The seeds of a movement: disabled women and their struggle to organize


Up against the male-centric nature of disability theory, and the slowness of women’s movements and feminist scholars to address disability as a political issue, disabled women are laying down the basis for a transnational disabled women's movement.

Since the 1970s, disabled peoples in differing global locations have increasingly realized that their interests and needs were not being served—that projects were not being designed in ways that they would have chosen and that ultimately, they were not in control of their lives. This led to the creation of self-help and single-issue disabled people’s organizations (DPOs) run by and for disabled people, addressing needs identified by their members. The creation of such groups, and networking between their members, marked the beginnings of the disability movement. For instance, the resistance to ‘charitable’ approaches saw the establishment of international DPOs such as the International Disability Alliance [2] and Disabled People’s International [3], whilst the protests and impact of organizations of disabled Vietnam War veterans in the USA, marked the rise of campaigns for Rights not Charity [4].

The year 1981 was designated the UN International Year for the Disabled, changed after intense lobbying to the International Year of Disabled People. Disabled Peoples International (DPI), was established that same year as a self-advocacy global organization, and operates not only at the international level but regionally, nationally and locally, with a large representation of disabled people from the majority world (mainly men) having senior roles within it. It has played a major role in the creation of greater disability awareness, particularly within the UN system, and has served as a powerful force in bringing disabled people together in planning for the Disability Rights Convention [5]. Giving further impetus to the rise of disabled people organizing was the adoption by the UN General Assembly of The Declaration on the Rights of Disabled Persons [6], on 9 December 1975.

However, despite progress at the international level, disabled women have in general been silenced within society, including by feminist movements, and denied their rights and equal economic and social opportunities due to prejudice, stigma and poverty. They face a pattern of discrimination that repeats itself globally, in differing forms, in rich countries as well as poor. The fear, anxiety, vulnerability and ignorance people experience when encountering disability are translated into societal restrictions on disabled women’s access to educational opportunities and to health care, and limits to their employment options, where they tend to be restricted to poorly paid and low-status jobs. Viewed as incapable of handling the maternal role and as carriers of malfunctioning genes, they are derided as mothers and denied children, too often through forced sterilisation. They are subject to physical, mental and sexual violence and abuse, both in the domestic and the public arena, and in the institutions to which some disabled women are committed. The negative perceptions of disabled women and the prejudice and oppression they face lead to low self-image for many. And when and if they challenge all this, they are met with incomprehension and, despite the new UN Convention, a marked lack of social and legal rights.

There have been several other aspects of disability organizing and politics that have worked against disabled women, including the male domination of disabled peoples’ organizations and movements; the male-centric nature of disability theory and thinking, which shapes political agendas; the lack of analysis and awareness of the intersectionality of disability politics with race and class, as well other
structures of discrimination; and lack of representation at bargaining and decision making tables. Underscoring all of this, women’s movements and feminist scholars have been incredibly slow at getting their heads around disability as a political issue, rather than a charity or welfare concern.

Given the male domination of the disability movement, disabled women who were politically active often drew upon feminism to aid their analysis of the gendered character of disability oppression. However, this was not a two-way process until early in the new millennium when for example, women’s activists especially those working on health issues in low-income countries, were beginning to explore political alliances with disabled women.

Following a 2004 Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank which found people with disabilities face the same or even greater risk for contracting HIV, as people without disabilities, Aids Free World, took part in Human Rights Watch's programme Rights Watch in which they discussed the links between HIV and disability, and called for action.

Addressing the use of the pre-natal diagnostic and sex-selection technologies to identify and abort both female and disabled children in a new eugenic impulse, especially affecting India and the South Asian countries, an article by Anita Ghai and Rachana Johri in the Indian Journal of Gender Studies recognises the tension between the feminist and disability activists around the issue of women’s choice, questions the ideology that regards abortion as the only option when prenatal testing reveals a birth abnormality and make the point that disability is to a great extent, socially constructed.

**Disability organizing and strategies**

Disabled women’s awareness of the oppression they face and their attempts to organize themselves date back at least to the days of “second wave” feminism in the 1970s across the western world as demonstrations were staged by feminist groups, by civil rights campaigners and anti-racist activists for equal rights and against violence. To organize and campaign for their rights, disabled women face all the difficulties that non-disabled women face, but mediated by disability.

