

**ORGANIZATIONS 'OF' THE DISABLED:
CHARITY VS. SELF-HELP**

A case for participatory inclusion through decision-making for
empowerment of the disabled



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CCS working Paper # 295

July 2013

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Acknowledgements

This paper would not have been possible without the encouragement of the Center for Civil Society team. I would expressly like to thank Mr Prashant Narang, Internship Director of the Researching Reality Internship 2013 and Ms Urvashi Kapuria , Internship Co ordinator 2013 for their help and guidance. I am grateful to my guide Arvind Ilamaram, whose critique and expert suggestions were extremely helpful in structuring this paper. As well as my co-interns who constantly buoyed my spirits.

I owe a debt of gratitude to Dr. Sam Taraporevala , Head of Department of Sociology at St.Xavier's College, Mumbai without whose help this paper could not have been informed by the rich interviews I was able to procure due to his efforts.

I would also like to express my gratitude to Mr.Javed Abidi convener, Disability Rights Group and Executive Director of National Center for Promotion of Employment of Persons with Disability (N.C.P.E.D.P) for his interest and providing invaluable information in the form of papers and reports along with interviews that have guided this effort. I would also like to thank all my informants such as Mr.J L Kaul, Secretary General of All India Confederation of the Blind ,Ms.Seema Tuli Principal Amar Jyoti , Mr.Dipendra Manocha, Founder of Saksham and Ms.Vandana Chaudhary a scholar of disability with disability who took the time out to speak with me from New York. I would also like to acknowledge Ms.Meenu Bhambhani separately for trusting me and sharing her Thesis with me.

Lastly, but not the least I want to thank my relatives for housing me and bearing with me and my erratic hours for two months.

The response I received from people within the field, be it Heads of Organisations or beneficiaries I was put in contact with through AADI(Action for Ability Development and Inclusion) , was heart warming. It reaffirmed to me the need for more robust research in this field to inform government action especially.

Executive Summary

Realising the dearth of literature on decision making by the disabled in the Indian discourse on disability, this paper seeks to introduce the discussion on Disabled People's Organisations(DPO) and their link to decision making.

Largely it is understood that NGOs serve to deliver services to the disabled and are called 'Organisations for the disabled'. But increasingly international discourse has moved to 'Organisations of the disabled', especially as the social model of disability has critiqued the 'hapless individuals' construct of the disabled perpetuated by the medical model of disability. Organisations 'of' the disabled are NGOs that are lead by or constituted by the disabled themselves. A DPO is by definition an NGO wherein more than 51% members are disabled. And thus, are included in the decision making activities of the organisation such that the organisation is no longer working 'for' the disabled but it directed by self-action in a way. The paper seeks to trace the movement of self organisation in NGOs in India and its implication on empowerment.

The paper explains self organisation in the move away from charity based approaches through self-advocacy approach of the Disability Rights movement in India. It then uses information from interviews to show approaches of the organisations lead by the disabled differing from the usual and how it is more empowering. This link of participation, decision making and empowerment is further emphasised through examples and secondary literature. e.g: more emphasis on dignity through better practises versus the 'legalised begging'¹ approach of charities. The contentious nature of funding is also addressed.

Lastly, but most importantly, the paper contextualises this debate on participation by persons with disabilities in decision making,in the current scenario of the new Anti discrimination Bill being drafted. The paper finds that despite the signing of the UN convention by India in 2007, its ratification is still under deliberation. To that effect the government has time and again ignored the

¹A sentiment presented to the interviewer in interviews both with heads of organisations as well as

“Nothing About Us Without Us” objective of the Disability Movement in India which since the lobbying for The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act in 1995 has directed the essence of the movement. e.g.the committee set up to meet the tenets of the Act has only 5 positions for the disabled out of 38 total seats mandated. The first chairperson appointed was not a person with disability. Even the current committee that sits for the deliberation on the draft of the new Bill (which is to be in line with the 2007 UN convention) has continued its deliberations even when 3 members with disability resigned, showing their disregard for the true nature of the convention. As Mr.Abidi notes, “It seems highly unlikely that the ‘nothing about us without us’ philosophy will ever be considered by the government.” While the government continues to evade, increasingly counter-productive policies continue to emerge. e.g: to attain free facilities from an NGO the beneficiary must provide a BPL certificate, procurement of which is costing the most in need as high up as Rs.3,000. (Information Source: Amar Jyoti Charitable Trust).

The paper brings forth the need for the support of DPOs in the current scenario in India. And emphasises the requirement for the discourse and empirical research in India to also consciously look at decision making as an effective tool for empowerment for Persons with Disability

TERMS AND ABBREVIATIONS

DPO: Disabled Persons Organisations

PWD: Persons with Disability

N.C.P.E.D.P: National Center for Promotion of Employment of Disabled Persons

A.I.C.B : All India Confederation of the Blind

ESCAP : Economic and Social Commission for Asia and the Pacific

Introduction

The struggle for citizenship is viewed as an affirmation of the value of choice, independence and control which disabled people conceive in terms of human rights (Barton, 2007).

With the latest Draft of Rights of Persons with Disability Bill, 2012, under discussion the issue of Disability Rights is as contentious a topic as it was 15 years ago when after extensive cross-disability lobbying in 1995 the First Act against discrimination of persons with disability i.e Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act was enacted by the Independent Government of India. (From here on referenced as 'The Act' or 'Act of 1995')

Despite differing estimates², empirical evidence as of 2007 by the World Bank suggests that between 4 to 8 percent of the population in India is comprised of persons with disabilities. This translates into 40-90 million people, i.e a sizeable number of our population which cuts across all barriers of religion, caste, and class, fall under this category. The disabled in India are subject to multiple deprivations and limited opportunities in several dimensions of their lives (Menon, 2011). Households with person with disabilities (PWDs) are 25 percent less likely to report having 3 meals per day year around, more likely to have members who are illiterate and children who are not enrolled in school, have much lower employment rates, and have very low awareness of entitlements and services available by law for PWDs (World Bank, 2007). As Menon and other researchers (Thomas, 2005 etc) state these households are likely to be over-represented among the poor and socially marginalized. Thus, there is no doubt of the need for empowerment for this community because as the literature provides, it is many a times social attitudes that perpetuate 'disability'.³

Though realisation of rights is one important step towards empowerment, this paper seeks to identify other agencies that are involved in the process of not just advocacy but also service delivery with respect to welfare of persons with disability. It wishes to highlight the move of the disabled from being 'passive service receivers' to a body that through self-advocacy and self-help demand them and have set up ways of providing for it themselves.

² **United Nations** estimate that 10% of the population has a disability, there are about 120 million people with disabilities in India (Universal Periodic review, National disability Network)

Approximately 90 million disabled people in India (**overseas development Institute, London, 2001**)

NSSO (July to December, 2002) - 1.8%

Census 2001 : 21 million people in India as suffering from one or the other kind of disability. This is equivalent to 2.1% of the population.

³ For more read the 'social model of disability' from any of the disability studies books.

