Chapter 5

Disability Studies as Resistance

The Politics of Estrangement

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The spirit of disability studies (DS) is often misunderstood in the excitement associated with the birth of a new field and in the context of an uncertain dissociation from the zeal of activism. I will make a strong point here with respect to the latter. Although, in earlier work, I have advocated the necessity of the two-way traffic between activism and DS theory building (Bhattacharya 2011), I now believe that disability-related activities in India, with their overemphasis on services, are alarmingly close to creating a hegemonic discourse that shrinks the space for the emergence of a DS discourse even further. In fact, what feeds each other within the Indian context is not DS and activism but activism and service, the former accentuating the latter. This association is threatening to develop into a nexus that will steadfastly keep DS out forever. Therefore, it is time now to move away for a while from the excitement of sloganeering and to build a tradition of true scholarship in DS that in fact feeds activism back in various new ways. The formality of this estrangement is best attempted, I suggest, by looking at existing practices through the lens of ableism and by engaging in exposing, strategizing and acting against disability injustice through a disability-centric understanding of various themes within the academia.

INTRODUCTION: WHY 'ESTRANGEMENT'?

This chapter proposes a controversial position that DS scholars working within India must take in order to first bring about recognition for the field and then 'save' it from being neglected and finally pushed towards ossification in the form of library archives. The idea proposed emanates from stray experiences with disability activism associated with both policymaking and scholarship since the beginning of the last decade, that is, 2001.

Before elaborating the stance in detail, let us look at its simplified version in a graphical form (Figure 5.1) that summarizes the underlying thesis of this chapter.

That is, it is services that disability activism is naturally geared towards, as shown in the first box. However, it is the blocking off of any connection between the first and the second box that must sound as a warning bell for DS scholars. In fact, the underlying thesis of the chapter, hinted as above, is a stronger one, which states that the very fact that disability activism is 'solely' geared towards services threatens to strategically keep DS out of the scene altogether. Although it is quite clear from considering social contexts and history elsewhere that it need not be so, that is, it is quite possible for activism to be geared towards 'both' services and DS. In fact, the general tenet assumed by DS scholars in the West is that there is no essential disconnect between activism and DS.

However, I will claim that the situation as in Figure 5.1 obtains as an expected consequence of strategic prioritization of the so-called practical things as opposed to the so-called theoretical things in the context of a struggling economy, where anything that smacks of 'studies' is perceived with suspicion, and the logic of a consumerist culture feeds

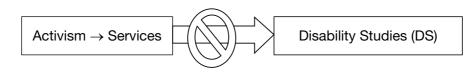


Figure 5.1 The status quo Source: Author.

this. Thus, this is in no way a unique situation limited to DS alone but is true of other branches of knowledge. However, what is ironic with regard to DS meeting the same fate is that this specific branch of knowledge, similarly to gender studies, is by definition moves hand-in-hand with activism. Ideally, activism is supposed to derive further fuel from DS and vice versa.¹ I will rather claim that in the context of extreme and/or uncertain economic situations, the definitional 'purity' of a particular form of knowledge is sacrificed at the altar of activism that is geared towards services (or sectorial benefits), although the latter is the manifestation of the former.

And that is where the danger lurks. In this chapter, therefore, I suggest a way out by keeping activism at abeyance—by constructing a politics of estrangement or abeyance. I will specifically suggest to incorporate the process of construction of knowledge as knowledge itself is a formal device representing the politics of abeyance. I will consider the unalienated examination of the self as an act of 'small liberation' within oneself from the perspective of disability research; this, I would suggest, is the closest one can come to the concept of 'activism' in the framework of DS I am suggesting. Further, I will elaborate this interpretation of 'activism' in the last section of the Chapter, titled 'Formalising Estrangement'. I present the following genesis as an exemplar of this strategy.

GENESIS OF THE IDEA: WHY 'RESISTANCE'

In my work first as the member of the Equal Opportunity Cell, University of Delhi, and then its coordinator, I have had to wage a series of struggles from the very beginning to evolve policies and run activities that are not solely service-oriented. The University Grants Commission's (UGC) mandate in this respect is about services to students, staff and teachers with disabilities. These struggles were waged against not only authorities and administrators but also sympathizers. Many of the scholars were invited to teach in the 'Disability and Human Rights' course there, but to even suggest it, to draw up the syllabus, the

¹ Although see Bhattacharya (2015) for problematizing the traffic from activism to DS.

