New Reproductive Technology

My Personal and Political Dichotomy

by Maria Barile

As a woman with disabilities, I am aware that what I advocate politically is often quite different from the social and cultural myths I was raised with. One day as I sat in my doctor’s waiting room, I came across a letter in a magazine that brought my political ideas into the personal sphere.

The letter was written by a woman who expressed joy about having a child of her own through new reproductive technology. I presumed that it was through in vitro fertilization (IVF).

For just a moment I found myself wondering what my genes would produce. Would I have a girl? What colour eyes and hair would she have? Would she inherit my characteristics? Would she be passionate about women’s issues and social justice, like I am? What if...? Then again, what if I had a boy who turned out to have severe learning disabilities?

These thoughts surfaced aimlessly in my mind, triggered by the letter from this unknown woman. For the first time I came close to understanding, from a personal perspective, those women who want a child of their own at any cost.

Wait a minute! This was my emotional side speaking, not my logic. At once, my political convictions interrupted this rather foreboding daydream.

It became clear that if I, with my knowledge of NRTs and the multitude of questions that result, can daydream about its possibilities, then undoubtedly most women who do not have the information I do, but who feel a great need to have a child of their own, can be easily seduced into considering IVF as feasible. According to the cultural and socially constructed beliefs I was brought up with, it is non-disabled women’s responsibility to reproduce, and I, as a women with disabilities could not, and should not reproduce. So, where did my daydream come from?

The message generally conveyed to the public creates the impression that the main objective of NRTs is to give people more positive and progressive options. For example, we hear that NRTs would allow women who could not otherwise bear children to do so and/or allow people to choose the type of child they want. However, this has negative implications for the human rights of people with disabilities.

How can non-disabled women and men who have constantly been fed misinformation about disability and persuaded to believe that the lives of persons with disabilities are “not worth living,” possibly be expected to choose anything but the elimination of a fetus that would develop into a child with disabilities? This view could be assumed especially of women and men who have never had any meaningful encounters with the community of people with disabilities. How can one make choices, let alone an “informed choice,” based on myth?

I believe that the choices individuals make will be based on socially-learned negative values with respect to disability. Social dogma dictates that one must be physically able and physically pleasing. These sentiments are subtly reinforced by our economic and social system and promoted by the media. This in turn gives rise to the view that the more one deviates from society’s physical and mental norms the more undesirable one is.

According to these standards, persons with disabilities are “unwell,” and unable to conform to society’s strict standards for physical and/or mental ability. Every economic system in the world has promoted the view that physical desirability and productivity go hand in hand. These systems value individuals according to their ability to compete in the reproductive market system. By “reproductive” I mean both the actual physical reproduction of the next “able-bodied” generation, and the production of “able-bodied” replacement workers in the competitive labour market. The so-called “undesirable” often becomes dependent upon the state, and this gives rise to the patronizing notion that ‘society takes care of disabled persons.’ Nowadays, we also hear, if you choose to have a disabled child then you are to be responsible for all its needs. Thus, individuals are deemed to be guilty of creating a social problem, a socio-economic burden. One of the main messages that NRT is subtly conveying is that it will eliminate this problem for society through a technique known as genetic manipulation, i.e. altering genetic codes to correct imperfections or introduce new genetic characteristics (CRIAW).
The fact is that every time a society faces economic difficulties, it tends to blame those in powerless positions, the undesirables, for wanting more rights and protection, and more of the national wealth. In the case of people with disabilities, the general public has been led to believe that the cost of physical, technical, and human access, as well as financial support, creates an economic burden. In other words, the changes that we in the disabled community demand in order to promote our rights often cost money. The state claims that if it allocates funds to fulfill our needs, it cannot spend that money on other groups. Those in power use this myth to create conflict between equality seeking groups.

In fact, by spending money to develop new reproductive technology, funds are being taken away from those of us who require assistance now.

If and when those who hold power—policymakers, state-controlled service providers, etc.—are no longer trespassers in our personal lives, when women with disabilities can make choices that are truly our own, and when our personal is political by choice, then perhaps women with disabilities from future generations can fulfill their personal dreams in areas of reproductive rights.

With respect to my daydream, I quickly realized that I was dealing with a multitude of emotions. On the one hand, I had acquired a new understanding of the personal realities of women who want a child of their own, that very heartfelt, but socially constructed sentiment most women internalize. On the other hand, I am also conscious of the realities that I, along with most women with disabilities of my generation, have internalized, the message that we should not, and do not, want to have children, “for our own good” of course!

But I am a woman and my disabilities are part of me. Ever since I can remember, I have been aware of the messages conveyed to non-disabled women about childbearing and the social rewards that appear to go with it. As a woman with disabilities, I have always wondered what it meant when pregnant women are told, “as long as the baby is healthy, it doesn’t matter whether it’s a boy or a girl.” What does that say about me and all those like me? It is not without cause that on a personal level I fear the illusory choices that NRT and its proponents claim to give women, i.e. that they can have exactly the type of child they want.

Maria Barile is completing a Master of Social Work at McGill University in Montreal. She has been active in the disability rights movement from the age of 16. Currently, she is the Vice Chair of DAWN Canada and Co-Chair of Action Femmes Handicapées in Montreal.

References


POSTER KIDS NO MORE

October 19-31
Arcadia Art Gallery
Exhibition Opening:
Friday, October 22, 6-10 pm
Performance Evening:
Saturday, October 23, 7 pm

POSTER KIDS NO MORE is a multidisciplinary programme featuring visual art, readings, dramatic and musical performances. With this programme, the curators intend to push the limits of the ways in which disabled women are commonly perceived. To date, representations of disabled persons have been limited to the patronizing and pathetic images used on charity posters. In this programme (unprecedented for A Space), disabled lesbian visual artists and writers will demonstrate that those oppressive images misrepresent the complex realities of disabled women.

Artists:

Snowfire
Sherree Clark
Julia Patterson
Anne-Marie Alonzo
Beth Majors
Two Feathers
Kathleen Martindale
Sherry Shute (and band)
Shenaz Sri
Jane Field
Lilith Finkler/Barbara Ruth

POSTER KIDS NO MORE is coordinated for A Space by Shelley Tremain

Arcadia Art Gallery is located at
680 Queen's Quay West

Gallery hours are Sun-Thur 1-5 pm,
Fri. evening 6-10 pm, Sat. 1-5 pm

Please contact A Space at 364-3227
for more information

Attendant services are available