As a state level study of 'economic and demographic well being of the disabled' by Susan Parish notes,

Rather than resources or capacity, political will at the state-level, a vibrant civil society, and the strong presence of non-government organizations(NGOs) with a disability focus, appear to be most important. (2011)

Keeping this emphasis on the role of NGOs in mind this paper argues that decision making promoted by the 'self-help' philosophy of NGOs, especially DPOs, realises the true objective of 'full Participation' as mentioned in The Act. To do so, the paper has looked at:

- a) The move away from charity based services to self-advocacy in terms of the Disability Rights Movement in India, to highlight shifting paradigms in approach to disability, which has informed the role of NGOs as well. e.g.: increase in Advocacy based NGOs from just service.
- b) The organisations that espouse the ideology of 'self-help' and how their approach is different from a more charity based/ philanthropic approach.
- c) The paper identifies the self-help philosophy as more empowering due to its role in promoting decision making and participatory inclusion. Such as executive levels of NGOs.

This paper is unique in that unlike other works on 'inclusion' in mainstream discourse, it does not look upon inclusion as a factor of correcting social exclusion which has resulted in homelessness, illiteracy and poverty among persons with disabilities(Thomas(2005), Yeo and Moore (2003), Hoogeveen(2005), Elwan(1999))⁴. Though all of these are valid concerns as depicted in the study cited above, 'Full Participation' as stated even in The Act has become restricted to 'participation' being realised in terms of 'integration' ⁵into main stream society.

As Boyden and Ennew (1997) state that there are two interpretations of the term 'participation'.

It can simply mean taking part, being present, being involved or consulted. Alternatively, it can denote a transfer of power so that participants' views have influence on decisions and knowing that one's actions and views are going to make a difference and may be acted upon, thus leading to empowerment. (Quality Protects Research Initiative, 2004)

⁴The assumed link between disability, poverty and health has been critiqued by Groce et al (2011) Working paper conducted under the Cross-cutting Disability Research Programme funded by the UK's Department for International Development (DFID)

⁵Meenu Bhambhani, 2005 in her thesis points out the issues in inclusion and integration discourse when it comes to demand for services **'They illustrate the confusion of the movement - does it aim at integration in which the element of choice is restricted, or does it aim at getting political power for "who they want to" (127), integrate with (Crescendo quoted in Charleton, 127)'**(As cited in Bhambhani, 2005)

Unfortunately, not much has been spoken about the second kind of ‘participation’ in Indian academia though the self advocacy movement does imply it.³

James Charlton (1998) calls the international disability rights movement:

A “liberation movement,” the essence of which is the demand for “ ‘Nothing About Us Without Us’ reflected in its principles of ‘independence and integration, empowerment and human rights, self-help and self-determination’.(Pg 16, as cited in Bhambhani, 2005)

The ideology of “Nothing About Us Without Us” has been adopted by the Indian movement as well, though as this paper will highlight in its last section the government may have passed the law for equal opportunity, protection of rights and full participation, but it hasn’t yet realised the essence of the ideology in its execution both in terms of the tenets of The Act, as well as its enactment.

The first subargument of this paper will focus on the movement itself; there it is obvious how the ideology functions in driving the various Rights Groups. It is in the second section, that this paper will seek to make a tangible link of this ideology to functioning of Disabled Persons Organisations (DPOs)⁶ versus the basic NGO model which would be run by a majority of nondisabled people. Key to this link is the aspect of decision making and self determination that is allowed by DPOs.

A study in 1998 by NCPEDP and NAB showed that only 22.07% executive body members were disabled and in the general body 54.23% were disabled. (This data was from 116 and 188 organisation respectively). As the study notes,

If NGOs that propagate empowerment of disabled people, themselves have such few disabled people in their decision making bodies, the situation seems quite dismal! (1998)

The situation hasn’t bettered nor has any academic thought within India been expended on this issue specifically. Though international forums like ‘Disabled People’s International’, ‘United Kingdom Disabled People’s Council’ ‘Independent Living Institute’ have published papers that highlight the impacts of DPOs.

Therefore, to conclude the paper will place the arguments, of participation and decision making made in it, in context of the short comings of the Indian Government while noting some of the attempts made by it to include NGO representatives.

⁶A DPO by definition are those organisations controlled by a majority (51%) at the board and membership levels by the disabled.

Methodology

For the purpose of this paper, due to its qualitative nature, the methodology too has reflected this by being restricted to Interviews and analysis of Disability network online portals. Secondary research in terms of studies on the issues related to disability, empowerment and decision making was also carried out.

Interviews:

When I entered the field looking to understand the phenomena of organisations for the welfare of the disabled being headed by the disabled themselves, I had only my college institute 'Xaviers Research Center for the Visually Challenged' in mind as reference. On contacting my Head of Department of Sociology who happens to be visually challenged and is also the Director of the Institute, I was immediately put in contact with Mr. Javed Abidi (Executive Director of N.C.P.E.D.P and convenor of DRG) and Mr. JL Kaul (General Secretary of AICB) among others.

I approached these interviewees as my Informants and have consciously differentiated between them throughout my paper. An informant is different from an interviewee in that he/she is more knowledgeable of the field than I am and the former also provided me with further contacts to interview. I did not approach them with a structured interview format but key questions that I had formed from the limited exposure that I had had. Through this method, my field of interest evolved while becoming more niche in that I started exploring the DPO model of decision making. This informed my secondary research and I was able to identify key research pieces on inclusion and analyse them while noting what they didn't speak about: Power in decision making.

Another set of interviews, besides one with informants who were mainly heads of NGOs, were with beneficiaries as it was important to get their views on NGO functioning as well.

Analysis of reports

I also reviewed reports by disability network, as well as disability knowledge foundations and other international reports on disability, to get a sense of ongoing issues as well as contextualise my research within it.

Limitations

Due to the short duration of the study, I have not conducted an in depth analysis, and the organisations referenced are not to be taken as representative of the whole. Rather, the organisation referenced are nationally recognised and headed by individuals who are experts in the field by virtue of their lengthy involvement. And so, given the information presented, this paper should usher in the need to look at Disabled People's organisations and develop a framework to allow for their effective participation.

The following section, will highlight how before 'self advocacy', 'charity' approach reigned. This is essential to understand the very backdrop of the movement by the disabled.

Disability Rights Movement: Move from Charity to Self Advocacy

“work builds and charity destroys” (tenBroek cited in Gupta,2001)

To contextualise the argument for self-organisation of disabled people’s organisations as against NGOs that work for the welfare of the differently abled, a study of the disability ‘movement’ in India provides key insights. The very need for a movement implied dissatisfaction with the prevalent scenario and the need for self organisation to advocate for ones rights. Thus, this section will not only provide the reader with clearer background to the present scenario but also strengthen the case for the need to move away from a charity model to one of self organisation, which in this section I identify with self advocacy, a key attribute of the movement all over the world.

There are varying views on the true start of the Disability Rights Movement (DRM) in India. Some postulate the cross-disability movement as the crucial factor (Bhambhani,2005) , while some demand that the self advocacy efforts of the Blind Movement ‘Organisation of the Blind’ which precedes the cross-disability movement should also be credited(Chander,2011) while some have stated that ‘the passing of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 owes much more to international pressure than to lobbying and protests by disability rights groups.’(Mehrotra,2011)

Thus, there is no doubt that there were many key events that lead up to the formation of the 1995 Persons With Disabilities (PWD) Act, but a larger historical preview of the paradigm shifts in the Indian approach to disability is useful in not only re-establishing the social and cultural construct of disability (as has been done in papers like Bhambhani, 2005) but to note that the shifts have gone from externally driven to more self-representing models.

