

## Stela Young's Dialectic on Disability

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**Abstract:** This paper is a retrospective study of a distinguished disabled woman, Stella Young (24th Feb, 1982 – 6<sup>th</sup> Dec, 2014), an osteogenesis imperfecta inflicted person who lived as an educator, comedian, disability activist, and broadcaster. Her thoughts and experiences of life as a disabled person on her Blog in ABC's 'Ramp up' will be the domain of this study. Her ideas on exclusion and marginalisation, sense of classlessness, sexuality, rights, social attitudes and architectural barriers experienced by the disabled people will be explored. Her thundering statement in her TED talk: Disability as 'inspiration porn' for non-disabled people, the objectification of disability is another area of this study. This study gives a different perspective on normative inclusiveness and suggestive normality of disabled persons in this beautiful world.

**Key words:** inspiration porn, normative inclusiveness, marginalisation

### Introduction:

Disability is conceptualized as being a multidimensional experience for the person involved. There may be effects on organs or body parts and there may be effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognized in ICF (International Classification of Functioning Disability and Health): body structure and function (and impairment thereof); activity (and activity restrictions), and participation (and participation restrictions) (WHO, 2007). The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes. The World Health Assembly on May 22, 2001, approved the "ICF." This classification was first created in 1980 and then called the International Classification of Impairments, Disabilities, and Handicaps, or ICIDH by WHO to provide a unifying framework for classifying the health components of functioning and disability. The ICF is structured around: Body functions and structure, additional information on severity and environmental factors. Activities (related to tasks and actions by an individual) and participation (involvement in a life situation). Main Document defines Disability as a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic diseases.

About 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning. The global disability prevalence is higher than previous WHO estimates, which date from the 1970s and suggested a figure of around 10%. This global estimate for disability is on the rise due to population ageing and the rapid spread of chronic diseases, as well as improvements in the methodologies used to measure disability.

The first ever WHO/World Bank World report on disability (WHO, 2011) reviews evidence about the situation of people with disabilities around the world. Following chapters on understanding disability and measuring disability, the report contains topic-specific chapters on health; rehabilitation; assistance and support; enabling environments; education; and employment. Within each chapter, there is a discussion of the barriers confronted, and case studies showing how countries have succeeded in addressing these by promoting good practice. In its final chapter, the report offers nine concrete recommendations for policy and practice which if put in place could lead to real improvements in the lives of people with disability.

And there is no dearth of NGO's and activists who are working on for a better world for the disabled persons. Amongst the many disability activists, we can bring to light the name of Stela Young (24th Feb, 1982 – 6<sup>th</sup> Dec, 2014). She herself was a disabled person. She was born with osteogenesis imperfecta, a genetic condition she describes as "having really dodgy bones". Consequently, she uses a wheelchair. She was born in Stawell in Western Victoria in 1982. Her parents, Greg, a butcher and record shop owner and Lynne, a hairdresser told that she was their "easiest child" because until she got her first chair she just stayed where she was put. Stella studied journalism at Deakin in Geelong before moving to Melbourne where she did a diploma of education at Melbourne University. She was a Writer, comedian and an activist.

She worked for a brief time in public programs at Melbourne Museum, where she taught kids about bugs and dinosaurs. Stella was the editor of Ramp Up, an online space for news, discussion and opinion about disability in Australia. She emerged as an activist at the age of 14 by conducting an access audit of shops on the local main street. Stella Young's advocacy included a membership in the Victorian Disability Advisory Council, Ministerial Advisory Council for the Department of Victorian communities and Women With Disabilities, Victoria. Young was a two-time state finalist in the Melbourne International Comedy Festival's Raw Comedy competition; and hosted eight seasons of Australia's first disability culture program, No Limits, aired on Channel 31 and community stations across the country. As the editor of ABC's "Ramp Up" website, Stella and her tribes have showed up a world where they challenge the people's perceptions of disability and how they celebrate the beauty of life. Unfortunately, Stela Young passed away at the age of 32 on December 8, 2014. Her untimely demise is a huge loss to the humanity.

