TOWARDS A METHODOLOGY FOR *DIS*-ABILITY RESEARCH AMONG ETHNO-CULTURAL MINORITIES

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The disability movement is a grass root level initiative drawing its early inspiration from civil rights issues raised by African Americans in the early sixties. Paradoxically, the movement's growth and development has not included cultural minorities. Multiple reasons can be cited for what might have been a natural affiliation. While it is common knowledge that it is advantageous for excluded groups to work together, this cannot be easily put into practice, as the constraints of the larger system loom large. In the case of Euro-American societies where a centralist state defines disability as a stigmatized category, marginalized groups are systematically kept apart and positioned to compete for scarce resources (for example, Ingstad/Whyte 1995; Bannerji 1984). Thus the emergence of an umbrella group working towards a common goal of equality and justice is rendered impossible and this accounts for the fact that the disability movement is separate and isolated from other civil rights organizations. The discourse implication of such a separation is that we use multiple words to describe the situation of marginal populations: *ethno-cultural*, *racialized*, *gendered*, *dis-ability*, *minorities*. The underlying grid of this terminology is that of the Other – not like us.

Racial minorities in North America and elsewhere have been engaged in an active struggle to transform a stratified system where skin color and gender make a significant difference in accessing valued social and material resources. Concerns surrounding persons with disabilities are cast in the same mold: their struggle for resources includes issues of personhood and dignity, as is evident in the gradual paradigm shift away from a *charity* model towards that of entitlement and citizenship rights. The underlying principle expressed is that disabled groups have the right to enjoy the quality of life and community participation that the able-bodied take as given. This again is due to the fact that the benefits enjoyed by the latter are built into the system, and they are thus not perceived as recipients of services. The struggle for equitable distribution of resources in a just society has other dimensions requiring further deconstruction. To begin with, the role of the state is central in defining populations as *problem areas* to be rectified through intervention strategies such as legislation and social programs. The state's power in shaping the environment within which persons with disabilities live and its control over distribution of rehabilitation goods and services makes disability into a business (Gritzer/Arluke 1987). In such a situation, those with vested interests provide services to those who are medically diagnosed as *dis*-abled. This form of political economic framing is sustained by ideological and sociospatial constructs. The *dis*-abled are further entrenched in the system through the powerful ideology of difference and Othering measured through hegemonic reference categories.

As disability and other forms of difference (race, gender, class) have been expressed in relational terms, reference categories come into play in different contexts. The question: "compared to what?" (Wolch/Dear 1993) leads to an understanding of disability as a measure of distance between the individual and the ideal of an *able* body. If disability is a statement about a person's deviation from a constructed *social norm* then we need to problematize the constructed and imagined spatial boundaries of difference. Within a broad spectrum of individuals with different physical and mental disabilities, the question that invariably arises is: at what point does any one person become *dis*-abled? (ibid.: 458) There cannot be a single identifiable point as any form of demarcation is contingent upon social and cultural expectations concerning established norms of work and appearance. It is apparent that we have not sufficiently problematized the relative nature of disability as well as those of *race*, ethnicity and gender. We frequently assume that we know who is able bodied and who is *dis*-abled and who is normal and who is different. Furthermore, the constructs of difference and normality are not absolute even within one social setting as varied criteria and norms are applied in differing contexts. Butterfield (n.d.) and Murphy (1987) observe that dominant implicit norms are used as reference points to evaluate and judge others distant from an implicit criterion. While this is true to a large extent, the implicit nature of the norm leaves room for negotiation and reconfiguration of imaginary and constructed boundaries. Value judgments about normalcy contain ambiguities embedded in specific spaces – an aspect that I will discuss below with reference to methods.

Before we engage in the discussion of methods, it is useful to ask what purpose does the drawing of imaginary boundaries serve? Western researchers have suggested that the impulse to distinguish between us and them, like and unlike, constitutes an integral part of representation. The formation of individual identity, for example, has been explicated in relation to the Other. Gilman (1988), among others, attributes the need for distinction to the wish to gain a sense of control:

> Difference is that which threatens order and control; it is the polar opposite to our group. This mental representation of difference is but the projection of the tension between control and its loss within each individual in every group. (ibid.: 458–459)

Preoccupied with the premise of difference, the Other's proximity and the transgression of socially constructed boundaries are taken as a threat to the well-being of individual identity because "they challenge the territorial position of the self" (Wolch/Dear 1993: 461). There exist powerful distinctions within our social landscapes which determine who can cross what boundaries, under what conditions, and at what times.

