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Creating Alternative and Demedicalized Spaces: Testimonial Narrative on Disability, Culture, and Racialization

By Parin Dossa¹

Abstract

The literature on disability, gender and “race” has benefited from the political economy perspective. With its emphasis on unmasking the workings of power, this perspective has brought into relief the systemic, institutionalized and spatial oppression of disabled persons, compounded in the case of gender and “race.” This narrative of deconstruction, however, remains incomplete in the absence of voice and subjectivity of persons with disabilities. Using narrative moments, recounted by an immigrant woman with two “disabled” children, this paper makes a case for an integrated framework for a study of racialized persons with disabilities. Here, the margins² are not out there in other spaces; they form part of the centre whose existence is brought into question by alternative and demedicalized spaces. The data are drawn from a larger study of health and well being of South Asian East African women in metropolitan Vancouver, Canada.

Keywords: Racialized women, disability, voice, narrative moments, citizenship and entitlements.

Introduction

In her work on *Feminism and Anthropology*, Moore (1988)³ calls for a dialogue between the two disciplines to correct the analytical omission of gender in ethnographic works. She notes that anthropologists can learn from feminist perspectives on gender as an axis of social inequality and feminists can draw upon anthropological insights on difference. We can then generate theoretical constructs on "how racial difference is constructed through gender, how racism divides gender identity and experience, and how class is shaped by gender and race" (ibid, 11). Over the last two decades, this paradigm has been expanded to include other markers of difference, such as "disability" and age. Its value in unmasking multiple systems of oppression in particular contexts has been noted (Jiwani 2006, Lee and Lutz 2005). Equal emphasis is placed on the paradigm's

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² Das and Poole (2005) have illustrated that the margins can constitute the centre of power and knowledge. They are embedded in the centre and not within discrete spaces.

³ At the time when Henrietta Moore published her work (1988), feminist anthropologists were making a case for the epistemological and methodological inclusion of gender. They argued that gender is not only about the study of women but that of society as a whole. Moore noted that women have always been present in ethnographic accounts but are excluded from theory. While she focused on disciplinary dialogue, she advanced the notion of intersectionality. Here, the emphasis is on how gender informs class and race and how the later categories shape our understanding of gender relations in multiple spheres of life: waged work, reproduction, kinship and ritual. Also, refer to an earlier work by Rosaldo and Lamphere (1973).

capacity to reveal multiple subject positions that has helped to bridge the divide between structural processes and lived realities of people (Bannerji 1995, Dossa 2004)

In this paper, I draw insights from the intersectionality paradigm to show how racialized women with disabilities negotiate and claim multiple cultural and social identities while critiquing the system for perpetuating the deficiency discourse on "disability," and racialization. I focus on the story of one woman (Tamiza) from a larger study on health and well being of South Asian Canadian Muslim women from East Africa. There are two reasons for presenting one narrative. First, I wanted to recognize women as "authors" of their stories without overlooking the power dynamics in research.³ Second, disenfranchised people tell a collective story owing to their shared experience of oppression. This point was brought home to me when women repeatedly informed me that one woman's story is everyone's story. Underpinning their stories were two questions: What is it like to have a racialized body in a disabling world? How can one create alternative spaces that bridge the divide between structure (the social model of disability) and agency (the cultural model of disability)? Theoretically, personal narratives reveal the embodiment of ideologies and norms, the articulation of which can lead to progressive change.

Methods

It was during the course of my field work on the health and well being of South Asian Muslim women from East Africa (1991-2001) that I met eight women, socially designated as "disabled." One woman had two children with disabilities. All the women were between the ages of 35 and 50. The women had lived in Vancouver, Canada from 11 to 30 years.

I met my first research participant at the South Asian Muslim Disability Issues Committee where I volunteered for six months. Further contacts were established through a snowball sampling technique. All the participants expressed surprise that I was interested in their lives. Their experiential knowledge had led them to believe that they were forgotten by society. In the words of one woman: "When I go out, I see people on the streets. They say 'Hi' and nothing more. I feel that I barely exist."

Interviews were conducted in Gujarati (my mother tongue) and English, according to the preference of the women. All the interviews were transcribed, or translated and transcribed, as required. Whenever the opportunity presented itself, I engaged in participant observation of their everyday lives (walking, shopping and attending community events), and I visited women's homes upon invitation. Establishing rapport is the first step in ethnographic research as Malinowski (1922) has so aptly demonstrated. As I interacted with the women, first through volunteer work and later casually, I began to appreciate the multiple ways in which they negotiated their everyday lives, doing daily battle as Mernissi (1988) has expressed it. The women relayed their

³ I do not underestimate the dilemmas and complexities that arise from the need to give space to the voices of the research participants. At times, we are compelled to make a choice between preserving the narrative content and advancing theoretical frameworks. We may therefore move back and forth between the two sets of data. This is the approach that I have adopted in this paper.

experiences with the not-too-friendly social service system. One woman related how she would plan her visits on the days when a particular social provider was on duty. This is because she had learnt that this provider was friendly and helpful. A second woman related how she did her own calculations to illustrate that she was not receiving her entitlement – note her reluctance to use the word assistance. All the women related stories of struggle with the system. They also worked towards reversing the popular discourse that devalued and dehumanized their lives.