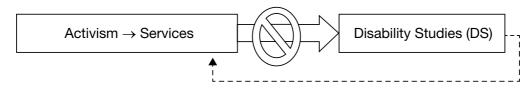


Figure 5.2 DS back-feeding activism

Source: Author.

ways it was to be run and many more issues had to be fought over. This situation prevailed not only in an academic event such as courses but also in other events, workshops and facilities, including the day-to-day running of the centre. The inclusion of a DS component in the various courses and organization of a conference with a broad DS perspective (in 2011) were pieces of resistance against this prevailing reality. With such a strategy as the basis, I suggest a new picture (Figure 5.2), though much like Figure, with an additional back-traffic from DS to activism (shown here in dotted lines):

Figure 5.2 claims that even if there is no traffic from activism/ services to DS, the latter through 'small acts of resistance'—to be elaborated further in the last section of the chapter—can inform and invigorate activism/services. I will now discuss briefly the need for this resistance.

THE VAGARIES OF THE PRESENT CONDITION

Due to a variety of reasons, we have seen the resurrection of the dominant discourse, a value system, around us based on various shades of empiricism—that all knowledge is derived from/reducible to aspects of experience, that is, reality cannot be knowable from reason or rationality alone. Policies, funding, sympathies and 'knowledge' are all geared towards what is 'visible' or visibly effective. Devaluing of DS because it is perceived as unnecessary is a sacrifice that awaits the fate of many other knowledge spheres. 'The Death of a Rationalist' need not be a recent newspaper headline but a process (and an operation) that was triggered much earlier. Further support for this status quo, namely, that empiricism is de rigueur of our existence, can be gleaned from the results of the PhilSurvey as given in Table 5.1.

Other	1,158/3,226 (35.9%)
Accept or lean towards: empiricism	1,254/3,226 (38.9%)
Accept or lean towards: rationalism	814/3,226 (25.2%)

 Table 5.1 Knowledge: Empiricism or rationalism?

Source: http://philpapers.org/surveys/results.pl (31 March 2017).

In fact, if we go by the various groups of respondents, the highest leaning towards empiricism obtains for (philosophy) undergraduates (42.4%) and the lowest leaning towards rationalism obtains for the group not affiliated to philosophy (22.9%) at all. Although this is a small survey restricted mostly to philosophy students and faculty, it, nonetheless, shows the trend clearly; the trend being, for every person who leans towards rationalism, there are almost two persons who lean towards empiricism. If this is the result of a survey conducted among philosophy-affiliated students and faculty, a similar survey in the context of an economically poorer region of the world will surely widen this gap considerably; and when such a survey is made open to the general public, the gap will be even wider.

There is, of course, one aspect of an empiricist view of knowledge that has a direct bearing on representations in a discipline like DS that cannot be ignored—the role of personal experience of disability. For its own good, a discipline like DS cannot deny the importance of the disability experience in DS discourse. I will come back to this issue in the next (and the last) section, where I outline the strategy/methodology for a renewed DS framework. This framework is based on an ecology of understanding that emphasizes the living body or *leib* or, in other words, it values knowledge that is situated or contextualized.

FAILURE OF PHENOMENOLOGICAL RESEARCH

In fact, the mutually feeding dyad of activism and DS has failed to produce any meaningful dialogue in the Indian context. So, the advice that DS should act as the theoretical arm of the disability rights movement has not taken off, as the two parties do not meaningfully interact with



Figure 5.3 *Receiver of services Source:* Author.

each other. In fact, all that a phenomenological consideration (i.e., the disability experience of individuals) produced was sucked wholly into activism, and it did not result in any research.

Both these points seem to directly clash with the other major theme that must also be considered, namely, the notion of subjectivity. If activism based on a rights movement cannot highlight the phenomenology of disability (i.e., disability experience of the individual or collective), how and where does subjectivity find a place? How can the disabled person be foregrounded? The present scenario can be aptly summarized in Figure 5.3.