Disabled women are finding other disabled women to relate to and share experiences with, sparking a growing self-confidence, and marking the beginnings of consciousness, self-help groups and political organizing. They are not only involved in establishing local disabled peoples organizations, but are contributing to the growth in national level bodies and inter-country linkages. One major stimulus for disabled women coming together across national boundaries was the establishment of the Platform for Action for the Beijing Conference in September 1995. An international symposium on the day before the Fourth World Conference on Women, brought together about 200 disabled women from 25 countries, and they were able to agree on a common strategy and position for disabled women to lobby for in the main conference. At the U.N. conference, women with disabilities were successful in influencing the language of the Platform for Action. The document stressed the need to eliminate barriers in the areas of education, employment, health, social services, and information.

**Disabled women: visions and voices**

Assisted by the widespread consultation and awareness raising that marked the development of the UN Convention on the Rights of People with Disabilities (CRPD), they are tentatively laying down the markers of emerging - if not yet solidified—international networks, which may form the basis of a future transnational disabled women’s movement. In order to build the movement in the face of strong challenges, there are a variety of strategies being employed; a few of them are outlined below.

Coalition building pulls together smaller local disabled women organizations and offers the potential ability to undertake broader initiatives, drawing on the skills and experience of the local groups and simultaneously offers contacts, research and insights gained from negotiating with government officials, funding organizations, and international bodies’ representatives at national level.
Strengthening organizations of disabled women established at the national level has played a vital role in supporting the strategic and practical interests of disabled women across their countries. Some disabled women’s organizations and networks such as Disabled Women’s Network Ontario [14] (DAWN Ontario) and Women with Disabilities Australia [15] (WWDA), have evolved over time into established, committed, campaigning groups with clear political agendas and constituencies, and can probably be termed movements.

Advocacy and awareness-raising, particularly in relation to the UN Rights agenda, are an important part of strengthening disabled women’s networks. A highly organized group of disabled women influenced the structure and form of the CRPD, ensuring that women were included through acknowledgment in the Convention Preamble by the States Parties [16] with specific acknowledgment of women and girls with disabilities’ greater risk of violence and abuse and further, in respect of their rights, states: "Emphasizing the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities".

Combined with Article 5 [17] of the Convention, women and gender issues are addressed in a clear and comprehensive manner. This task has been vital for establishing disabled women’s rights [18].

One of the ways in which disabled women are making strides in connecting with each other is through the internet, which has helped overcome at least some of the challenges to disabled women’s organizing faced in travelling, with physical access, and communicating. Disabled women are slowly discovering that the internet can act for them as a political tool, enabling contact, building communities, and enhancing political action. The e-group International Network of Women with Disabilities [19] (INWWD has continued to expand since Beijing in its mission [20] to enable women with disabilities from all around the world to share their knowledge and experience, enhance their capacity to speak up for their rights, and empower themselves to bring about positive change and inclusion.

Movement achievements and the future

Beijing marked a watershed [21] in terms of disabled women’s inclusion in women’s struggle for rights, even though the platform document did not spell out what disabled women’s specific barriers to accessing their rights were (Darnborough 2003). The swell of activity and awareness that has been raised through the planning and campaigning towards the establishment of the UN CRPD has led to greater clarity about the breadth of possibilities for disabled women to build movements within and across countries within the majority world. Yet, disabled women’s movements cannot depend only upon links to major international bodies like the UN. The constituencies on which we build our agendas, and the coalitions we form will be vital to our movements’ futures as will be our politics, in guiding the choices we make.

The future is impossible to predict. Yet, we look to a time of widespread recognition of the place of disabled people, and disabled women, in our world— where our inclusion in all that happens around us comes with the acknowledgement of us all as fully embodied women, vulnerable and strong, ever changing, working in solidarity alongside others, towards our dreams in a world where we may all potentially flourish.

Within this article, the terminology ‘disabled woman’ is used by preference, rather than ‘women with disabilities’, (known as the ‘person first’ approach). The former is used by women claiming an identity as disabled, often used by those with links to the social model of disability. This naming also indicates disabled embodiment. This latter has been adopted within the UN Convention on Rights for People with Disabilities, on the basis that one is a woman first and disability is a secondary characteristic.

This is the third articles in a series on Women’s Movement Building. Read Srilatha Batliwala on Beyond individual stories: women have moved mountains [22] and A transformative strategy: the true value of investing in women’s rights. [23]
Janet Price is a disabled feminist who is based in Liverpool, UK, and Taranaki, New Zealand. She is actively involved in queercrip politics and is on the board of DaDaFest [25], a disability and Deaf arts organisation in Liverpool. She teaches at the Liverpool School of Tropical Medicine, and works with CREA [26], a feminist and sexuality rights organisation in Delhi, India, and with a coalition of groups working in disability, sexuality and justice across Africa.

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