Participants were interviewed two to four times in their homes or cafeterias. Interview schedules included storytelling as well as semi-structured questions, as these methods enable women to reveal their own experiences in the context of social, historical and economic relations. Each interview lasted for two hours or more.

In the interview schedule and the narrative guide, I focused on a broad set of questions to capture the dynamic interplay of structural factors and the remaking of the world – always a process. Specific categories included the everyday life, the family and the community ties, pre- and post-migration experiences, social networks, housing, job opportunities, and access to social and health services.

Though unique, each woman's story resonated with others; the stories as a whole served as testimonials speaking to the larger issues of displacement, migration, resettlement and social exclusion. While telling their individual stories, the women spoke in a collective voice, evident in their switching from the use of "I" and "you" to "we" and "us." This genre of speaking reflects their need to work for social justice through the very act of sharing their life experiences. The women were aware that their stories formed part of a chain of experiences shared by their cohort.

Tamiza's Story⁴

Tamiza is the mother of two children, one of whom has been diagnosed as autistic, the other as hydrocephalic. Tamiza came to Canada in 1976 with desirable social capital. Her fluency in English and a B.A. degree from Tanzania, a British colony under UN Trusteeship, meant a deceptively easy entry into the job market. She found work the very next day but in the lower sector of the labour force, preserved largely for immigrant women (Bannerji 1995, Ng 1996). Tamiza worked at two jobs: as a bank teller and as an evening baby sitter. Within a period of two years, she got married. The couple had two children, both of whom were diagnosed as "disabled." She was fortunate to have family support. Her major struggle, highlighted in multiple contexts, was to secure social services and to ensure that her children were recognized as persons who were just different. Tamiza identified two challenges: unfamiliarity with the social service system and inaccessibility. "I think it is wrong to keep these services 'hidden.' I let the others [minority women] know that these services are there. It is their *right* to use them," (original emphasis). Tamiza made a clear distinction between mainstream and minority populations. She considers the latter to be more disadvantaged and "this is why it was hard for me to find out what services were available. Even then, I had to struggle to get these services." I acknowledge that accessibility is an issue that affects mainstream

⁴ This study forms part of a larger project on the health and well being of Muslim women in metropolitan Vancouver. Two other narratives have been published (Dossa 2005, 2006).

population differentially. Those who are educated and conversant with the system have a less difficult time in negotiating what is otherwise a bureaucratic maze. But systemic exclusion disadvantages racialized minorities (Dossa 2004, Lee and Lutz 2005). We may note that disability and race act “as mutual projects of human exclusion, based upon scientific management systems, successively developed within modernity” (Mitchell and Snyder 2003, 843). The authors highlight the horrific effects of the congruence of race and human “defects” within the framework of eugenics. This complex “has become the focal point of European and American efforts to engineer a ‘healthy’ body politic” (844). Exclusion and social erasure of racialized people or those with disabilities have compromised their humanity; hence the widely used term: “We are but human.” The task of reconstitution is carried out foremost by the participants through the stories they tell about their struggles, their aspirations and their accomplishments.

In telling her story of raising these children in a society that continues to segregate and stigmatize people with disabilities, Tamiza exemplifies a perspective captured by Yee: “But we know the issues that face us because we have lived them, they are our lives” (1993, 4). Action and reflection (praxis) constitute the axis of Tamiza’s testimonial narrative. Here, self-representation is rendered into “re-presentation of an experienced embodied social reality” (Bannerji 1993, xx).

Racialization and Disability

Tamiza is a legal citizen of Canada. Yet, she is referred to as an “immigrant woman,” a politicized term applied to all women of colour, regardless of the number of years in Canada. White women, as Bannerji (1995) argues, are referred to as “Canadians” and not as immigrants, despite the fact that they may be landed immigrants. Designated as the Other (not like us, the outsider), women of colour are excluded from full citizenship entitlements in such areas as social services, housing, health and cultural rights. Their exclusion is attributed to the fact that Canada is a white settler society. It was “established by Europeans on non-European soil. Its origins lie in the dispossession and near extermination of indigenous populations by the conquering Europeans” (Razack 2002, 1). This form of structural exclusion gives rise to a racial hierarchy of white privilege. Europeans are entitled to land and citizenship rights while others are not. Among the latter are non-European people, “scripted as late arrivals, coming to the shores of North America long after much of the development occurred” (ibid. 3). Race, then, forms an integral part of the national hegemonic narrative. “If Northern people are identified with strength and liberty, then Southern people are viewed as the opposite: degenerate, effeminate, and associated with tyranny” (ibid.). As we enter the 21st century, this racialized script has been re-deployed. Non-European migrants are perceived as “crowds” at the border, threatening the ordered world of the original white settlers (Lee and Lutz, 2005 Jiwani 2006).

Critical “race” and anti-racist scholars have drawn our attention to the chameleon-like nature of race, noting that the operation of this powerful construct cannot be defined once and for all.⁵ Lee and Lutz, for example, have noted that “race,” racism and

⁵ Working with other/non-western societies, anthropologists have long demonstrated the fluidity of race, a construct used to advance colonial agendas, see for example Boas (1911) and Stoler (2002).

racialization are social processes. Therefore, they must not be taken as “innate biological givens” (2005, 6). They further observes that racialization, as “an active process of construction and reconstruction of ‘race,’ necessarily intersects with other systems of structured inequalities: gender, nationality, language, class, sexuality, and ability, among others” (7). This paradigm of intersectionality shows how systems of inequality function at particular moments in history. In the case of gender and race, the paradigm has fostered an understanding of “the forces that have shaped the historically specific pattern of racialization [inequality] in Canada” (Dua 1999, 7).