Figure 5.3 shows that the disabled body of the individual acts only as the receiver of various services, the latter being a result of activism. But the individual experience of the body does not find an expression in this unidirectional flow since services are never reinforced or informed by individual experiences of the disabled body. In short, the disabled subject is never foregrounded in its recipient-only role.

AGENCIES AND SERVICES

I will very briefly touch upon some instances, in this section, of governmental policies (international and national) and non-governmental organizations (NGOs) to highlight the connection of these agencies with providing services for disabled persons. In other words, this section further highlights the deep connection of disability with services as a prevailing status quo. It should, however, be noted that there are many NGOs that do not place such a premium on services. A related issue is the inevitability of the component of services with anything that is related to disability; this, I believe, is due largely to the charity view of disability that continues to rule large parts of the disability experience in India. In short, the services component cannot be avoided and should not be either. However, my point here is about the over-insistence on services that now threaten to take over and engulf all that is there to do with disability. How can DS remain unaffected in such a scenario?

In the rest of the chapter, I will discuss how the following two aspects emerge as possible pieces of resistance for the *en passé* that ensues once activism is divorced from DS:

- 1. Reorienting the politics of DS: dislodgement of the ableist stance and embracing a critical DS approach.
- 2. Reorienting the politics of activism: challenging ableism in every sphere based on a disability justice approach.

With respect to these, I will offer some examples, but first note that both the approaches assume challenging ableism as the foundational basis of resistance. With respect to the first point, an examination of the fragment of the discursive constructions at respite centres reveals that the normalization model of disability has inherent ableist posturing. With respect to the second point, the position I wish to emphasize has to do with resisting a certain normalization of services as a privative engagement.

Non-governmental Agencies

As per the tenets of the proposal advocated here, the back-traffic from DS to activism/services is the only hope to prevent the complete disconnect between the two. Although the last section identified the disabled body being subjected to a recipient-only state, in a fouryear time gap between the presentation of the present chapter and its written-up version, a surprising change in the NGOs has taken place in relation to their commitments to services. I would like to read this

change as a result of the pockets of research that have been going on in DS in this country.

With a search string such as 'India NGO disability', the first noncommercial and unbroken link obtained in August 2013 was that of the NGO Astha. And the very next one is Give India, both of which clearly showed the connection between NGOs and services, as services is the main theme in their mission statements. The snapshots of the home URL from 2013 are shown in Figures 5.4 and 5.5.

The home page of Astha has the following mission statement as the first point: 'To provide *services* to children/persons with disability and their families'. Similarly, the Give India home page declares that it has seven pages on 'services' for the disabled. Both of these, thus, clearly show the connection between NGOs and service, and providing services is clearly the very raison d'être of these organizations.

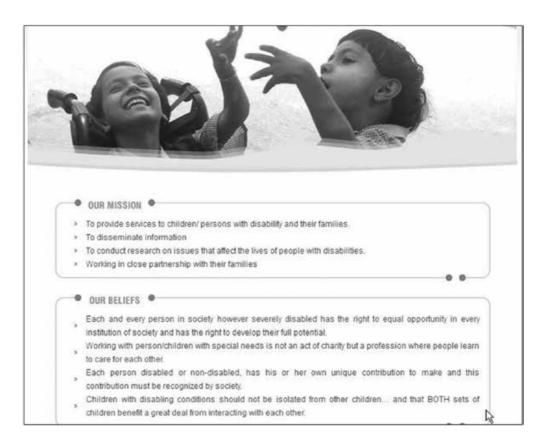


Figure 5.4 The home page of the NGO Astha from 2013



Figure 5.5 The home page of the NGO Give India from 2013

However, when one uses the same search string now after five years (in 2018), the scenario has altered considerably. For Astha, their mission statement no longer mentions the word 'services' and instead states two points:

- 1. To work in partnership with children and persons with disabilities and their families.
- 2. To uphold rights and work with all stakeholders to build an inclusive society.²

Give India, on the other hand, has completely focussed on 'giving' as a concept and wants to 'promote efficient and effective giving that provides greater opportunities to the poor in India' as their mission.³

How did this change happen? The change from a service-oriented NGO to an organization that is focussed on inclusion is the result of the DS discourse the world over, and, I believe, due to pockets of 'resistance' in the form of DS in India that has begun to take effect.