As conducting an in dept study of the historical shift was outside the scope of this paper, it is through the literature of papers by Bhambhani, Chander and Mehrotra that the author has sketched the backdrop to the movement.

Historical Review

1. Precolonial and Colonial period

The Colonial State paid least attention to the issues relating to disability. So, during most part of the period of the colonial rule, the approach toward disability was influenced by the

ethics of Hinduism leading to the karma (actions of past lives) model and Christianity leading to the charity-oriented approach.(Chander,2011).

D. Rama Mani (as cited in Bhambhani,2005) also touches upon the perception of disability as an issue of charity in ancient and medieval India. Both Mani and UshaBhatt(1963) argue that eighteenth century missionaries and other inroads of western civilization caused the old order - that of families providing for their disabled kith and kin - to crumble. If charity and welfare models were in place before the onset of India's colonization by the British, medical/pathological/rehabilitation⁷ models were initiated during the colonial period. Yet, these remained predominantly charity-based.

While echoing similar views about the colonial period, Maya Kalyanpur and AnuradhaMohit (2002) diverge somewhat from Mani's analysis by emphasizing that many institutions set up during this time were patterned to perpetuate custody of, rather than care for, disabled people. They further argue that their "asylum-like character...unleashed in its wake the process of dehumanization of the PWDs" (pg.165 As cited in Bhambhani, 2005)

Thus, there was a break from the earlier kinship based care that was provided for the disabled. It is with this background that Miles (2002) argues strongly for recovering histories of disabilities in south Asia to **enable the improvisation of self-help strategies through references to the past.**'It is within the family that south Asians with disabilities have experienced the most responses whether in childhood, in adulthood or as elderly persons. Yet the category of the family or community as the first level of response to disability has been barely documented in history. PWDs largely appear as beggars in records from antiquity to the present, and **begging was not necessarily a despised activity.**'(Mehrotra,2011)

Miles(2002) further argues that with the colonisation of India by the Britishers, large-scale charity missionary activities started under official patronage. With their colonialist attitudes, they completely ignored indigenous culture and belief systems. The identification of the benefactors and beneficiaries did help in reaching out to the poor and destitute, but there was no substantial impact on the disability situation. Disability was never a real issue for them to bother about (Dalal 2002).(As cited in Mehrotra, 2011).

⁷The medical model of disability sees disability as only the function of the medical handicap. It works on the 'personal tragedy model' where the handicap itself is seen as limiting and akin to a 'tragedy' or burden. **Disability was viewed as a diseased state and the emphasis was on curing, correcting or attempting to ameliorate the problem so that PWD became as "normal" as possible.**(Bhambhani, 2005)

2. Post Independence

I found MeenuBhambhani's demarcation of the post independence period by the decades very useful in showing the progressive shift up to the 1990s. Though it is important to realise that some approaches overlapped or started in a decade prior, they still wouldn't be classified as a shift until it was prevalent for an extended period of time. Another, facet to keep in mind is that as JagdishChander (2011) points out the blind movement in India preceded the cross disability movement and thus some of its approach to self advocacy can be linked to activities since the 1940s⁸and came into full realisation by 1980s⁹, a whole decade before the cross-disability movement did so.

Thus, a more generalised overview from my readings shows the following trends:

i. 1950s-1960s: Focus on Rehabilitation, different from charity.

Bhambhani focuses on Usha Bhatt's (1963) book, *The Physically Handicapped in India: A Growing National Problem*, which she calls a pioneering work on disability post independence. To summarise, Bhatt argued that a number of factors exacerbate disability; these include "poverty, illiteracy, malnutrition, rural economy, unemployment, and fatalism," absence of any state laws, lack of physiotherapists, lack of occupational therapists' services, and societal attitudes of neglect (15-25). Bhatt further claims that lack of adequate health care services combined with social stigma further "excludes the crippled individual from all social intercourse"(27).(Bhambhani,2005). And thus, reflecting this attitude independent India following the policy of welfare, set up the National Council for Handicapped Welfare to frame policy guidelines for the entire country and to prioritise disability programmes. This council, comprising central and state ministers and rehabilitation experts, regulated the activities of the central and state governments and of voluntary sectors.(Mehrotra,2011) The mandates of these organisations followed the narrow diagnostic categories derived from a medical model of disablement and due to state funding were restricted to doing so. (Mehrotra,2011)

⁸Eg: Appointment of LalAdvani as 'officer to be responsible for the execution of services in the field of blindness' under Ministry of education in 1947. (Chander,2011) But asChander notes, LalAdvani who 'happened to be blind, was appointed for the post '. And thus, it still wasn't self-advocacy as a sustained effort.

⁹ The self-advocacy movement of the blind, which I(chander) call the 'movement of the organized blind' in India, formally began in 1970 with the founding of the National Federation of the Blind (NFB), popularly called the 'Federation.' It was initially known as the National Federation of the Blind Graduates (NFBG). with the exception of some sporadic activities carried out by the NFB in the 1970s, it was not before 1980 that the Federation had established a strong base of support and started acting as a powerful lobby.(Chander, pg:10)

More fundamentally, they simply did not reflect the views of disabled people but instead subscribed to the belief that scientific experts such as physicians, social workers and occupational therapists were best suited to define and solve the problems faced by PWD (Malhotra 2001).(As cited in mehrotra,2011)

And therefore, this phase of rehabilitation focused on physical rehabilitation and institutionalisation. This was different from the missionary run nongovernmental efforts pre-independence in that more focus on service provision was coming into being, though this still hadn't evolved to include the voice of the disabled themselves such as can be seen from Malhotra's quote above and in Bhambhani's observation of Mani's arguments:

*The government responded to the needs of disabled persons by making meager budgetary allocations to be given in the form of grants-in-aid to NGOs for delivering services in the area of education, rehabilitation, training, and employment. **These NGOs, however, remained dominated by able-bodied, philanthropic individuals and professionals.** There was hardly any opportunity for disabled people to plan the services and programs meant for them. (Emphasis added)*

ii. 1970s to 1980s:Community Based Rehabilitation and International Advocacy Groups

Bhambhani notes that:

In the 1970s, the focus had started shifting to integrated education and employment, whereas in the 1950s and 1960s the focus had remained on medical and vocational rehabilitation. This shift can be gauged from the changing focus of five-year plans.

The second, notable shift was the move from institutionalisation to more community based rehabilitation approaches¹⁰, which tried to bring back the care of the disabled to the community. The philosophy of CBR sought to integrate disabled people into societal mainstream by bringing the medical model from the institutions to the community (Bhambhani,2005).Practitioners of the CBR approach claimed that an emphasis on productivity and self-reliance would mark a shift from the concepts of charity and compassion.