### **ABC's "Ramp Up"-- A methodological consideration:**

ABC's Ramp up is an online news space for news, discussion and debate about disability in Australia. Stela Young was its editor. Disabled persons express their views and experiences of life in this platform. The space has news, blogs, opinion, audio pieces and photos. Articles in it are a way to the window to the world of disability. Their experiences highlighted in these articles make them aware of the real world of disability enriching their life with the wisdom and support for each other. This body of work is concentrated on Young's blog in "Ramp up" (Young, 2014). There are 47 articles in it. It was written between Jan, 2010 to Dec, 2014. Besides that, her impressive TED talk delivered in Sydney in April, 2014 with the title "thank you, I am not your inspiration" (TED, 2014) with the underlying concept of disability as an inspiration porn for non-disabled people is the domain of the study. Her philosophy on the life of disabled persons and perceived constructed images endorsed by non-disabled persons are analysed here. Line of thought includes-- a negation of disability as a fragile vignette in this world, deconstruction of a metaphysical principle upholding the view of disabled person by able persons, endorsement of ableism and normalcy out of disability and propounding the concept of universal accessibility for absolute freedom.

### **Exclusion and Inclusion--a Social model:**

Total inclusiveness of all variegated people in any space is a non- attainable state of affairs in many social settings. Needs of disabled persons are often overlooked in many architectural designs. Disabled persons are all the more made disabled by architectural barriers in many contexts. In many cases of social participation, disabled persons are restricted from being a part of the group participation just because of the lack of physical accessibility. Access design has not yet become a universal phenomenon. Stela young has brought her story and the idea of social exclusion out of lack of accessibility rather than physical impairment. In her heart warming article, politics of exclusion, she thoroughly has written about people's attitude towards disability. There are two kinds of disability: the disability which is inherent with the disabled body, the other one created by the architectural barrier or any social mechanism that leads to disability. The later one; the social model of disability is adding more disadvantage to the inherent disability. The social model moulds more disability with its inaccessible environment and hostile attitude. Absence of ramp makes somebody a disabled person in many cases. Stela feels that disabled persons are not wrong for the world they live in, but the world is not yet right for them.

Stela finds Scott Hamilton's quote "the only disability in life is bad attitude" quite a pejorative, reasoning that she adds that, no amount of smiling at a flight of stairs has ever made it turn into ramp, no amount of standing in the middle of a bookshelf and radiating a positive attitude is going to turn all those books into braille. It was in fact Stela's pejorative reference to disability as perfectly normal as perceived by Hamilton. She has also mockingly made a didactic point on the controverted views of the disabled persons in the social setting: of personhood, rationality, liberation politics and the inadequacy of our society.

### **Disabled body -- political statement:**

Stela says that disabled bodies are inherently political. Anything you do on a non- normative body is political somehow. In one of her blog she says that she dances as a political statement. She mostly dances for all the same reasons as anyone else does. Because it healed her spirit and filled her with joy; each foray onto the dance floor bringing the possibility of that delicious frisson that comes from locking eyes with someone and knowing, in that moment, that you're dancing just for each other; because it made her sweat, move and connect with people and felt like she had landed in her skin finally. "And I dance because, in the end, dancing is a way for my body to have a conversation about these things, the pulsating waves of a hundred people sharing thoughts and dreams and ideas about what it means to be alive. It's my body, and I'll bloody well dance if I want to."

Stela makes a strong statement that dance floors are not for disabled persons and comments that People are surprised by her presence She reproduces that a dance floor does not just connote a place for moving, but also for sensuality and sexuality. From traditional courtship behavior to straight-up cultural metaphors, dance and sex are inextricably linked. She adds that the culture we live in continually asexualizes non-normative bodies without any hinge.

Stela's above experience clearly tells that the idea of an acceptable social order in any act done by disabled body be it dancing or something else is something people find it difficult to endorse and accept as well. It was a kind of sexual humor; topical reference being dancing and delightful bodily functions.

In fact, the validity of the analogies of the performances of the abled bodies vis- a-vis disabled bodies seems to lie underneath the practical socio-cultural fabric of acceptance. Her extraordinary psychological insights brought out the notion of infantile solidification of sexuality perceived by non- disabled persons as if their heart and soul is incrustated in the cardboard figures of non-normative structures of human bodies.