² http://www.asthaindia.in/home.php (accessed August 25, 2013).

³ http://www.giveindia.org/t-abtus_mission.aspx (accessed May 9, 2018).

Governmental Policies

In the first example, I will highlight the role of services in the World Health Organization's *World Report on Disability* published in 2011. The first two recommendations made at the end of the report reveal the insistence on services:

- 1. Recommendation 1: Enable access to all mainstream policies, systems and 'services'.
- 2. Recommendation 2: Invest in specific programmes and 'services' for people with disabilities.

Only the last of the total nine recommendations talks about research:

Recommendation 9: Strengthen and support research on disability

However, within this recommendation, we find the following as one of the suggestive areas of research, 'barriers to mainstream and specific *services*, and what works in overcoming them in different contexts', thus bringing services back even in research.

As for translating the recommendations into actions, the roles of different agencies and their function are outlined as follows:

Government

- 1. Barriers to mainstream and specific 'services', and what works in overcoming them in different contexts.
- 2. Regulate 'service' provision by introducing 'service' standards and by monitoring and enforcing compliance.
- 3. Allocate adequate resources to existing publicly funded 'services' and appropriately fund the implementation of the national disability strategy and plan of action.
- 4. Provide technical assistance to countries to build capacity and strengthen existing policies, systems and 'services'—for example, by sharing good and promising practices.

Disabled Persons' Organizations

- 1. Represent the views of their constituency to international, national and local decision makers and 'service' providers, and advocate for their rights.
- 2. Contribute to the evaluation and monitoring of 'services' and collaborate with researchers to support applied research that can contribute to 'service' development.
- 3. Conduct audits of environments, transport and other systems and 'services' to promote barrier removal.

'Service' Providers

- 1. Ensure that staff are adequately trained about disability, implementing training as required and including 'service' users in developing and delivering training.
- 2. Develop individual 'service' plans in consultation with disabled people and their families where necessary.
- 3. Introduce case management, referral systems and electronic recordkeeping to coordinate and integrate 'service' provision.

Private Sector

- 1. Develop a range of quality support 'services' for persons with disabilities and their families at different stages of the life cycle.
- 2. Ensure that ICT products, systems and 'services' are accessible to persons with disabilities.

Quite surprisingly, out of the 12 action points, the words 'service' and 'services' appear 14 times, and there is not a single action point that is not devoted to services. Thus, even at the international level, governmental-level policies establish an undeniable link between services and disability.

Let us now briefly look at the Persons with Disabilities Act (PwD Act) and the RPwD Bill and Act in this light to gauge the situation at the national level.

In the chapter on Education in the PWD Act, 1995, Article 28 deals with research for designing and developing new assistive devices, teaching aids and so on, which has been partly revised in the RPD Bill of September 2014 by getting rid of assistive devices (in the section on research and development) and instead it mentions 'issues which would enhance habilitation and rehabilitation of persons with disabilities' (Article 27). The 2012 version of the Bill, though, had an article (28) on assistive devices. In the 1995 Act, within the same chapter, Article 30 deals with providing transport facilities, supply of books and so on. These provisions have been retained since the 2012 version of the Bill and in new RPD Act of 2016 as well (Article 179(g)).

In the chapter on Affirmative Action, Article 42 of the older Act deals with aids and appliances to persons with disabilities. The new Bill of 2012, through the suggested Articles 50, 52 and 53, talks about accessibility of services, access to goods and services and provision of service animals for PwDs, and the later versions and the Act of 2016 do not have these provisions. In the 2012 version of the Bill, the emphasis in general had been about accessibility of services. In its Article 57 (human resource development), it clearly talks about the development of human resources in appropriate numbers to make services to disabled persons available (see Articles 57(1)a and 57(1)c). It should be noted that there is no article in the UNCRPD, the motherboard for the RPwD, equivalent to Article 57; therefore, it is only expected that the later versions as well as the final Act do not have these provisions.