¹⁰CBR became an extant and much sought-after panacea in India - especially in Southern India - and other developing countries in the 1980s. CBR gained impetus after it received global recognition with the 1982 UN Declaration of the Decade of Disabled Persons and the adoption of World Programme of Action Concerning Disabled Persons (Thomas, 1990). CBR became the buzzword of the 1980s. (Bhambhani,2005)

1980s

There were other key developments in the world that started the ball rolling for the latest paradigm shift towards self-advocacy.

One, being that 1981 was declared as 'International Year of Disabled People', which created the space for self advocacy approaches to even reach India and other countries.

Two, scholars like Mani argue that it was the decade of 1980s that positive policy action started to emerge in support of disabled people. Governmental actions included giving and extending reservations in the educational institutions and employment, identifying jobs to be reserved for orthopedic, hearing, and visually disabled people in group A, B, C, and D¹¹, repealing of the Lunacy Act of 1912, and replacing it with the 1987 National Mental Health Act. Also in 1987, the Justice Baharul Islam Committee was appointed to draft legislation emphasizing rights, equal opportunities, and full participation for disabled people. NGOs working for the disabled began to show more awareness of events of strategic policy and started taking action accordingly. One can say that NGOs and their actions were barometers of rising consciousness.(Bhambhani, 2005)

It provided for an 'ideology-based movement based on interrogation by disabled people of ableist structures.' This is evident in Mani's caution that legislation may not be a one-time panacea for the problems of persons with disabilities in India.(Bhambhani, 2005)

iii. 1990s and The 1995 PWD Act.

Mid 90s brought in critique of the CBR approach calling it a form of're-medicalisation'(Coleridge,1993) as the focus yet wasn't on allowing the disabled to participate in his own care.

The 90s also more importantly ushered in a cross disability, self advocacy based movement in India .

In 1990, the NGO sector was still dominated by able-bodied people who were largely dependent on government funding for their existence. The education of disabled children was still under the purview of the Ministry of Social Justice and Empowerment instead of the Ministry of Education and, disabled people were still relegated to C and D category jobs in the government sector. Also, with economic liberalization opportunities for

¹¹ There are four groups of jobs that are identified by the government to be reserved for people with disabilities. The A and B groups include executive level positions and C and D include clerical and low-paid positions.

disabled people in the job market were shrinking day by day. It was in 1994 that some young like-minded disabled advocates, the prominent among them being Javed Abidi, Anuradha Mohit, Sarabjeet Singh, Ali Baquer (non-disabled advocate), A.K. Chowdhury (non-disabled advocate), and Lal Advani formed the Disabled Rights Group (DRG) to lobby India's policy makers to accept the recommendations of the Justice Baharul Islam Committee and accordingly pass the legislation. The formation of the DRG was inspired by none other than the stalwarts of the US Disability Movement - Judy Heumann and Justin Dart - who informed these young disability activists via a satellite conference that the Americans with Disabilities Act (henceforth referred to as ADA) was the result of a sustained campaign by a self-help advocacy movement of disabled people (Abidi, 1995).

Sustained campaigning and through contentious political action (defined in next section) such as sit-ins, protest marches etc by disability rights groups the Persons with Disabilities Act was finally passed by the Indian Parliament on 31st December, 1995 and became a law on 7th February, 1996 with the President, Dr. Shankar Dayal Sharma, giving his assent.

Conclusion

I wish to conclude the historical review section at the juncture of the passing of the Act but in no way does this imply that the trajectory of self advocacy stopped here. In fact, the true essence of self advocacy came to be realized after the passing of the Act. As Ali Baqar and Anjali Sharma's book *Disability: Challenges vs. Responses* (1997) establishes

The PWD Act can be translated into reality only if disability activist groups maintain a constant vigil and participate in decision-making process on issues concerning disabled people.

What this section has hoped to establish in the mind of the reader is that the movement may have risen in 1980s but the seeds for the need for self-representation came from a) the need to resist medicalisation of disability i.e. it being seen only as a physical limitation on the individual and b) the rise of consciousness of the disabled due to the social model of disability being formulated through the disability studies perspective on development.

The next section will link self-organisation in service provider NGOs to decision making process and empowerment, now that the charity model's fallacies have been highlighted.

Self-Organisation: Self-Determination and Self-Help

“Individually we are the victims of discrimination . . . Collectively we are the masters of our own future” (tenBroek cited in Matson, 1990, p. 14)

From the previous section it should be clear how disability group organisations like National Federation of the Blind, Disability Rights Group (DRG) in India as well as the likes of Disable In Action by Judy Heumann in the U.S and Campaign for Accessible Transport (CAT) in the U.K functioned in bringing together persons of disability to champion their own cause. (Shakespeare,1993)¹²

But having said so, as the last section summarised, it was not until the 1990s that positive political action was realised and this Coleridge(cited in Bhambhani,2005)reiterated in 1993 when he said that “The major reason for this is that institutions - which are gathering point for disabled people -are ‘lulled by inertia and their boards are dominated mainly by people, both able-bodied and disabled, who have made an emotional and charitable response to disability’” (159).

Another facet, of the nature of the movement was the use of ‘contentious political action’(Barnartt and Scotch,2001)in the context of Indian situation included: dharnas (picketing), hunger strikes, rallies, disruption of rail and road traffic etc by the radical self advocacy groups(e.g: National Federation of the Blind in 1980,81 ; Chander,2011) This as Chander notes garnered plenty of interest by the media and pressurised some governmental action. ¹³Thus,

The organized blind in India began to challenge the hegemony of the service agencies for the blind like the National Association for the Blind that were predominantly led by sighted philanthropists who primarily adhered to a charity-based approach(Chander,2011)

Similar developments are noted by Bhambhani, but the methods of the cross-disability movement was focused more on lobbying and then post the Act it depended on litigation and approaching the Chief Commissioner for Persons with Disabilities. A post made especially after the Act.

So, though the last section clearly showed the importance of self organisation for the purpose of advocacy , for the purpose of this paper, I feel the argument should not be restricted till there.

¹²Shakespeare in his paper titled ‘Disabled People’s Organisation: A new social movement?’ notes the disability rights movement as indicative of self organisation. Thus, a similar understanding is assumed for the last section

¹³E.g: NFB struggle for employment in Uttar Pradesh, yielded immediate results as 213 qualified blind were engaged in gainful employment by the end of the spring of 1982 (Giri, 2005; Singh, 2005; S.N Shrivastava, personal interview, June 7, 2005).(Chander,2011)

Thus, with the following definition of self organisation:

Self-organization is a process where people form groups and assign tasks to themselves or the group, by responding to triggers in the environment or system, that spontaneously increases the organization of the environment or system.(Hermann Haken (2008))

It is clear how these groups had to self organise to have their needs met.

Persons with disabilities regularly experience powerlessness in their lives, particularly when taking life decisions about where and with whom to live, or where to work. Being unable to make decisions regarding their lives leaves people with disabilities at the mercy of professionals and family members. However, this vulnerability is not an inevitable consequence of having a disability. Rather, it is a product of society and thus can be changed by society – through advocacy (Jenkins and Northway, 2002)

What isn't seen as an aspect of self organisation is the phenomena of proliferation of the disabled in the service delivery organisations as well as advocacy based one. Yet, these organisations by virtue of their composition call for a belief in 'self-help' philosophy and concepts of 'self determination'. I will highlight those processes in my analysis of the NGO/ DPO model of service delivery.