Once a dividing line is drawn between *dis*-ability and *able-bodied* and also along *race* and ethnicity, we encounter a situation of naming the difference, a process that assumes such an intensity that no non stigmatizing discourse exists for those who are labeled (Zola 1993). Western discourses on the variant *dis*-abled, racialized and gendered bodies have an epistemological grounding in colonial capitalism that we are only beginning to understand in all its complexities. While we cannot underestimate the power of sociospatial relations and ideology in the construction of difference and marginalization of the Other, this is only part of the analysis constituting the systems approach dominant in the seventies and eighties. Human action and agency provide invaluable insights into resilience, negotiation and remaking of life worlds. Realizing the loss of this dynamic, Anthony Giddens (1985) has dubbed the relationship between structure and agency one of the central problems of modern social theory. Theoretical and methodological insertion of human agency into structure has taken varied forms salient among which are: 1. life narratives and stories; 2. space; and 3. embodiment. These critical approaches are of special value in the study of racial (ethnocultural) minorities with disabilities as they enable us to move away from the dominant victimization mode, where *culture* is reified and frozen in time and place, towards embodied social agency.

Towards this end, I discuss some methods that lend themselves to identifying agency and its interpolation into structure (as part of a continuum). The methods are exploratory in nature and are presented to invoke discussion. The following should therefore be taken in the spirit of sharing of ideas rather than a systematic study. The objective is to invite others to further experiment with non conventional modes of research.

LIFE NARRATIVES AND STORIES

The genre of narrative/story posits the presence and voice of the subjects of research. In taking note of detailed accounts omitted in positivist approaches, it captures the humanity of individuals who otherwise have been rendered socially invisible. The narrative genre has been found to provide a medium for understanding of cultures (as lived reality and therefore in flux) as it permits greater collaboration between a researcher and the subjects. More recently, a narrative approach has been utilized to capture the way in which medical and other systems impinge on and impact on individual/family settings. The narrative genre then does not lend itself to a coherent and polished synthesis where contradictions are dismissed. Rather, a recurring theme is one of multi-stranded connections of people, places and events – a scenario that defies strict confinement within the unit of one dominant discourse. Through narratives, one does not only have an appreciation of what it is to be human but also of how one's humanity is played out in the dynamic interplay of disability, gender and *race*. The core concern is not that of mere construction of narratives, but subtleties of change between disparate worlds: the intricate interface between discourse on the medicalization of *dis*-abilities (construction of the variant body, process of *labeling*, politics of social services) and non-medicalized interventions and life aspirations. The point being that narratives of the ethno-cultural minorities capture experiences and provide insights into processes that include triple social constructs (*disabled*, racialized and gendered) and their reconstitution by subjects.

> Life stories have been defined as testimonials, a process of struggling towards a particular consciousness, that both reinterpret and remake the world. (Ong 1995: 354)

Narratives of minority persons with disabilities reveal the different ways in which they negotiate socially constructed labels of Othering and claims to subjectivity (Dossa forthcoming). The following outline serves to contextualize this further.

1. The telling and listening paradigm of narratives (Ong 1995) has the effect of lessening the personal and pedagogical distance between the

narrator and the researcher. The resulting double-voiced discourse captures the speaking subject's perspectives and that of the listening subject's location in research. The dialogue between the two voices can be extended to include the reader. It is within such dialogical encounters that alternative perspectives may be identified.

2. Recording of narratives serves a therapeutic purpose. As individuals begin to understand their own experiences informed by multiple constructs (*dis*-abled, racialized and gendered), ideological underpinnings come to light. This process reveals a deeper understanding of historical and *cultural* constructions of social categories – the first step towards effective change and transformation.
3. From a research perspective, the narratives contain invaluable data on the overall social history of an epoch. In the case of ethno-cultural minorities with disabilities, contradictions of social politics, immigration policies and experiences of *race*, *dis*-ability and gender emerge as part of historical and social developments. Ethnocultural minorities may have been subject to colonial and postcolonial legacies; some may have come as refugees and many are subject to compounded forms of negative labeling. Interrelationship between *dis*-ability experiences and *race* and culture can then be explained reflexively within the overall social history of a particular period.
4. Other than the individual and consciousness raising dimensions, the recording and discussion of narratives point to action-based and policy orientations. The rich and touching elements of narratives provide an impulse for mobilization and activism. This form of shared consciousness allows one to transcend isolated horizons for a common cause.
5. Life narrative data challenge hegemonic perceptions of ethnocultural minorities as victims forever struggling to overcome numerous constraints. Alterity and other ways of being encoded in narrative data provide a much-needed critique on social inequality and injustice.