Thus within the context of the governmental policies, although we see encoded within the policies a deep connection between services and disability at the international level, at the national level, there have been various correctives to not encode them in a similar fashion within the polices and the acts. Similar to the examples in the case of NGOs, we thus find a change in the framing of policies in the governmental documents that can also be attributed to pockets of resistance emanating from a reimagined version DS outlined here.

DISABILITY STUDIES

In this section, in order to understand how best to reimagine a DS project sans services and also to return to the promise of Figure 5.2,

I will outline, very briefly and partially, some of the major ideas on DS that, nonetheless, provide a window to a possible characterization of DS programmes anywhere. The review below will also show that, structurally, services do no figure anywhere in a DS programme and therefore cannot be the central concern of DS.

Linton (1998) is one of the foremost in advocating the discipline of DS and laid out the characters of such a discipline. She advocates DS as an interdisciplinary field of inquiry, which is nevertheless grounded in the liberal arts, structured and designed to study disability as a social, political and cultural phenomenon. However, she advocates DS theorists to deal more directly with 'impairment' and recognize its significance in the complex characterization of 'disability'.

Furthermore, she also advises revised applied approaches, especially teaching in the applied fields, need to be based on ideas of inclusion, self-determination and self-definition, though they should be called 'Not Disability Studies'. DS should also have a say in the curriculum of rehabilitation education.

The research by Cushing and Smith (2009) was an interesting survey of the growth of DS, where they identified three key dimensions of growth: independent, hybridized and integrated. They reported that the Society for Disability Studies developed and adopted a set of 'Guidelines for DS programmes', and the common threads between those and other approaches are listed as follows:

- 1. Challenges the dominance of medical, individual, deficit-based models of disability (while not dismissing their contributions).
- 2. Considers disability part of the continuum of human experience (Linton disagrees with this).
- 3. Examines the environmental and social barriers to greater participation.
- 4. Interdisciplinary approach.
- 5. Inclusive: participation of disabled people and their families is essential.
- 6. Accessibility in DS courses, conferences, journals, websites and buildings.
- 7. Geographical specificity and diversity: accounts for cultural and historical contexts.

These guidelines are based clearly on the achievements of the rightsbased movements launched by disabled people the world over, especially an equality-based model like the social model (Oliver 1983, 1990; Oliver and Barnes 2012; UPIAS 1976). Note also that except the issue of accessibility in the sixth point, to some extent, nothing remotely smacks of service; with regard to accessibility, we will elaborate further its current conceptualization within the notion of disability justice, in the section 'Formalizing Estrangement', and claim, in fact, that this reconceptualization leads to resistance and activism, respecting the back-traffic from DS, as in Figure 5.2.

During their research, Cushing and Smith (2009) also faced the following issues from observers, which provide us with further characterization of a field like DS:

- 1. Does being located within the medical sciences automatically discredit you from being DS?
- 2. Should a module be called DS even if only a course or two deals with DS theory directly?
- 3. Do applied courses that deal with progressive themes like social inclusion, autonomy and human rights (but not critical theory) count as DS?
- 4. Can a degree that primarily trains people to work in the interventionist services be DS?
- 5. What difference can be achieved in applied professionals' outlook via a DS course or two?
- 6. Is a little DS better than no DS or more harmful because of the dilution?

These are subtle and advanced findings that any worthwhile DS programme must grapple with at some stage. Their findings with regard to growth of DS in hybrid and integrated settings are of importance from the point of view of deciding the 'location' issue of a DS programme, namely, the question of where does DS belong.

In an important work, Campbell (2009) shifts the spotlight on disability to a more nuanced exploration of epistemologies and ontologies of ableism. Instead of the prevailing practice of examining disability from the perspective of disableism, she suggests that we concentrate on what the study of disability tells us about the production, operation and maintenance of ableism.

Wolbring (2012) is another step in the right direction. He suggests an extended form of ableism which can become a seed for new discourses, perspectives and paradigms that focus on ability favouritism as a basis for analysing existing and future cultural dynamics. He contends that DS scholars face numerous impact challenges such as (a) who to serve (academia, disabled people or both); (b) which field of academics to impact; (c) which problems to tackle; (d) which space to influence and (e) the ghettoization of the DS field and its impact.