Definitions:

Self-determination

'Self-determination has emerged as a core element in models of quality of life. This characteristic reflects the way individuals become competent in directing the course of their lives. It is expressed in self-regulation, psychological empowerment, self- realization, and autonomy (Wehmeyer, 1996). In the case of advocacy, a model of active self-determination expresses itself as making one's views heard in the pursuit of autonomy. *The Strategy for Equality* (Commission on the Status of People with Disabilities, 1996: 106) describes advocacy as being *concerned with getting one's needs, wants, opinions and hopes acted upon.*' A similar understanding of self determination would work in context of service delivery organisations in that they are set up by individuals with 'experience of disability'¹⁴ to meet the needs,wants of the disability community by self identification, or insightful needs assessment .

¹⁴ Defined on the next page as: 'individuals with disability or knew of someone with disability which was closely linked to them starting the organisation'

Self-Help

Taken from publications by Economic and Social Commission for Asia and the Pacific (ESCAP)¹⁵ on self-help organisations of people with disabilities:

"Self-help" means mutual support and empathetic human relationships. It is group solidarity which enables disabled people who are experiencing similar hardship to support each other and to overcome common difficulties through the exchange of practical information, insight and knowledge gained through personal experience. That solidarity and mutual support serves as a basis for collective action to improve the existing situation of people with disabilities in society.

A "self-help organization of people with disabilities" is an organization run by self-motivated disabled people to enable disabled peers in their community to become similarly self-motivated, and self-reliant. The organization may engage in efforts to provide community-based support services through mutual support mechanisms and advocacy for disabled persons to achieve their maximum potential, and assume responsibility for their own lives. Thus, a self-help organization of people with disabilities may be characterized by self-determination and control by disabled people, self-advocacy and mutual support mechanisms, aimed at strengthening the participation of people with disabilities in community life.

It is important to note that this is different from a 'self-help group' by virtue of structural difference between a group and an organisation.

With these definitions in mind, I will now seek to analyse the information I gained from my informants in the field within the framework of defining these NGOs as Self-help Organisations.

In the interviews conducted by me, I approached the Heads of NGOs for the welfare 'of' the disabled, my only criteria that they had 'experience with disability'. In this, the working definition of 'experience with disability' was that, these could be individuals with disability or knew of someone with disability which was closely linked to them starting the organisation. I have taken the example of 3 organisations and their approach to the different aspects within service delivery NGOs (Employment/Vocational training, Products/services, Appropriation of Funds) to elucidate the difference from what I identify as a more charity based approach.

¹⁵Available at: Disability Information Resources, online portal
<http://www.dinf.ne.jp/doc/english/intl/z15/z15006mg/z1500602.html>

1. Employment/Vocational Training

Right to employment has been a major issue among the advocacy groups, since even before the enactment of the PWD Act 1995. This has been said to be linked to the fact that disability is largely a socio-economic issue in developing countries (Thomas , 2005)

The placement record of disabled people through Special Employment Exchanges shows only 1, 00, 000 disabled people being placed in 41 years, since Independence.¹⁶ Also, According to the National Sample Survey conducted between July – December 2002 (58th round) 74% of disabled in India are unemployed. These are statistics almost 2 decades apart, showing that this is still a major issue in the field of disability.

Besides, right based advocacy for better implementation of legal quotas, efforts by the NGO /voluntary sectors in providing, firstly, the necessary skills for gainful employment and secondly, the push for actual placement, need to be acknowledged too. And Thus, one can include these NGOs within service delivery NGOs rather than just advocacy based NGOs.

A study published in 1998 conducted by N.C.P.E.D.P in collaboration with National Association for the Blind highlighted the 'Role of NGOs vis-à-vis the Employment Scenario with reference to people with disabilities'. Javed Abidi the convener of DRG is also the executive director of NCPEDP and was one of my informants in the project. Having received a copy of this study, some of the highlights are as follows:

- Out of the 150 organisations that were contacted 119 responded.
- 65.55% organisations were providing placement.
- Average employment rate was only 30.85%
- Even in this 51.85% of the disabled are self employed.
- Range of Income:

(% is out of total number of disabled people placed in the last 2 years)

- Below Rs.1,000 : 47.50%
- Rs 1,000 – Rs 2,000: 40.77%

And therefore, out of the total number of disabled people placed in the last 2 years (1996-1998) by the 119 participating organisations 88.27% get less than Rs 2,000 per month and only 11.73% earn above Rs 2,000 a month (0.20% earn above Rs 6,000).

¹⁶ See www.ncpedp.org

The same study also annexes the 'Vocational Training being given to Disabled People'(Annexure 7) , which lists all the skill training these organisations provided to make the disabled person employable:

Shree Ramana Maharishi Academy for the Blind	Industrial Training, Agro Based Training, Craft Skills and Computer Course
Blind Men's Welfare Association	Not applicable
Action on Disability and Development (ADD) India	Not applicable
Baroda Citizens Council	Tailoring, Sewing, Turner, Driving, Wire man, Radio and Tape-recorder Repairing, Computer Software, Motor Rewinding, Air Conditioner Repairing, T.V. Repairing, Beautician, Mehendi and Ear-top Making
Suniye	Not applicable
The Spastics Society of Northern India	Block Printing, Bulk Mailing and Individual Skill Training
Seva-in-Action	Cover Making, Doll Making, Training in Petty Shop, Looms and Agriculture
Sweekaar Rehabilitation Institute for Handicapped	Book Binding, Making Envelopes, Candles & Chalk Pieces and Tailoring
CBR Forum	Not applicable
Muskaan	Block Printing, Stationary, Masala Making, Candles and Diyas
Dwar Jingkyrmen	Machine Embroidery, Tailoring, Hand Embroidery and Screen Printing
People's Craft Training Centre	Tailoring

Mr.Abidi when pointing these out very aptly said "This is what the disabled are seen capable off". This attitude of the NGOs also can be seen as'token vocational training' as the aim was to tout someone as employed without actually ever aiming to raise the quality of life of the beneficiary.

With the disabled having no say in what was to be provided such things as arts and crafts, book binding, folder making are identified even till today as the most common skills imparted to the disabled. But at least with the case of NCPEDP, one can note the conscious effort to provide technical training, and remarkable strides in placing individuals in private sector jobs. The business processoutsourcing (BPO) jobs and the information technology (IT)sector has been seen to be the greatest potential employer ofPWDs (*The Hindu* 2005,february 7, as cited in Mehrotra 2011).

Another is the path breaking initiative by an organisation called A.R.U.N.I.M. which has started a unique initiative which is creating employment opportunities for people with intellectual and developmental disabilities in a profit making mode in a competitive market.(Interview with ThilakamRajendra on 1-06-2012, dnis.org)

Their objectives are:

- To build an entrepreneurial approach in vocational and sheltered units and bring change in the work culture to match the expectations of the competitive market outside.
- To utilise the existing and learnt skills of producer members and challenge the designers to create market worthy products.
- To introduce A.R.U.N.I.M. products and services as a preferred brand with better quality and packaging so that it becomes customers delight.
- To move away from seasonal charity sales and provide a perennial marketing channel.