FORGOTTEN SPACES, (RE)MEMBERING LIVES

In recent times, critical social theory has advanced the framework of the social construction of space for the understanding of *race*, ethnicity and gender; yet there is a paucity of data (with the sole exception of physical environment) on how multi-layered spaces impact on the lives of people with disabilities. While this in some ways is a reflection of the intense marginalization of persons with disabilities, this oversight ultimately relates to the fact that social and physical spaces are constructed for able-bodied individuals where white, middle class males fare well (Wendell 1996). The non-existence of *spaces* for those who are *dis*-abled further isolates their conditions and experiences. We have not as yet developed spatial discourses that provide insights into how societal values, practices and structures impact on lives (Soja 1989). That space has much to do with multiple marginal positioning of ethnocultural minorities with disabilities may be demonstrated by drawing cues from critical geographers, as well as cultural and feminist anthropologists (Dyck 1995; Kerns 1997; Emberley 1993; Fine/Asch 1988; Minh-ha 1989). These critiques suggest that space, and its concomitant place and also time, cannot be delineated within a unitary framework. Spaces are gendered, *raced* and disabling both in their representations and how they are experienced. Dyck (1995), for example, has shown how women's work evokes spaces that are not legitimated in dominant representations. A focus on everyday space(s) of home, streets, neighborhoods and work reveals complex interdependencies that challenge dichotomous representations of pubic and private, and productive and reproductive spaces. The point that needs emphasis is that actors remake and bring specific meanings to different spaces as they experience them.

Given the centrality of space in human experience three distinctive dimensions of space may be identified to advance the interests of ethnocultural minorities. First, members of cultural minorities have themselves undergone spatial changes of (dis)placement, as they have moved physically from one geographical area to another. In their new location, spatial categories are reworked and subject to configuration giving rise to networks and identities as individuals interact in new and emerging contexts; cultural and/or sacred spaces form part of this complex as ethnocultural minorities interact with one another and with the larger community. Social interactions include *physical spaces* of residence and construction of physical buildings (community organization or a place of worship) as well as other urban spaces: streets, neighborhoods and shopping malls. Thus an emphasis on space allows us to explore the cultural and religious practices of minorities beyond the articulation of elites towards the everyday practices of ordinary people. Spaces of everyday life situations are replete with meanings and nuances integral to understanding situations of disabled persons from ethnocultural backgrounds.

Second, visual clues and more tangible aspects of spatial organization are easiest to identify. Canadian Muslims with disabilities, for example, often symbolically expand the spaces of their bedrooms in residential and institutionalized settings with rosaries, the Qur'an, recitation tapes and calligraphic engravings (Dossa n.d). The visual is easier to accommodate so far as it remains within the private space of the *resident*. Its display in the living room or lounges would be problematic as it would take up the space of more dominant and apparently neutral representations. While one can argue that artistic and/or consumer items form part of the way of life in the host country, these items do not necessarily reflect meaningful and historical experiences of ethnocultural minorities with disabilities. By and large, visual clues within group homes or institutional settings, neighborhoods or streets do not convey a multicultural landscape. For minority persons with disabilities, the minimal existence of expressive spaces may translate into social barriers that are not addressed within the popular discourse on community integration.

An overlooked and third spatial dimension of ethnocultural minorities is that they form part of communities that live globally on multiple sites. This connection to a diaspora foregrounds spatial overlapping transcending national boundaries in intricate ways. Constituted space of this nature may be conceived in the form of an imagined life that contributes to moral and ethical discourses that touch on fundamental issues of *what makes us human*. The service delivery system can benefit from the ethically informed constriction of space. The grounding of the former within the political economy is not conducive towards promoting humane perspectives, as these come to light through the spatial construction of reality. Re-mapping spatial landscapes to include insights from the diaspora (other ways of being) brings us closer to being-in-the-world – experiencing it with mind, affect, emotion and the body. This point takes us to the third method of embodiment.