With respect to the last issue, he raises the question: How can they convince others, not directly related to their area, of the utility their work has for 'others'? DS-based research, especially the work around the concept of ableism, has strong utility outside DS.

SUMMARY

In summary, let me just point out that apart from the obvious overlaps, the two salient points that emerge from studying carefully the above literature on DS are the following:

- 1. The politics of DS: dislodgement of the ableist agenda/stance
- 2. Epistemological question: positioning of DS.

For any DS programme to sustain itself, these pillars must be first established. In conceptualizing DS within such a strategy, we can see that there is no scope of overemphasizing a services component. As for activism, as long as it keeps to the politics of DS as in point 1 intact as its goal, then it is least likely to become merely a fodder to producing services.

EPISTEMOLOGICAL RE-VISIONING

With respect to the two tenets discussed in the previous section, I will offer some examples in this section to consolidate the point that not only is there no place for services in a DS programme, but any DS approach must also adhere to the two principles. For the 'politics of DS', a look at the concept of respite centres reveals that the normalization model

of disability (Wolfensberger 1998) has inherent ableist posturings. In one study, Rhoades and Browning (1982) point out that certain respite group homes consider inappropriate appearance, poor eating habits and bad manners, poor cooking and shopping skills, inadequate skills for managing money, inadequate skills to use public transportation, inability to make and keep appointments, poor work habits and inappropriate sex behaviour as highly undesirable. Principles of normalization are applied to suppress these behaviours so that the 'retardation' will be invisible to others or go unnoticed; the 'retarded' person goes from the point of visibility to invisibility, thereby learning to blend.

However, interestingly in this study, the programme coordinator's voice (Rhoades and Browning 1982) is without ellipses or hesitation, pause or even fast speech phenomenon like 'wanna' for 'want + to' or 'gettin' for 'getting' and so on to make it look more standardized and therefore in opposition to the residents (with 'mental retardation' or MR) voices elsewhere; similar are the voices of the home staff and staff members. Here is a random sample:

Resident:

See my mom lives by herself now since my dad died and she's gettin' pretty old. I wanna get married when the time is right I wanna learn how to shop and cook and keep my budget and things like that.

Programme Coordinator:

It is here that the cooking skills, housekeeping skills and budgeting skills are truly probed. Up to now, the resident did not have to purchase food and had to cook only one evening meal a week. Once in the independent kitchen, the resident is monitored on a diminishing basis until it is shown that he or she can indeed function independently in this area. When a resident is able to purchase food, prepare meals, maintain the kitchen, pay rent and live within a budget, he or she is ready.

Although the coordinator's statement is admittedly a report or summary, the 'voice' that is constructed in this manner is, nevertheless, contrasted with the 'speech' of the resident. A careful DS perspective would be more sensitive to this portrayal and would instead try to look at the work in respite centres from the point of view of the person with MR rather than the other way round. I may also point out that 'picking' on the discourses of this nature is quite in line with a postconventional theoretical approach like that of the Critical Disability Studies (CDS; Meekosha and Shuttleworth 2009), which, apart from looking for social justice—based as it is on a modernist paradigm like the social model—extends the disability paradigm beyond the social, political and economical planes to several other planes, including the discursive.

With respect to 'Positioning of DS', I will briefly discuss two examples from sign language from my previous work.

The multimodal property of sign languages opens up dimensions otherwise invisible in spoken languages. Centring sign language in language studies can thus enable us to look at language—the pure representation of the human mind—in a new light (Bhattacharya and Hidam 2011). In terms of practice, this implies that if adequate services are provided in the classroom with deaf students in terms of teaching through sign language, acquisition of this medium of communication will open up an enriching experience for the hearing student such that it may radically alter their understanding of the world around them. In this perspective, an inclusive education will transform the lives of the so-called non-disabled majority students in immeasurable ways.