In the area of disability and culture, the paradigm of intersectionality has served to bridge the gap between the social and the cultural model as discussed below.⁶ Developed to explain the fluidity and ambiguities surrounding group and individual identities, the paradigm has brought to the fore “multiple relations of power that intersect in complex ways to position individuals and collectivities in shifting and often contradictory locations within geopolitical spaces, historical narratives, and movement politics” (Stasiulis 1999:194). The emphasis is placed on the importance of seeing different kinds of oppressions at work, intertwined and separate. Equally significant is the point that the paradigm fosters a sense of connectedness across cultural and national boundaries. Racialized women with disabilities do not consider their struggles apart from mainstream women with disabilities, a point brought home by Tamiza. The theoretical import of this insight is noted in the work of Harding. A feminist theorist and philosopher, she makes a case for lived experiences of historically-silenced populations. She argues that it is through the identification of multiple/intersectional social locations, a standpoint epistemology, that we can produce a useful body of knowledge (1998). This stance “entails an epistemological as well as ethical obligation on the part of dominant groups to theorize as rigorously as possible their own position as socially situated subjects of knowledge” (Hirsh and Olson 1995, 1).

Disability and Culture

The literature on disability and culture reveals the need for a conceptual link between rights of persons with disabilities to fully participate in the life of a society, and cultural recognition that valorizes difference. Defining culture as a signifying system through which a social order is communicated and reproduced, scholars such as Atkin and Hussain 2003, Hussain 2005 and Waqar 2005 have worked towards reversing the representations of disability as undesirable and flawed. Persons with disabilities, they note, are ordinary people; they are neither super-heroes nor tragic individuals. The focus on culture has added depth and breadth to the social model as it gives weight to the politics of recognition. As Scott-Hill expresses it, “...groups suffer injustices and inequalities on the basis of unequal and unfair distribution not only of economic capital but also of symbolic, social and cultural capital. Certainly, it is the latter form of capital that has assumed particular significance in the global village” (2003, 100).

⁶ There exists an analytical distinction between the two. The social model of disability places emphasis on structural factors that exclude persons with disabilities. The cultural model of disability focuses on affirmation of multiple social and cultural identities.

Ethnic minority scholars have used the model of culture to highlight the interface between disability and ethnic culture (Waqar 2000, Jakubowicz and Meekosha 2003, Atkin and Hussain 2003). Referring to disability as politics of disablement, and culture as politics of identity, they have made a case for convergence of what are otherwise two separate social movements. Atkin and Hussain (2003) have noted that disability studies would be enriched through greater emphasis on cultural diversity. They show that the cultural lens would serve to reinforce the point that disability is a dimension of normal difference. The cultural lens perspective highlights two interrelated points. First, it validates the point that we are the bearers of cultural and historical traditions that shape our understanding of everyday interactions, with the caveat that cultures are not static. They inform and are informed by socio-political and economic factors. Second, it recognizes the existence of a hierarchy. Following the orientalist divide, the western cultures assume superiority over and above the Other. The latter's heterogeneity is erased in the process.

Nevertheless, it is through culture(s) that we can appreciate multiple identities that persons with disabilities and ethnic minorities adopt to claim their citizenship rights. For example Hussain (2005) and Roberts (2000) have argued that identity politics are important in the struggles of disenfranchised populations. "Struggles over cultural politics, then, far from being irrelevant, are at the heart of current debates in disability studies" (Riddell and Watson 2003, 10). To reiterate, the disability movement has worked towards reversing the medical and rehabilitation model with its emphasis on normalizing the individual body. In the same vein, the civil rights movement has worked towards reversing the social oppression based on the difference of "race"— a difference that has led to the denigration of cultural minorities. Ultimately both the movements have sought to seek recognition and justice, moments of which are captured in Tamiza's narrative.

Reading her Narrative

The birth of a baby is a joyous occasion, and this was Tamiza's experience. "Faizal's birth brought a lot of joy and happiness. We were so happy that I decided to have a second child right away." Faizal was toilet trained and walking by the time he was one year old. "But I knew that something was wrong. I was constantly comparing him with my sister's son." She observed that he was not learning and following directions like her nephew. She took him to a pediatrician and he informed her that everything was fine; all that she had to do was give him some time, as boys are slow. When Faizal was placed in a day care, his teacher put him into a special program. "They took my child and kept him with mentally retarded children. I had never been exposed to disabled children before. I said: 'My child does not belong here. My child can walk and talk. If you can't provide the service, I will take him somewhere else.' I was so hurt that Faizal was thrown with other mentally retarded children. We took Faizal to a specialist and he said that my son is autistic."

Tamiza's response, "My child does not belong here," has societal origins. Until such time when her son was diagnosed as autistic, Tamiza had no exposure to children with disabilities, an indication of their social invisibility. This is despite the fact that the community integration movement had gained momentum at the time of Faizal's birth in the early eighties. As Kittay (2001) has observed, the movement's entrenchment within

liberal democracy does not advance the interests of people with disabilities or those of other marginalized groups. This is because the human rights discourse of liberal democracy is not action-oriented. The premise at work is that once the rights of people are enshrined in Charter documents, they are implemented as a matter of course (Henry et al. 1995). But this is not the case as there is a gap between discourse and lived realities of people.