A.R.U.N.I.M also follows the DPO model for its membership, where it states that they must have more than 50% membership of persons with disabilities of which 5% must have developmental disabilities. It stimulates the same policy for even non registered groups. (This policy is discussed further in the next section) Such change in thinking is indicative of the importance of a discussion on participation in decision making by the groups most affected by the services provided by any organisation.

Linking personal experience to innovation

Mr.Abidi

Nature of Disability :Orthopaedic

Studied Mass communication from Wright State University, Ohio.

When he returned in 1989 to India, he wasn't worried about getting a job as he had a U.S degree with a 4.0 GPA and numerous newspaper clippings(Bronstein,2004) . Only, reality in India was much different, despite his qualification no newspaper would even give him a chance. Eventually by grasping an opportunity and quick thinking Mr.Abidi could give in a report others weren't able to get access to and thus, it wasn't long before he was able to gain employment in Times of India. He left this job eventually to take over the disability unit at the Rajiv Foundation which lead to the formation of NCPEDP. Not everyone's story can be a story of success, but it is personal experiences in the difficulty of gaining employment that became key to the drive to take a different approach to 'employment' of the disabled.

2. Providing Products/ technology

Modern Technology is probably the most important aspect to improving the quality of life of a person with disabilities as well as helps them attain social integration on their terms. In a developing country like India where the majority of disabled population still resides in the rural areas, access to basic technology, like a wheelchair or white cane or hearing aids also sometimes seems quite impossible.(As noted in a number of studies e.g: Borg(2011))

To illustrate, I am going to take the example of one Service based organisation 'Saksham', whose founder was one of my Informants. By linking his personal experience and the approach of he took in his organisation, one can see how NGOs would function in sensitizing the product delivery process.

DipendraManocha has been called the pioneer in bringing DAISY the accessible reading software needed by the Blind. He also established "Saksham trust in the year 2003 to undertake activities for empowerment of persons with disability." In my interview he reiterated the need to empower the disabled through access to technology. This needn't be complex technology at first. For example, he told me that Saksham's very first project was to announce that the trust would help deliver white canes and charge courier charges only, if the visually challenged wished to purchase them on a needs basis. This was remarkably different from the scenario earlier, where, based on the charity model, distribution of free white canes was something carried out by Rotary clubs on every 15th August or 26th January. What this model lacked was the understanding that the blind didn't need canes only when someone decided to give them for free! As Mr.Manocha pointed out, at least in urban areas the blind were open to paying the paltry Rs 10 charges as at least the need to wait on others was cut out and so was the harrowing experience of travelling to a center somewhere far off to procure a cane when it was urgently required.

Thus, from this example one can see that gaining access to white canes on a need basis was itself such a simple yet empowering process. Saksham has since formed a technology

research cell where it hopes to connect with companies abroad that might have advanced to better technology and make them aware of the market in India. On the *Saksham* website, one can till today see the product of white cane on its list, only with inflation and better versions, it costs Rs 110 now.

Linking personal experience to innovation

Dipendra Manocha

Nature of Disability: Totally Blind

His involvement with the DAISY (Digital Accessible Information System) software came from the personal experience of being unable to access the texts online or in his library during his doctoral. His Bio-data as an Ashoka Fellow states that:

“By devising and sourcing tools that remove the communication barriers that come with visual and hearing impairments he demonstrates how one’s disability is irrelevant to his/her identity as a citizen, and creates an environment where disabled people are expected to contribute and be competitive in society. The goal of Dipendra’s work is to improve both disabled people’s self-image as well society’s perception of them.”

His own experience with environmental limitations such as inaccessible books or even the compulsory distribution of white canes, allowed him to more keenly identify what needed to be changed. This fits in perfectly with the social model of disability which sees the individual limited not by his disability per se, but rather the unwillingness of the environment to make provisions for them to take active part.

3. Appropriation of Funds :

“Let them loose their limbs, but not their dignity” (tenBroek)

Something the charity model relies heavily upon is the need to ignite sympathy in the hearts of its donors. Such that the need to portray the beneficiaries as destitute individuals, upon hard time and requiring the benevolence of the society for their upliftment is part and parcel of the process of having an NGO. Even today, nationally recognised NGOs like Amar Jyoti Trust(Amir Khan included them in his show ‘SatyamevJayate’), claim to be ‘always out with a bowl in our hands, but we don’t mind. We know it is for a good cause’. Fortunately, for them the focus now has shifted to identifying projects and funding them rather than the ubiquitous ‘poor disabled children or women’ or the NGO itself.

When one of my informants, Mr. JL Kaul started off the scenario wasn’t so conducive. Having himself found employment in a government office due to his typing skills, even reaching that point had been an uphill task. From the ‘special school’ he went to, to the battle to be eventually allowed to partake in mainstream college education was the first of the many he continued to fight. Taking from his school experience, where he had to endure the degrading practise of being treated as the *“Laacharbaccha”*, had to gain donations sometimes even sent the children to someone’s death bed, keeping in line with some of India’s backward superstitions in relation to disability. Unfortunately, the practise of donations being given on the condition of *“distributing sweets”* or *“touching the children”* is not unique to the 1960s or 70s but even till today Mr.Kauls nationally recognised association *“All India Confederation of The Blind”* receives visits from educated adults such as DU principals who offer donations but with the added *“my pandit told me to distribute white sweets”*. Mr.Kaul, knowing the deprecating effects on ones psyche when a beneficiary is paraded in such a manner, flatly refuses any such offers. He maintains, *“he’drather they lose the money than their dignity.”* Here the link of personal experience to approach to funding is clear.

The organisations mentioned except A.I.C.B and A.R.U.N.I.M are not DPOs but rather are headed by persons with experience of disability. It is important for the purpose of this paper to highlight the link between DPOs and decision making because the objective of this paper is to bring to focus an alternative to empowerment of the disabled through bettering the service delivery with a more inclusive participatory model.

DPOs and their link with Decision Making

A Disabled Persons Organisation "is an organisation whose constitution requires it to have a membership and managing board with a majority of disabled people, and whose objectives are the rights and equality of disabled people". This could be specified as more than 50% of full voting members must be disabled people and a minimum of 75% of the management committee must also comprise of disabled people as is the case at United Kingdom Disabled People's Council or it could be any other variation.

Henry Enns, in a Disabled People's International (DPI)'s discussion paper emphasises: DPOs play the following functions:

1. Self representation:

As Jim Derksen urged disabled Canadians in 1975:

"Let us reason together, let us deliberate on our problems and needs, let us consider our abilities, and when we have agreed on the problems and solutions let us articulate our opinions and ideas in a strong and united voice." (Derksen, 1975, p.1a)

2. Identifying Grassroot needs:

Paulo Freire explains in *Pedagogy of the Oppressed*:

"... those who recognize, or begin to recognize themselves as oppressed must be among the developers of the pedagogy. No pedagogy that is truly liberating can remain distant from the

oppressed by treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption." (Freire, 1970, p. 39)

The way DPOs help do so is by:

- i. Organising Local chapters
- ii. Open forums
- iii. Democratic Representation

"Before I can represent a group of people, I must first consult with them. This process involves sharing with these people my knowledge or expectation that certain issues among the many which concern these people are likely to become subject to public debate in the near future. I must solicit from these individuals informed opinions on these issues and receive from them instructions to represent these views. These instructions constitute my authority as a representative." (Bowe, 1980, pp. 13-14)(As cited in Enns)

3. Representation to Government Service Providers and UN bodies.

Additionally, DPOs have also been associated with 'self-development', developing 'mutual Support and solidarity', 'networking mechanisms and promoting public awareness' as well as 'vehicles for self-help projects'.