Bauman's (2008) example of iconicity discussed in Bhattacharya (2014) is a fine example that clearly shows that the metaphoric performance is bigger than just a generation of proposition as derived from quantifying terms and variables:

[H]ow one of my students at Gallaudet University explained the process of reading Foucault. He first signed that it was difficult to read, with his left hand representing the book, open and facing him, and his right hand was in a V shape, the two finger tips representing his practice of reading, re-reading, and then finally, his fingers got closer to the book, and finally, made contact; at this point, the eyes of the V shape then became a digging apparatus, digging deeper into the text. He then reached in between the lines of the page, now signified by the open fingers of the left hand, and began to pull ideas and new meanings from underneath the text. The notion of reading between the lines gained flesh, as the hands literally grasped for buried meanings. The result of reading Foucault, he said, changed his thinking forever, inspiring him to

invent a name-sign for Foucault. The sign he invented began with the signed letter 'F' at the side of the forehead, and then twisting outward, showing the brain undergoing a radical reorientation.

POSSIBILITY OF DS IN INDIA

If we are to look for a possible framework to introduce a DS programme that does not get overshadowed by the practice of activism that is geared only towards services, the governmental machinery does not provide a good guide. Inequity in higher education has been a concern, and UGC and the Planning Commission have had specific recommendations to improve the situation. Among the various recommendations that were made, a few of them were directed towards improving the quality in higher education. There are at least three other existing UGC schemes that offer this opportunity: (a) Centre for Study of Social Exclusion and Inclusion Policy, (b) Centre for Human Rights and (c) Centre for Potential for Excellence in a Particular Area.

By looking at the first one, an analysis of the current situation (Bhattacharya 2015, forthcoming) with respect to a representative sample of the 35 currently existing centres, set up under the 11th Plan, reveals the state of affairs. If it is a representative sample, although 30% of them have a disability-related objective, none of them have any research output, activity (seminar, conferences, workshops and special lectures) or degrees in disability. Only one of them has a research associate specializing in a disability-related field. We can only conclude from this fact that although disability falls within the ambit of social exclusion in almost exactly the same lines as other forms of exclusion, disability as a sector/oppressed group is simply forgotten/bypassed in this context of higher education.

INVERSION OF THE PRESENT CONDITION

I present here one example, although there are many, that inverts the situation encountered earlier (see Figure 5.3) in the context of searching for a disability perspective for disaster mitigation and resilience (Bhattacharya 2013). I wish to present a case for turning our gaze

towards a strong form of sustainability, which involves a social critical view of the dominant value system, and trace it to Hunt (1966). The effect of any human tragedy is pronounced manifold due to impairment and special needs. The severity of the effect demands measures in terms of preparedness at a heightened level, involving quick egress, accessibility in sheltering and appropriate rehabilitation. Such lessons, I suggest, when incorporated in disability services become more effective and meaningful. In fact, a DS perspective, suitably fortified by this aspect of disaster mitigation and resilience, can act as an essential tool in planning for disasters. Policies may benefit from a reassessment by considering disability as a construct and eliminate the ableist bias in existing policies and agendas.

This epistemological inversion is afforded by reimagining a different centre than prevailing practices and turning disaster mitigation of disabled persons to mitigation by them; the inversion that I wish to emphasize is shown in Figure 5.6.

This way of questioning a culture, biased as it is to engender inaccessibility in the first place, is based on a politics of dislodgement of the ableist agenda, and yet, at the same time, it finds echoes in the notion

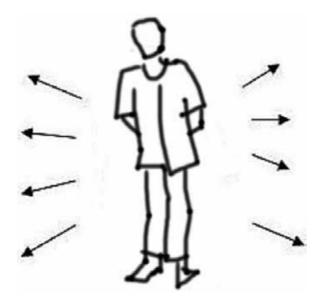


Figure 5.6 *Provider of services Source:* Author.

of disability justice that increasingly incorporates differences and challenges normativity in every sphere.

This inversion lies at the centre of the estrangement politics that I am trying to outline. In this inversion, the notion of accessibility is viewed differently from an equality-based approach like the social model. It is instead based on the premise of questioning normativity—one of the pillars in any DS programme mentioned in the summary of the section on DS.