In the course of raising her children, Tamiza experienced the multiple ways in which persons with disabilities are segregated and excluded from society. She does not think that her own community is exempt from this entrenched practice. Two reasons may be cited for this state of affairs: (a) Disability as positive difference is not socially recognized in most contemporary societies (b) and her own community has internalized the dominant discourse on disability equals deficiency. She struggles to create a space where her children can have a sense of belonging and claim their citizenship rights as Canadian-Muslims. Below I delineate the political contexts that allow us to see her struggles as part of a larger process. This includes alternative spaces (pockets and enclaves) where progressive change can occur.

Narrative Moments:

How I raised my children⁷

Tamiza's first son, Faizal, was diagnosed as autistic. This condition is defined as "a complex developmental disability that typically appears during the first three years of life" (Autism Society of America 2000, 2; also Waltz 2005). The society's web-based write-up explains how autism as a *disorder* creates problems of communication with the outside world. The reader is informed about the possibility of aggressive and self-injurious behaviour along with the fact that individuals with autism may also exhibit unusual responses to people and resist change. A biomedical focus is evident in the discourse of individual deficit: "disorder," "aggressive," and "self-injurious behaviour." The section, "What are People with Autism Like?" highlights further disorders such as "lack of spontaneous or imaginative play." Under the heading "Effective Approaches," we learn that early intervention is the best solution to the "problems" associated with autism. Autism as an abnormal condition that requires professional intervention is the sole focus of the article. Its authoritarian, all-knowing tone leaves little room for experiential and embodied knowledge of people who are autistic or those who care for them. We are not questioning the benefits of early intervention, but the focus on disease/defect/abnormal discourse is dehumanizing. The article makes no reference to the message that people with disabilities have spelled out loud and clear: "We are not defective beings but people who are different." Its emphasis on disembodiment (a universal autistic person) erases differences of race and gender, both of which require consideration, as they constitute the axis of social inequality.

Tamiza takes issue with the deficiency discourse on autism as an exclusively neurological disorder. "He (Faizal) is high functioning and verbal. He can talk and he can let his needs be known. Most of the autistic children that I have encountered are non-

⁷ It is not my intent to portray Tamiza as heroic. She considers herself to be an "ordinary human being," (her words) struggling to assert the rights of her children as "citizens of Canada," the country where they are born.

verbal.” Tamiza's focus on the lived reality of her son is emphasized in other scenarios, for example, in her articulation of his voluntary work in the mosque.

He is a volunteer. He picks up all the garbage and distributes flyers. He also helps with other things. He has learned a lot from the community and the community has learned from him. If I keep him in the closet like some other parents do, *the community will never learn, they will never learn* (emphasis original). Faizal has taught the community so much. For example, when it comes to distribution of ritual food, everyone is supposed to take one. If someone asks for two, he says it loudly: “You are not supposed to take two.” No one can dare ask for two when Faizal is around” (the mosque).

Tamiza portrays her son as active in the community. Her emphasis on mutual learning flies in the face of the dominant discourse focused on medicalization and the dependency status of people with disabilities. More importantly, her speaking about her son's activity, otherwise unnoticed, suggests the enactment of a different kind of citizenship that Das and Adlakha refer to as “publics constituted through voice” (2001, 512). What is otherwise constituted as private, such as the domestic or a place of worship, is politicized to effect a paradigmatic shift. Here, disability and impairment are located “not in (or only in) individual bodies, but rather as “off” the body of the individual and within a network of social and kin relationships” (ibid.). I argue that sociality, however tenuous, makes it possible for a person with disabilities to claim her/his citizenship in all kinds of dispersed sites. This potential is brought to light in the second vignette.

You know I do not "hide" my children. When people ask me, I tell them that they are "special needs" children. If they do not understand, it is their problem, not my problem. I tell Faizal that he should use Islamic words, *al hamdulillah* (everything is due to Allah) and *sukhran lillah* (I am grateful to Allah), all the time. His workers [caregivers] ask what does this mean and this way they learn more about Islam.

Affirming a Muslim identity means being part of the global *Umma* (Islamic community) whereby one lives within and outside national boundaries; in other words, inter-nationally. Nation states do not promote deterritorialized and borderland positions. Pluralism is antithetical to a imagining of a nation state (Dossa 2004). The latter is “a regime of order and knowledge” (Malkki's 1995, 4) instituted to maintain power and hegemony of one group to the exclusion of others. Yet cracks and ruptures appear on this imagined landscape, giving rise to alternative discourses and imaginings.

Alternative discourses and imaginings is the subject matter covered by Fatima Mernissi, a Moroccan feminist scholar. In *Doing Daily Battle*, she presents the narratives of nine Moroccan women showing the activist stance of each woman as she goes about pursuing her education or establishing herself “from peasant to citizen of the world” (1988, 145), among others. Mernissi seeks to show that the words of the women,

meticulously documented, reveal Morocco that remains unknown. This is because the female point of view though suppressed presents a different picture compared with that of the pervasive male. "In their own view, women see themselves as a race of giants doing daily battle against the destructive monsters of unemployment, poverty and degrading jobs" (5). It is in this context that the women conduct their activist work, asserting their independence in economic terms, in the running of their households, and through the medium of self-expression. Tamiza's daily battle is not unlike that of the women in Morocco as she too struggles to secure resources for her children and affirm their identities as participating citizens. Like the women in Mernissi's study, Tamiza creates an alternative space, revealing a world different from the one created by a presumably able-bodied society with its narrow and exclusive parameters.