Decision making or rather the involvement in the process is a key feature of DPO organisations. But first, one needs to define Decision making. For the purpose of this paper even a simple definition such as, 'decision making is the act of expressing choice and preference and being able to act upon that choice.' can be used.

Thus though in the earlier section I spoke of the benefits of self organisation over the charity based approach in terms of the approach of the individuals, it is important to remember that unless a

democratic structure of participation is followed, the workings of an NGO can be autocratic or worse, follow a top down approach where of the educated elite a few partake in decision making. This is reiterated by Bhambhani in her thesis when she speaks of the need of effective and dynamic leadership(which she has associated with Mr.JavedAbidi) for a movement to be realised but adds a note of caution:

In the light of this statement one can say that the movement has a top-down approach and that the agenda for the movement is not decided in a democratic way. There is little participation in agenda-setting from members of the disability community and this has prevented the movement from trickling down to rural areas. The issues addressed pertain to higher education, employment in government and corporate sectors, and accessibility in public places. These issues concern largely urban and educated disabled people, whose number is much smaller¹⁷ than that of disabled people in rural India.(Bhambhani,2005)

Though my informants were affiliated with various organisations, AICB whose executive secretary is Mr.Kaul, is one such DPO that insists on realising all the functions of a DPO by mandating that its executive committee follow the majority model, but also establishes in its memorandum that any NGO wishing to be its affiliate must also follow the “self-help” philosophy and in general body meetings, send delegates in such a way that more that 60% of disabled persons are present at the time of the meeting . This shows their dedication to ensure that the decision making is democratically in the hands of the disabled, so as to ensure that the steps taken coincide with the concerns of the individuals.

A recent example of the success of the DPO model is A.R.U.N.I.M. a start up organisation and path-breaking initiative of the National Trust:

¹⁷ According to the latest NSS Report (2003) the prevalence of disability in rural in India was 1.85% as against 1.50% in Urban India.

We are currently working with 196 member organisations pan India to facilitate livelihood and self reliance of persons with disabilities with a special focus on developmental disabilities. The challenge is to increase the earning capacities of producer members with disabilities under sheltered units of N.G.O.'s through promotion of market driven products and services. The transition from rehab sheltered workshop cum production centres to becoming sustainable enterprise models has just begun.¹⁸

ARUNIM's membership policy states that

- 'The sheltered workshop/enterprise can have inclusive groups with at least 50% persons with disability of which 5% members to be with developmental disabilities.
- The NGOs/Co-operatives working with or without peoples with disabilities to have 50% persons with disability of which 5% members to be with developmental disabilities. Where there less than 5% developmental disabilities the decision would be taken by ARUNIM board. This holds true even for non registered NGO groups

Thus ARUNIM is another example of the path breaking and innovative thinking that DPOs represent. This, to me is a function of their ability to not see 'disability' as lack of ability but as an opportunity. The social models view point is extremely helpful in encouraging these groups to come up with innovative methods to increase involvement.

On a concluding note, Participatory models are useful to keep in mind if one is to evaluate these NGO/DPO structures.

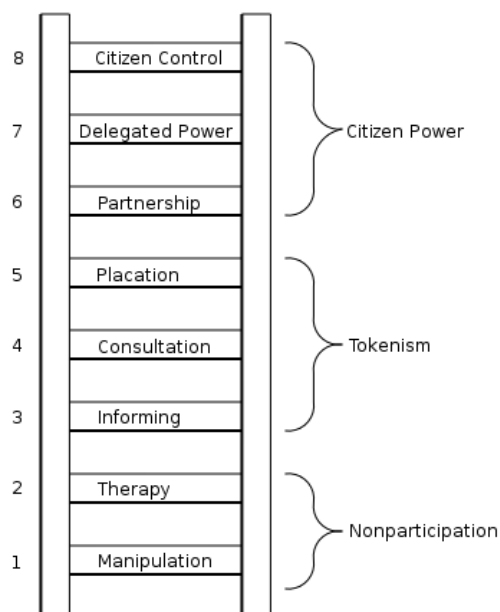
Participatory Inclusion Models

Along with service coverage has come the realisation that functional independence alone is not enough. Issues of participation, ownership and mutual support are gaining increasing emphasis. The field of disability rehabilitation has thus moved from a medical and impairment orientated activity, to one focusing on rights and group organisation. (Thomas,2005)

¹⁸Interview in Dnis.org Volume 9 Issue 6 - June 01, 2012 "There needs to be clear distinction between an activity centre and a vocational course": ThilakamRajendran

The role of these organizations (DPOs) includes providing a voice of their own, identifying needs, expressing views on priorities, evaluating services and advocating change and public awareness. As a vehicle of self development, these organizations provide the opportunity to develop skills in the negotiation process, organizational abilities, mutual support, information sharing and often vocational skills and opportunities. In view of their vital importance in the process of participation, it is imperative that their development be encouraged. (WPA¹⁹, p. 8)

But the process of ‘participation’ can occur on many levels as literature by Sherry R Arnstein Shows:



Thus, ‘consultation’ even though counting as participation is still not reflective of high level participation, which is what every citizen should aim for. An example of the consultation model is NCPEDP. From the time of its formation with the Rajiv Gandhi Foundation, though Mr. Abidi has been its Executive director, the other trustees are not disabled. Though, from the very beginning they formed a parliamentary structure where they had representatives of NGOs from each state as far as

¹⁹World Programme of Action Concerning Disabled Persons

possible, when discussing issues related to the NGOs directives/goals. This structure is a consultation based structure as the final power of decision making does not rest with the disabled.

A self-help group conversely would be on the second rung from the top because here there will be participation but the projects will be disabled initiated and disabled run.

Interestingly the model postulates that participation which has disabled-initiated projects but then employs relevant stakeholders to meet with their demands is a higher level of participation, because it isn't about always running the project but having the right to be provided with the services on a demand basis. So once a project is initiated, say 'inclusive education', it has to be worked upon in collaboration with other bodies to meet the objective of the project. This is to avoid ghettoisation where one community serves only its own.

COUNTER ARGUMENTS: "NGOs = Legalised Begging?"

