabled individual. This gaze is always one sided. The disabled subject is left at the receiving end being objectified and judged for a natural (yet so called abnormal) state of Being that is given to them. The burden of being accepted is always placed on the disabled individual. This in itself is a marker of the fact that the mainstream has overlooked the existence of the disabled community for far too long both on the individual and the communal level. The realization of this negligence reminds us that we need to change the way we interact with the disabled both on ethical and humanitarian grounds.

The disabled body is a site for protest, it is itself a resistance to the 'normal' world. It is possible to change the lives of the disabled only after we agree as a community to change the mindsets of the abled community. The correct way is to let the disabled own an existence of their own. The scales of judgement of the abled community must not be applied to the disabled community.

A reading of these poems has opened my eyes to the real situation of the disabled body that resonates strongly with my own experience in life growing up as a child/ student/ lover with disability. In all these phases of life, the experience of disabled individuals is compromised at various levels. There is a denial of choice for the disabled. This denial is normalized because as a society we refuse/neglect looking at the deeper existential needs of persons with disabilities. The limitations of the disabled body are understood to impact only the external factors of the disabled subject's body. Affirmative actions, quotas and disability support systems are expected to resolve the issues in the lives of individuals with disabilities. But the deeper desires and emptiness that the persons with disabilities feel cannot be accounted for and healed by the external changes that public policies are making at present.

There is a need for a more humane and immediate intervention as per the needs of the disabled community. The abled mainstream must participate in the collective act of ‘listening’ to the disabled community. This act of listening can in no way be a one-sided act. This time around public policies and laws need to be made in a two-way process where the abled community must with utmost dedication be at the receiving end. The poems of Sarah Ismail are way more than a plea. They are a refusal to the pressures of the abled world. She becomes the spokeswoman of the disabled and makes a clear statement that the persons with disabilities refuse to live a compromised life. By explicating the experiences of the disabled subject, Sarah Ismail is giving power back to the disabled. Her poetry is an act of denial of the subservient position. It is an act of authentic existential intentionality-an act of volition against the fossilized standards of society and governance that we have long lived with.

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