Faizal lives in a group home. Tamiza stated that this is the best situation for him as he can participate in various activities. "He is so busy that I can only reach him in the evenings." Tamiza also wants to ensure that Faizal grows up as a Canadian-Muslim. She is painfully aware of the fact that the group home is a mainstream institution. It does not cater to the needs of the multicultural population, in terms of culture or religion. Tamiza stated that Faizal gets exposure to his culture and faith during the weekends when he goes home and attends mosque. By ensuring that Faizal prays every day in the group home and that he uses Islamic words during the course of his interaction with service providers (mainstream), she has carved out a space where he is able to express his identity as a Canadian-Muslim.

Faizal's practice of Islam (he also says his prayers in the evenings) establishes his presence in a group home in Canada. This is a significant step given the fact that Muslims "have found themselves bearing the brunt of a new wave of suspicion and hostility, and strongly voiced if imprecise doubts are being cast on their loyalty as British [includes Canadian] citizens" (Modood 2005, viii). The issue here is that racialized people with disabilities claim a multi-layered identity; it is within this complex sphere that their ascribed status of disability as an absolute marker is subverted.

To explore this process of alterity and becoming, I present narrative moments from everyday life. This vantage point allows us to link local scenarios to structural and institutional complexes without diluting experience and subjectivity.

Disability as Tragedy

At the time we were coping with my first son, I was already pregnant. At this time I was seeing a gynecologist. We had to pay \$500 extra for this service. When I did not hear from the doctor, I phoned him. There was no reply. I phoned again and asked the secretary why the doctor was not getting back to me. She told me that there was something seriously wrong with the baby that I was carrying. But she would not tell me. I told her that I wanted to know. She said that it was Chinese New Year and that the doctor is not available. I said: "I am coming there right now." I phoned my husband at work and I told him that there was something wrong with the baby that I was carrying. He came right away. When we saw the doctor he said "your son has hydrocephalus," and he left the room. We had never heard of this word before. My husband said, "let us go to the library." We

did some research and found out as much as we could. We phoned my brother who is a doctor. He told us that if he has hydrocephalus we are going to have a lot of problems. I said: "I don't want this baby. I cannot take care of two disabled children." I was six months pregnant and it is illegal to have an abortion at this time. But there was a doctor who was willing to perform an abortion. I did not sleep the whole night. In the morning, I told my husband that I want this baby. My husband was very supportive. He is my best friend. I am ashamed that I was considering aborting my baby.

This account brings home a poignant issue faced by parents with children who have disabilities: the tension between the desire to raise a child with a disability and societal pressure not to bring such children into the world. It is this scenario that explains why Tamiza considered aborting the fetus. The actions of the three medical practitioners are revealing. The first one walked out of the room, dismissing the unborn life through body language, while the second focused on problems in raising a child with hydrocephalus. The third doctor's willingness to perform a late and therefore an illegal abortion speaks for itself. Strangely, the indifferent gynecologist and the "sympathetic" doctor both give the same message: it is not desirable to bring a child with disabilities into the world. We must not rule out the possibility that the practitioners did not have anything to say. Their professional training and socialization into the norm that the lives of people with disabilities are of less value may have contributed to their silence. Likewise, Tamiza may have considered the choice of not raising a "disabled" child.

Disability-as-tragedy is a view perpetuated in genetic screening.

It takes considerable theoretical agility to urge the public to support screening programs so as to prevent the conception of handicapped individuals while at the same time insisting that full respect be paid to such developmentally disabled adults that are already among us (Daniel Wikler cf. Reinders 2000, 1).

From Tiny Tim to Telethon, the public discourse of childhood disability emphasizes personal tragedy and vulnerability. These discourses are in turn, reproduced through daily encounters with other children, with adults and with a variety of institutional contexts (Priestley 1999, 93).

There exists a profound contradiction: we cannot take the lives of the unborn (read "defective" fetuses) and at the same time respect people with disabilities among us. The message contained in the promotion of the screening program is, in effect: "Disability is not a desirable condition and therefore it should be nipped at the bud." Such a stance has wide implications, as it diminishes the advocacy work of people bent on reversing societal oppression of people with disabilities. "We do not think of ourselves as lesser human beings." This is the point of view reiterated by disability scholars and advocates.

People with disabilities are reminded of their socially constructed abnormality in everyday life situations within neighbourhoods, workplaces, and social and medical

institutions. But these situations do not preclude human agency. People on the margins challenge “the dominating centre by creating a public space and employing empowering poetics of the periphery”... (Cheungstiansup 2001, 32). In niches and crevices within dominant systems, persons with disabilities remake their worlds, affirming their worth and value as human beings.

As people from the disabled community are apt to point out, however, there are many other stories to be told about disabled people besides the medical ones. Many of these people reject the suggestion that either they or their relatives are living deplorable lives that would better not have been brought into existence. Whether the cause of their disabling condition is called a genetic 'defect' or not, they do not think of their lives as such as being defective. Rather they view their lives as valuable because of what they are capable of doing, just like everybody else (Reinders 2000, 3).