### **Disabled, yet a full life, therefore a perfect inspiration porn:**

Stela Young on her TED talk quite humoursly hit hard the world with the phrase "disability as an inspiration porn" for non - disabled persons. She described that Inspiration porn is an image of a person with a disability, often a kid, doing something completely ordinary - like playing, or talking, or running, or drawing a picture, or hitting a tennis ball - carrying a caption like "your excuse is invalid" or "before you quit, try". She gave a plenty of commentary / dramatic use of disability/ ability experiences in a pejorative reference to being bravery or effrontery.

She explains in her way that there comes the idea of inspiration porn; so that non-disabled people can put their worries into perspective. So they can go, "Oh well if that kid who doesn't have any legs can smile while he's having an awesome time, I should never, EVER feel bad about my life". It's there so that non-disabled people can look at us and think "well, it could be worse... I could be that person".

"In this way, these modified images exceptionalise and objectify those of us they claim to represent. It's no coincidence that these genuinely adorable disabled kids in these images are never named: it doesn't matter what their names are, they're just there as objects of inspiration. But using these images as feel-good tools, as "inspiration", is based on an assumption that the people in them have terrible lives, and that it takes some extra kind of pluck or courage to live them. However, for many of them, that is not true. Because they are doing exactly the same thing; catching public transport to places of employment. They are just doing it sitting down. There are no such big steps in many ways that requires more effort. The same case applies to those kids in the inspiration porn pictures too - they're not doing anything their peers don't do. We all learn how to use the bodies we're born with, or learn to use them in an adjusted state, whether those bodies are considered disabled or not. So that image of the kid drawing a picture with the pencil held in her mouth instead of her hand? That's just the best way for her, in her body, to do it. For her, it's normal."

Stella also brings out the role the news media shapes the way people think about disability. Most journalists seem utterly incapable of writing or talking about a person with a disability without using phrases like "overcoming disability", "brave", "suffers from", "defying the odds", "wheelchair bound" or, most favourite, "inspirational".

"The idea behind the phrase "inspiration porn" is that it shames people with disabilities. It says that if we fail to be happy, to smile and to live lives that make those around us feel good, it's because we're not trying hard enough. Our attitude is just not positive enough. It's our fault. Not to mention what it means for people whose disabilities are not visible, like people with chronic or mental illness, who often battle the assumption that it's all about attitude. And we're not allowed to be angry and upset, because then we'd be "bad" disabled people. We wouldn't be doing our very best to "overcome" our disabilities".

It can be said that a disabled body not only does not constitute her/ his as a person but is also a kind of limit for her spirit. What is it for a disabled person to be a person and not a thing? It is to have a rational individuality which owns itself; but the body limits his/ her expansion and reduces her field of activities. Stela advocates True humanism, the idea of respecting the being, the destiny and the person she / he becomes.

The search to liberate disabled persons from the limits of matter by using extra external mechanisms makes them world see as a wholesome abnormal being. However, this is the case of the body itself transcending to another realm of normalcy. This is something people overlook in the process. And the whole piece is reflected as an image of ultimate inspiration in the eyes of abled persons, a case of bravery or effrontery. The journey is not easy in the eyes of the abled

people. Neither disabled find it easy to tread her life not in the sense of physical hardship but in the spectacle of the society.

### **Deconstructed sexuality of disabled persons:**

Stella Young wrote: "People with disabilities, and in particular those of us with non-normative bodies, are routinely desexualised, degendered and infantilised. Sexual identity and even gender identity become secondary to our bodily identity... But seeing a reflection of my naked self pop up regularly in my Facebook feed with nary a NSFW warning in sight has served as a reminder that my body is not considered sexual, no matter what I do with it," Stella continued.