For the realisation of any good argument, there is a need to acknowledge the counter arguments as well. Rather than cite studies to show counter arguments, I will highlight the view points of my younger informants. Unlike, the heads of organisations when I spoke to the second generation, so to speak, I found a more murkier picture. It is not as easy to assume that NGOs by the disabled would be more conscientious when the incentive to do so isn't as strong, considering the charity model is still largely prevalent among donors. As one University student recounted her experiences with the 'equal opportunity cell officer', a wheel chair bound individual, it becomes clear that just by virtue of being disabled it is in no way ensured that one will have the inspiring and educated attitudes as that of my earlier informant's Mr.Abidi and Mr.Kaul or even of the hardworking students themselves! One incident particularly stuck out, when for the some event the equal opportunity cell was approached for performing an act for the closing ceremony, the students were clear that they would perform only if it were on the condition that it was for the 'closing ceremony' and not a display of 'what the disabled people can do, now that they have 'equal opportunity'!', It was this very

officer who lied and said it was for the closing ceremony leading to utter humiliation felt by the students when they eventually went on stage and were announced and spoken of as a “special act” and taken as an event for gaining sympathy and awareness of the disabled, something the disabled students, did not want. Thus, as Rijul an M.phil student reiterated to me, to write a good paper on NGOs and involvement of the disabled, I must keep in mind that there is no black or white. And account for the shades of grey that come with human variation.

Having said that, the essence of the argument of this paper is to highlight democratic participation, this might be a utopia, but it is a utopia worth having. The civil society/voluntary sector/NGOs that form the link between the still largely unaware poor and illiterate disabled population and the realisation of their fundamental rights have to take a more active role. And the fact that this censure is coming from an increasingly conscientious disabled populace, speaks for the need of their involvement in carrying out the objective of improving the quality of life of this community.

Scrutiny of Government Actions

IN KEEPING WITH THE “NOTHING ABOUT US WITHOUT US” PHILOSOPHY

As the introduction stated, the new Disabled Persons Rights Bill is being drafted based on U.N.C.R.P.D guidelines, which includes taking a more social model perspective to disability and thus, provides for inclusion of more disabilities as well as addresses additional concerns. In this section a reading of the reports on government action for this drafting this bill will provide insights into government’s attitude towards the philosophy that is the true essence of ‘participation’.

Having read the previous two sections it should be clear in the mind of the reader that NGOs/DPOs play an important role in liaising with the government to meet the demands of the disability sector. Yet, perhaps because of this, the government has rarely if at all wished to follow the ideology of “nothing about us without us” which demands for the disabled to be part of the decision making that is ‘for’ their welfare.

Examples:

- The committee constituted to see to the functioning of the act of 1995 had 38 members of which only 5 are required to be disabled and must represent each area of the five disabilities recognised by the act: Hearing, Vision, Orthopedic, Leprosy-cured, Mental . Of these 5 one need to be a women representative and one has to be a SC/ST representative.
- The issue of inclusive education has nationally been recognised. And though a the government seeks to work towards inclusion, it is yet unable to bring itself to ‘include’ members with disability in its committee drafting the guidelines!(dnis.org: Volume 9 Issue 11 - August 15, 2012 ‘Committee drafting R.T.E. guidelines on disability has no disabled member!’)
- D.R.G member on the civil aviations committee resigned because even though she had been placed there to ensure that the airport and flight authorities showed more sensitization to the needs of a disabled traveller, the “ Ministry seems to be buying time and pacifying the sector’s anger with the Committee without any definite commitment to stop such gross violations.” She said in her letter. (Volume 9 Issue 7- June 15,2012)

On the Disability News and information service online portal there are many more examples of the government's on non compliance or outright avoidance of including the disabled in issues pertaining to their welfare.

But for the purpose of this paper and with relevance to the current scenario it is important to discuss the evolution of the Bill that is as of 2012 the latest version.

1. On March 1, 2010 the network reported that MukulWasnik Minister of MSJE was talking of the 'possibility of a new law based on U.N.C.P.R.D
2. On April 1, 2010 the network reported that the Ministry was now setting up an "expert committee" :

More than six months down the line since the disability sector placed its demand for a new Disability Act instead of the proposed amendments, the twists and turns in the ongoing drama within the precincts of the Ministry of Social Justice and Empowerment (M.S.J.E.) seem to be getting more and more interesting. The latest 'twist in the tale' being the report that an 'Expert Committee' is now being hurriedly put together to study this demand!

What will be interesting to observe is as to who in the opinion of the Ministry are 'experts' on the issue. This decision will determine whether M.S.J.E. is indeed serious about this nation wide demand or whether it is more interested in an eye-wash. If reports are to be believed, M.S.J.E. has only contacted fringe elements of the sector as of now.

3. On May 15, 2010 the network reported that out of 27 members of the committee only 3 are disabled.

Rajiv Rajan of Disability Law Unit – South has shot off a letter to the Prime Minister expressing their displeasure. "This under representation of disabled people in the Committee completely flouts the spirit "Nothing about us without us" of the United Nations Convention on the Rights of Persons with Disabilities", he said.

4. On January 15,2011 the network reported that even with resignation of 4 members, 3 of whom were persons with disability, the Committee went ahead with its meeting on January 2 and then on 13 and 14. Point to consider: the meeting on January 2 had barely 10 people in attendance out of the total 36 Members!

As of 2012 there is a Bill 2012 up on the website, and the information on SudhaKaul who chaired the committee if available as well. The minutes and recommendations considered imply that NGO proposals are being looked at but the disregard in including said members onto the committee shows clearly the attitude of the government and that needs to change.

Other Issues with Government Policy

Another, point of contention is the need for a BPL(Below Poverty Line) certificate to avail of free services provided by the NGOs. As Amar Jyoti Charitable Trust's Principal pointed out, to get the certificate the individual must pay a fee of Rs 3,000. This has lead to moneyed individuals procuring the certificate and presenting it at NGOs to avail services, while the poor in need of these services can no longer be 'legally' serviced by the NGOs. There is a serious need to look into such arbitrary policies.

Conclusion

The Constitution of India ensures equality, freedom, justice and dignity of all individuals and implicitly mandates an inclusive society for all including persons with disabilities. The policies of the Government of India towards the welfare of persons with disabilities have been reflected in the enactments, schemes and through institutions established for various relevant activities. The Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 and National Policy for Persons with Disabilities released in 2006 are two of the initiatives which emphasized the importance given to this particular issue by the Government of India. (Disability statistical manual)

But as the last section highlights this hasn't been enough. Political will has had to be driven by self advocacy group as seen in the section on the 'disability rights movement', while service delivery has had to be streamlined with not only the perceived needs but also the demands of the people with the help of NGOs and DPOs.

To ensure that this is done in a democratic manner and that even within the NGO sector the provision of these services should not become an action controlled by a few (either disabled or non disabled), the DPO participatory model of decision making is a model worth investing more research into.

Some, pitfalls of a completely NGO run scenario are that in like any other organisation, sometimes people at the top can and do lose sight of what motivated them from the beginning. The fact that many of these individuals have to depend on NGOs to meet their basic needs is a matter of embarrassment, not a solution. It is a stop gap till we can effectively realise their citizenship. In fact, for true empowerment societal attitude has to change such that the notion of 'disability' is removed.

As Sharmishta an M.Phil Student at DU university told me, for her true empowerment is when "No one looks at her walking down the road and seeks to ask how she manages." The point in time when her 'disability' will no longer make her stand out, will be the day true empowerment has been actualised.

In the words of the protagonist in Ship of Thesus, "Why is it so surprising to not be limited?"

In a world where we seek equality among unequal individuals, the best form of equality would be to allow each to be unique, without forming a hierarchy by privileging a few.

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