Tamiza's decision to give birth to her baby is a commitment to bring to the fore this second script: disability = difference = valuable. Tamiza's initial awareness of the task at hand, that is, raising two children who are socially constructed and imagined as “abnormal,” was brought home when she saw another woman in the hospital.

During this time I met another Mum. She had a baby girl who was disabled. We turned to each other for support. The baby girl did not survive. Their marriage also broke up. In such a situation [having a disabled baby] you make it or break it. I was lucky.

“We turned to each other for support” speaks to the lack of social support for people with disabilities and their caregivers. This is a theme highlighted in the disability literature (Kittay 2001). Tamiza considers herself lucky to be in the “make it” scenario. She has family support, but her situation is still compartmentalized. The social service and health sectors address the “physical” and medical needs of her children. Her family and community cater to their social needs.

When I was pregnant with Ayaz, I was monitored every week. At the same time Faizal was going through tests. So I was struggling with two things at the same time. When I was seven months pregnant, the doctors had to drain the fluid from Ayaz's brain as they were scared that his eyes would be affected. I had a C section at seven months. When they delivered the baby, I did not see him for five months. When I held my baby the first time it was very hard. He was in the hospital for a long time. He had a couple of surgeries as they had to make sure that his optic nerve was not damaged by the fluid in the brain. There was one thing after the other.

Monitoring, surgery, eyes, fluid, optic nerve, brain – these are corporeal words. Here, the body is subject to what medical anthropologists refer to as “the scientific tradition of reductionism.” This tradition assumes that to understand “the properties of the whole, we must first consider the units that compose the whole” (Lock 1993, 370). Such an approach dismisses experiential knowledge as irrelevant. Cultural influences of all kinds are viewed as getting in the way of revealing relevant facts “in the depths of the body” (ibid.). Lock takes issue with this in two ways. First, she argues that medical knowledge, while of value, is partial and fragmentary and rests on an abstract plane unconnected to time and space. “A person however, is clearly not an abstract entity, but a conscious being perpetually in a state of change, whose body is the centre of ongoing dynamic interactions among physical and social surroundings” (ibid. 371). Second, our body insists on meaning, rather than existing as a surface to which things are done. The emphasis here is on the body as an active agent, whose engagement with the world does not exclude “the very sinew, nerves, and bones of the body” (371.).

The biomedical discourse that reduces her children to body parts (“fluid” and “optic nerve”) is not what Tamiza accepts as her reality. She focuses on social relations.

When Ayaz was born, both my husband's and my own family got together. I have a lot of support from my husband. We have become like friends. We laugh and cry together. We share our feelings. We have become very close. My mother quit her job to take care of Ayaz. Faizal was in the day care. But Ayaz needed a lot of care. His head was big. For three months he could not hold his head up and it was so big. I have been very lucky. The children have brought us a lot of happiness and joy. How could I have rejected my own baby [considered abortion]?

In the last three decades, storytelling has been given centre stage in the works of anthropologists and feminist scholars globally. This genre’s potential for grass-roots research has been noted and recognized. To recognize storytelling as a creative activity, narrative scholars have identified critical and reflexive perspectives. Gelya Frank suggests that gathering information on a life story must be accompanied by “a methodology in action as a source of primary data” (2000, 22). This stance, she argues, allows us to see how the biographical self is influenced by and also influences a particular cultural milieu over time. Frank observes that if stories are listened to in an appropriate way they have the potential to effect social change. This is due to the fact that when readers engage with stories and their various interpretations, new meanings are created that will reverberate in the readers’ own local culture and sometimes the dominant culture as well.

Julie Cruikshank (1998) suggests that we pay attention to how stories are analyzed and translated across boundaries. This focus, she argues, breathes new life into stories as it creates greater appreciation of how the stories can be retrieved and reintroduced in new contexts. Commenting on the stories of marginalized groups, Razack (1998) notes that they reveal the world that we ought to know and they suggest knowledge of a just world. To grasp the meaning of the storied content and the multiple ways in which it is expressed, we must pay attention to the larger sociopolitical contexts

that suggest the complex ways in which individuals are connected to the world. Storytelling has thus achieved a level of theoretical and methodological sophistication. Frank, for example, identifies reflexivity as an important principle that addresses the charge that research about less privileged women can be potentially exploitative. The principle of reflexivity allowed Frank to ask questions such as, “[h]ow I came to understand Diane, how working with her transformed my understanding of her life, and how our collaboration may have influenced the life story Diane has to tell” (2000, 2). Addressing the issue of betrayal in field research, Ahiwa Ong cautions us not to assume that subjects of our research are devoid of power and agency. She advances the point that we need to have a more complex understanding of power understood as “a decentralized, shifting and productive force, animated in networks of relations rather than possessed by individuals” (1995, 353). This stance, according to Ong, is vitally significant as it enables our subjects to be part of the “cultural conversations in metropolitan centers” – a location that gives central space to people who are otherwise relegated to the margins. Re-examined notions of reflexivity and power are of value, as it is through such activity that progressive dialogue can be fostered.

The above discussion establishes one point: stories/narratives have the potential to effect social change, provided they form part of the larger political, social, historical, cultural and literary landscapes of societies. Racialized women with disabilities are not part of the Canadian landscape. Their structural and social exclusion are intense. Yet their stories must be heard if we want to write a different kind of Canadian history: a history where women with different abilities and from different cultural backgrounds have an active presence. As Minh-ha has expressed it: “It will take a long time, but the story must be told” (1989, 119). Our listening must then be directed to the process of how we come to know about the lives of those who tell their stories and what we do with the stories once we have heard them.