Stella's words reflect the idea that sexuality and physical beauty are often overlooked when it comes to people with disabilities. And we don't see enough of people with disabilities dressed sexily or engaging in sexual acts in the media. She also brought the case of 18-year-old Brisbane teenager Madeline Stuart's story of modeling. Madeline (who prefers to be called Maddy) has Down syndrome. She set out to develop a healthier lifestyle through exercise and eating less, and as a result lost 20 kilograms. She told her mother she wanted to be a model and Maddy's profile skyrocketed on social media for some time.

Jamie Brewer was the first model with Down syndrome to strut the catwalk at New York Fashion Week. The 'Changing the Face of Beauty' campaign is advocating for disability in advertising and fashion, with over 100 American clothing lines signing on children with disabilities to model their clothes. Her mother Roseanne describes Maddy as confident, with no hang-ups about her body. She told the Daily Mail: "I think it is time people realised that people with Down syndrome can be sexy and beautiful and should be celebrated".

However, when Maddy's picture was featured on social media, commenters suggested the teen was being too sexualised. Maddy was in a modest peach-coloured bikini, showing off her arms and stomach, with her auburn hair curled around her face. While there were some supportive comments, many seemed uncomfortable that Maddy was embracing her body and sexuality. However, some others opined that if it's perfectly alright to objectify and sexualise "normal" women, it can be done the same for the intellectually disabled; better yet, women in wheelchairs, and women in vegetative states!

Stella states that the sexualisation of the female body seems not to apply for disabled persons. She adds that a naked body like hers is a curiosity, a statement, a rebellion. But a naked body that conforms more closely to the socially constructed ideals of beauty, even if that body is performing a biological function and not a sexual act, is pornographic, indecently exposed, censored. She wants more bodies like hers be represented in art, fashion and media.

This is a case of a crucial state for theorizing identities and politics within the power relations of the able and disabled. It highlights the regulation of sexual boundaries in the media with an emphasis on the malleability and saleability of both sexual identities and sexual politics. She says things that people make sexist slur on disabled bodies, way more of infantilism rather than a sex object

### **Conclusion:**

Stella makes a Philosophical statement meant for a rhetorical purpose. She refuses to remain invisible in front of the world. She counts her/ other's struggle to be that which pleasures, delights, and fulfills desire. They are more than happy being transformed individually, collectively, as they make radical collective space which affirms and sustains their subjectivity, which gives them a new location from which to articulate their sense of the world breaking the stereotypes of the society.

Stella Young's hard hitting statements and views on the people's attitude towards disability brings out the sharp contrast between what exists in non-disabled people's world and disabled people's experience of life. Stella Young, being an exceptionally wise and bold has brought up the issue of disabled persons on a broader, visible platform. Her views and the activism has really provoked the translucent vision of disabled people's world. Besides that, her humour has added a real charm and pungent voice to the world making people see the beauty and ugly side of the world we live in.

Identity which is socially produced and the inherent identity which is self- reflected stand in tension with dominant ideologies or discourses. Young's activism bestows the ground for a distinctive standpoint, that is, to determine whether it meets the requirements for a universal awareness, universal accessibility and the explicit promotion of heterogeneity in public. However, the question of the ideal of impartiality amounts to questioning the possibility of moral theory itself

among the people. The ideal of normative reason as standing at a point transcending all perspectives of disability is both illusory and oppressive.

Stela brings out the epistemological value of understanding the experience of disabled persons who occupy the social landscape that differs from the dominant abled group. She gives a voice to the existent social structure to push away the marginality imposed by man-made barriers. She strives to create a site of radical openness and possibility for all the marginalized disabled persons.

#### **Bibliography:**

1. Stela Young. (2014, April). *I am not your inspiration, thank you very much*. [Video]. TED Talks, Sydney. YouTube. <https://www.youtube.com/watch?v=8K9Gg164Bsw>
2. Stela Young. (2014, December, 8). Ramp up Disability. Discussion. Debate. <https://www.abc.net.au/rampup/?type=blog>
3. World Health Organization (2007). International Classification of Functioning, Disability and Health- children & youth version. Geneva, Switzerland.
4. World Health Organisation (2011) <https://www.who.int/publications/i/item/9789241564182>
5. Walmsley J. Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 2004,32:65-71. doi:10.1111/j.1468-3156.2004.00281.x