FORMALIZING ESTRANGEMENT: AN ECOLOGY OF UNDERSTANDING

At the heart of this inversion proposed above lies the underlying determining factor of the true nature of human ecology, where a person is not understood in abstraction detached from their environments and inter-connections but is rather understood in totality. This is a familiar theme—knowledge being contextually specific. However, I would like to read it from an even older tradition of Husserl's (1913/1982) concept of *Lebenswelt* or Life-World: We experience objects as not something that occupies space—time and is made of some material but as objects we deal with in kitchen, streets, gardens and so on or in practical or social activities such as dinning or playing together. Each of us experiences his/her own body not as a physical system of bones, organs and so on, but as 'my body'. He uses two expressions to distinguish these aspects of one's body: my physical body (*körper*) and my living body (*leib*), and it is through empathy (*Einfühlung*) that we experience 'other I's'.

I return now to the methodological question of how to practice the politics of estrangement/abeyance and to the strategy of how to incorporate experience (and therefore subjectivity) within our studies on the face of a new DS vision that is removed from concerns for services. In fact, the answer lies in our understanding of ecology envisioned above. More specifically, I suggest that we adopt within this renewed vision of DS a 'fractured foundationalism' perspective of Stanley and Wise (1990), which, among other things, advocates strategies for a feminist sociology which treats 'knowledge' as situated, indexical and elliptical, as small slices of reality confronting each and engages in unalienated research where the act of knowing determines what is known (Morris 1993). If we are to resist oppression, then we need the *means* to do so. The means to resist oppression, we believe, are to be found where all of our oppressions are themselves to be found. Without knowing *how* oppression occurs we cannot possibly know *why* it occurs; and without knowing how and why it occurs we cannot find out how to avoid its occurrence, how it is that liberation might be achieved. (Stanley and Wise 1990, 165; emphasis in original)

In order to know how oppression occurs, we need to find out the minute details of mechanisms, experiences, behaviours and conversations of such occurrences; in other words, we need an ecology of understanding.

One of the abiding characteristics of the critical conceptualization of disability that gives rise to the very recent current of 'disability justice' is its desire to understand through its various ways of challenging the equality-based notions of access, the ways of organizing and building community spaces based on mixed-ability and cultivating solidarity between people with different disabilities (Mingus 2010).

This is the so-called second wave of the disability rights movement and is being waged most prominently in the underbelly of Canadian disability quarters in Toronto and other cities. Here, values are based on interdependence and a new politicized notion of care. Interdependence is an antidote to the capitalist social construct of independence. As Eddie Ndopu says:

[A]ny attempt to politicize care in relation to organizing calls for something different. It calls for new ways of negotiating liberation. It calls for a new praxis and a new kind of activism. (Hande and Mire 2013, 11)

I would like to claim that this new way of organizing resistance can be seen through a disability justice lens emanated from a reconceptualization of DS as we understand it from a purely sociopolitical and predominantly Marxian perspective. Rather this reimagining is achieved through a quest of knowledge that is not rooted in knowledge alone but first and foremost in disability injustice. If this is not done, then the injustice will remain invisible and therefore unrecognized. So, the primary 'act' of DS must be to expose injustice and then to outline a strategy. Only then can activism begin.

This has to be the sequence in every act of DS; no act of DS can assume that injustice is already exposed—one has to engage in it anew every time, and not just in terms of statistics, but in acts of obvious neglect and ableism. Thus, the steps in DS that is proposed here are as follows: step 1: expose; step 2: strategize; step 3: act.

In step 2, we have all the concerns of organizing spaces and critical membership. This step of strategizing must also lay down all the previous knowledge gained in this domain, that is, it must rely on a network of knowledge and not pretend it to be an isolated case of injustice calling for right-based action strategies.

Note that if one engages in all that that have been laid down as part of step 2, one would realize that this is nothing but DS. In addition, 'emancipatory' research will be an automatic consequence of this framework that constantly conceptualizes and reconceptualizes strategies based on feedback cycles from field actions.

CONCLUSION

Having elaborated in detail the prevailing situation that this chapter began with, namely, the blocking of traffic form activism to DS, by looking at existing national and international policies and governmental frameworks for possible DS programmes, I have argued for a renewed notion of 'activism' by reconceptualizing DS through the lens of disability justice; this form of 'activism' is aided by an epistemological inversion of the perception of what service for a disabled person means. This back-traffic from DS to activism is at the centre of a politics of estrangement proposed in this chapter.

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