Tamiza's attempt to embed the family story into the biomedical frame is important as it provides her with the space and grounding to deal with multiple issues that she faces as a mother of two children with disabilities. We may note, at the risk of repetition, that children with disabilities do not get the support that is given to so-called “normal” children. To compound the situation, people with disabilities are denigrated and devalued on the grounds that they are not like us – they are the Other. For Tamiza, familial support gave her the anchor to venture into the outside world. “When I had so much family support, I knew that they were behind me and it was easier for me to explore what was out there.”

Medical education at Harvard school begins with *entry* into the human body, notes Good (1994, emphasis added). This stance is problematic as it trains medical students to look at the human body as an object to be skillfully manipulated. Good argues that the inward gaze into the body is out of step with the bodies that we interact with in our in everyday life. Tamiza has embodied knowledge of this insight. In her account, she does not focus on the medical (read compartmentalized and dehumanized) vocabulary. In the interview, she emphatically observes that her children are contributing members of society. She notes that they have been instrumental in creating a special bond between her natal family and her in-laws, and between herself and her husband. She reiterates the point that her children have as much to teach the community, as they have

to learn from the community. This is a crucial point as, in the institutional context, people with disabilities are reduced to a population of service consumers who cannot give but only receive. This one-dimensional perspective erases the element of reciprocity, the bedrock of social relationships.

The demedicalized/alternative model is realized, not within the discrete entity of the individual body, but within a network of relationships. Reinders (2000), among others, argues that our social lives are in actual fact our moral lives and our moral selves develop within the social relationships that we find ourselves to be part of. To accept responsibility for other people, we must regard our own lives in terms of those relationships (Das and Adlakha 2001). It is this aspect that is illustrated in Tamiza's account.

Advocacy work on the part of subordinate groups requires adoption of a new subject position. This position is of interest as it goes beyond the unit of an individual that in Western philosophical tradition is unitary and centred, and created out of the binaries of Self-Other and Subject-Object. Rather this new subject is heterogeneous as well as political. "There are many narratives by women of colour around the world that propose and enact new forms of locating themselves within societies. These forms are both oppositional and non-essentialist, and confront and fracture the self-other opposition in the name of inclusion, multiple identities, and diasporic subject positions" (Grewal and Kaplan 1994, 2). Tamiza adopts multiple subject positions to advance the interests of her children.

Multiple Subject Positions

Tamiza is constantly reminded of the different ways in which she and her children are excluded from social situations. Within her own community, she noted that she is not free to move around and socialize freely at events she attends with her younger son, a wheelchair user. She has to wait for people to come to her. Likewise, she feels that people do not know how to approach her children. Their entry and exit points of interaction are confined to hello or how-are-you exchanges. Tamiza has identified two groups of people, the general populace and the service sector. The former barely notices her children, except for those who have come to know them as "the neighbour's children with special needs," as she expressed it. It is interesting to note that Tamiza's narrative makes greater reference to service providers than regular people, per se. Interactions between service providers and people with disabilities tend to be instrumental and functional (Dossa 2006). Tamiza seeks to rectify this situation. It is this context that prompts her to relate two scenarios.

First, when Faizal graduated from high school, Tamiza had a party at her house. She invited people who interacted with Faizal on a daily basis: teachers, service providers, bus drivers and classmates. "There were thirty people. Five of them were in wheelchairs. I had a barbecue and I served the food in my best chinaware. Why not these children should have fun like anyone else?"

Second, when Tamiza has to take time off from work to tend to her children, she lets her employer and co-workers know "the real reason. I can take sick leave and I don't have to let them know about my children. I am not going to hide my children."

These accounts emphasize one point. Tamiza wishes to establish her children's presence in the public sphere so that they can be "heard" and "seen," a conclusion I draw based on two questions: How are situations framed? What stories are circulated at particular moments in time and space?

Political and social issues are invariably at work in how people at the margins frame situations. Tamiza is well aware of the fact that graduation parties are not held for youth with disabilities on the scale and level enjoyed by their able-bodied counterparts. She is determined not to have a party exclusively for "the disabled graduates." This would lead to their confinement within a discrete and depoliticized sphere where they would be doing their own thing, unnoticed by the larger world. Tamiza brings under one roof people who do not otherwise meet given the nature of their task-oriented work. The coming together of service providers, educators and students with disabilities in a party atmosphere is conducive to creating a milieu for social interaction. Here, youth with disabilities are seen as human and not as abnormal beings to which things are done in a fragmentary way. Serving food on her best china serves to convey the message that people with disabilities have a right to lead normal lives and have fun. In presenting an example of interaction among people who otherwise do not come together socially, Tamiza points to a scenario that should be commonplace. But this is hardly the case. People with disabilities continue to live segregated lives. Furthermore, they are not free from the impact of two practices that disability activists consider dehumanizing: a utilitarian focus, as opposed to an interactive one and compartmentalization of services that erases the identity of a person. Tamiza's desire to bring about change is informed by the dominant discourse that renders people with disabilities as the Other, especially those who are also racialized.