EMBODIMENT

An excerpt from the life narrative of a Canadian immigrant family from Uganda captures some of the questions addressed under the rubric of embodiment.

> Every day before going to work (Mwanza), I (Khatoun) carried my disabled daughter (Razia) from my house to my mother-in-law's house for six years. Here (Canada), every Saturday, we pick up Razia

> from her group home and take her to McDonalds for lunch before she visits us for the weekend.

These two sentences from Khatoun's life narratives bring into relief spatial location/dislocation of a *dis*-abled body. What are the conditions that lead to Razia being cared for at home in one country and being able to utilize social services in another country? How is the border crossed from home care to social service care and what are its implications for people whose very existence has been questioned by society? What kind of meaning does disability have in different cultural settings? These questions inform retelling a life lived at certain historical moments that involve cross cultural encounters, encapsulated in the image of the body. The latter is of interest for two reasons. First, contemporary scholarship in human sciences regards the body as a site of contestation, control and management, as revealed in the image of a medicalized and consumerist body (Falk 1994; Featherstone 1982; Featherstone et al. 1991; Foucault 1979; 1980; Lock 1993). Second, consideration of representations of the body in Western society is necessitated by the fact that the Western hegemonic discourse of the body is transposed to ethnic and *disabled* bodies. The conception of the body implicit in these representations postulates the body as passive recipient of subordinating forces. These impulses render a partial understanding of the engagement of the body in complex spaces; while it may be defined by the needs of hegemonic systems, the body establishes points of intervention to reveal human agency at work. An appropriate and promising line of inquiry is that of embodiment, that is, the being-in-the-world of struggle, negotiation, and reconfiguration of life where affect is an important component. The body's engagement with the world in terms of *embodied sociality* and the role of affect through which "individual bodies together with others articulate a common purpose, design or order" (Lyon/Barbalet 1994: 48) needs more emphasis. For persons with disability, the linkage between affect and the social cannot be assumed as the possibility of disjunction is very real. In a situation where the condition of disability includes gender and ethnicity, the disjunctures and reconstruction of lives may include the crossing of multiple borders. The method of embodiment lends itself to apprehending this multi-faceted phenomenon.

The body and its praxis of embodiment as a way of being-in-the-world is given little conceptual space. The epistemological foundation of the medicalized consumerist body can only be challenged with the view that

> we do not have bodies, we are our bodies and we are ourselves while being in the world ... we write – think and feel – (with) our entire bodies rather than only (with) our minds or hearts. It is a perversion to consider thought the product of one specialized organ, the brain, and feeling that of the heart. (Minh-ha 1989)

Appreciation of embodied praxis requires that we pay more attention to interactive, relational and social aspects of the body together with affect. In the depiction of the body as social and as engaged in the making of meaning, it is hard to conceive of the body as being only passive. The tension between having bodies (the underlying base of the consumerist and medicalized gaze) and being bodies (interactive aspect of self) may be addressed through affect. The latter can then be conceived of in relational terms. It follows then that

> social relations implicated in emotional experiences involve the body: not simply the body as a physical entity subject to external forces, but the body as agent. (Lyon/Barbalet 1994; also refer to Csordas 1994; Frank, A. 1991; Frank, G. 1984; Lutz/Abu-Lughod 1990; Lutz/White 1986)

Affect has its foundation in sociality; its location within the body forms the basis of embodiment.

The question of what it means to be human – an unrealized anthropological quest – continues to remain submerged, as we have not focused on methods that allow a sustained inquiry on this important subject. The methods suggested in this paper lean more heavily towards social agency. I remain convinced that it is through this channel that we can (re)gain the ability to go beyond a situation and connect with life worlds, which through their very difference, encapsulate central questions of existence. Hermeneutically open *texts* generated from non-conventional modes of research constitute one way of connecting. After all, it is only through the discovery of common ground that we can engage in embodied praxis where socially constructed distinctions and boundaries become less significant. If this appears to be a utopian image, the alternative discourse of Otherness is paralyzing.

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