Tamiza was happy that I was interested in her story. She was well aware of the fact that her children, like others diagnosed with disabilities, had been rendered socially invisible. She related that when they visited places where people saw them often, they would greet them. But beyond that there was no further interaction. "They [society] do not know how to address my children. They do not realize that they are human beings like us. They need to learn." In presenting Tamiza as an advocate, I do not intend to portray her as a heroine. She herself acknowledged the fact that as a mother and a human being, she was engaged in securing citizenship entitlements for her children and in the process she felt it necessary to speak up for other persons with disabilities, racialized and mainstreamed.

Her stance on acting as an advocate for all people with disabilities suggests that she does not want to be confined to the scenario: "let them fight their own battles but they cannot speak for us [mainstream sector]." Tamiza chooses to act as an advocate for all people with disabilities. When I asked Tamiza if she would be facing the same issues in her native country of Tanzania, she said: "Over there the issue would be that of resources. I would still have to struggle for people to take them for what they are, 'good human beings.' But this struggle would be less." She notes:

There are a lot of good programs inside this country and nobody is getting handed them out. You have to find out these programs and apply for these programs and make sure that as a taxpayer it is your right. You should not

be made to feel guilty that it is taxpayers' money. You should not be doing this [spending taxpayers' money]; you should be doing this on your own. You can't because there are a lot of major expenses you are looking at and you need assistance. You should not be ashamed to ask for it. But nobody is going to tell you for sure that "look this program is available and your child might be entitled for it."

Tamiza reiterates two intertwined issues: entitlement to programs and their inaccessibility. She recognizes that some good programs are in place but that people do not know of their existence. She stated that she was able to secure services in bits and pieces of information gathered from the people she interacted with on a daily basis or through chance encounters, such as a conversation with another mother while waiting to see a doctor. Once she learnt about the services, she noted that it was not easy to secure them. "There were papers to be filled and you had to prove that you were entitled to the services. They asked for medical reports." Tamiza felt that as a minority it was more difficult for her "as you do not know the system as well as they [mainstream people] do." Yet, she noted that because she had family support she had the time to inquire "what is out there." Her fluency in English helped her to secure services though she emphasized that it was an uphill battle.

I think that the social worker or somebody else in social services should come and sit with you and [tell you] what is available and what you need. And if you want to get in touch with us this is the way you apply for it. Because the parents go through so much, so much to deal with. The last thing they want is to worry. Apply for this home, fill up this application, go and see this person. You feel you are begging. They put a lot of stress on you. I want to give this message. There should be more information available to know what is out there.

Tamiza was concerned that the services were given as charity. Her experiences of raising two children convinced her that she was entitled to services. She believed that "as a citizen and as a taxpayer," it was her right to access and use the social provision that her children needed to live like everyone else.⁸ Tamiza then advocated for their/her rights as well as those of the others. The two processes are intertwined.

Conclusion

⁸ We need to emphasize the point that it was Tamiza's struggle to secure social provision for her children that made her realize that services are entitlements. Her children do not have to wear the label of "disability." She wants society to recognize them as "good Canadian-Muslims." In the process she claims multiple identities. She is not only a "caregiver" for her children. She is a mother, a worker, a wife, a citizen, and an advocate for persons with disabilities. She recognizes that her struggles are compounded because of her "race" (the Other/immigrant woman). Through her struggles, she identifies demedicalized and alternative spaces that go beyond the diagnoses of "disability" and that bring to the fore her children's and other people's humanity. Like other women in our study, she presents a testimonial narrative.

The core issue addressed in this article is to show how Tamiza – a racialized woman caring for two children with disabilities – speaks to identify the fault lines of the system/social service sector and also suggest avenues for change. Of particular interest is the narrative strategy that Tamiza uses to share with the reader her experiential knowledge of the system. We note that in the beginning she had no exposure to children with disabilities, a situation brought about by structural factors: social invisibility of people with disabilities and immigration policy that excludes on the grounds that people with disabilities are not potential wage earners. Early on, Tamiza discovers that she had to learn and negotiate the system on her own. She presents herself as a protagonist, a position that marginalized women adopt so that they can be heard, such is their silencing in society (Dossa 2004). She makes it a point to get to know the system inside out, once she realizes that it is structured to remain out of the reach of people, especially for those with an outsider status. “Nobody, not even your doctor, will tell you that such and such a service is available. You have to find this out on your own.” Tamiza spends a lot of energy and time to ensure that her children have the best of what is available; she acknowledges that her children were able to get into the system because they started early in life. Other factors at work were that both Faizal and Ayaz had well-defined medical diagnoses and that Tamiza was fluent in English. Being brought up in colonized Tanzania, she was able to familiarize herself with “how things work in the West.”

Although Tamiza feels that she was able to secure services to her satisfaction, she is not content. Her source of dissatisfaction arises from the fact that service provision comes with a price: services are given to her as charity and their task-oriented focus dehumanizes her children. Tamiza then wages a second battle: she presents herself and her husband as taxpayers, making the argument that services are entitlements. Tamiza portrays her children as persons, an issue taken up vociferously by disability writers and activists; she adopts multiple roles that allow her to bridge private-public and East-West divides. She identifies herself as a citizen, a mother, a waged worker, an advocate and a Muslim. She ensures that the struggles of racialized minorities do not remain confined to the discrete space of the Other. Our role as researchers then is to provide broader contexts so see how the personal is indeed historical and collective (testimonial). It is at this level that we can discern the parameters of alternative and demedicalized spaces, evoked by the narrative.

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