

**THE SEEDS OF A MOVEMENT—
DISABLED WOMEN AND THEIR
STRUGGLE TO ORGANIZE**

BY JANET PRICE

FROM CHANGING THEIR WORLD 2ND EDITION
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The Seeds of a Movement – Disabled Women¹ and their Struggle to Organize

By Janet Price

Introduction

This paper is an attempt to map out some of the challenges that disabled women have confronted in their struggle to fight discrimination and build their own movements. 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 nineteen seventies. Although such a short paper cannot present a complete global picture, it records some of the history of their organizing, marking the inequity that disabled women across the globe have struggled with and surmounted, whether at the level of small local groups facing specific challenges, in national bodies addressing policy and law-making, or in focused international linkages working with the UN and others on establishing global rights. And finally, it asks: where now for disabled women?


'Diversity is what makes a movement' (Hickey 2010 New Zealand Maori). More obviously than in many movements, disabled women have been compelled to address the question of their diversity: they come with different sexualities, ethnicities, classes, religions, and other differences, in addition to their distinct impairments and the rights they consequently prioritize also vary as a result. What will build a strong movement of disabled women is their recognition of and combined political response to the discrimination and prejudice they collectively face, which is constituted not just through their similarities but through their multiple differences.

Disabled women have in general been silenced within society, 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 on 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. Disabled women are commonly perceived as asexual, which means that the majority of them are denied the possibility of close relationships or marriage. 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

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1. Within this document, I will use the terminology 'disabled woman', rather than 'women with disabilities', (known as the 'person first' approach). 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. In using 'disabled woman, I am arguing a political point, linked to the creation of Movements for disabled women. In part, I adopt disabled woman because it indicates an identity, a consciousness of oneself as disabled, something that I propose is necessary to the possibility of a movement formation. But more importantly, 'disabled woman' refuses the separation of the physical or embodied women from her disability, indicating that they are both inseparable aspects of a phenomenological whole. This allows disabled women the possibility of being whole within their gender and disability. The alternative is that gender and disability, especially disability, are immediately categorised as signs of a 'broken body'.

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 Convention², a marked lack of social and legal rights.³

While all disabled women are affected by poverty and social prejudice to some extent or another, the effects of this vary depending upon the status of women locally, the nature of their disability, which country or culture they live in, their social class, race, ethnicity, or caste, and their age and sexual orientation, among other factors. Irene Feika, Deputy Chairperson of Underrepresented Groups, Disabled People International, notes how widely the negative influences spread.

'Women with disabilities have been largely neglected when it comes to research, state policies, the disability and women's movements, and rehabilitation programmes... This reality is especially true of women with disabilities in cultures where the role of wife and mother is considered to be the primary role for a female.' (Feika in Rao 2004)

Disabled people generally and disabled women in particular have struggled against prejudice that holds them comparatively helpless, in need of support from others to manage their lives, their homes and their desires for the future. Globalization, industrialization, mechanization of the work place, and the shrinking of self-sufficient communities where tasks could be found appropriate to the capabilities of most of its members, have all led to disabled people being seen as less productive or as a drag upon the community (Oliver 1990:27). A charitable perspective, imported into many colonized countries as part of European Christian ideologies, strengthened in the mid-20th century, resulting in the creation of welfare-style charities aiming to assist disabled people, but generally run by non-disabled people. Impairment-specific groups such as societies for 'the Blind,' and 'the Deaf', or generalized welfare groups that work for physically or intellectually disabled individuals, have provided support and services but are controlled almost inevitably by non-disabled people.

Box 1: Defining Disability and Disabled People

Who are disabled people? Commonly understood and widely used are definitions that draw on *medicalized* notions of 'the disabled body,' which assume that medicine, through a mixture of treatment and rehabilitation, can affect a 'cure'. The disability community has rejected this medicalized approach and developed alternative definitions that are culturally, socially or economically informed.

Some of these are based on the *social theory or social model of disability* that believes systemic barriers, negative attitudes and social exclusion (purposive or inadvertent) are the ultimate factors defining who is disabled and who is not in a particular society. The social model does not deny that some individual differences lead to individual limitations or impairments, but rather that these are not the cause of exclusion. The origins of this approach can be traced to the 1960s and the disabled people's Civil Rights / human rights movements. The specific term *disability* – to replace the then widespread term "handicap" – itself emerged from the United Kingdom in the 1970s. In 1976, the UK organization Union of the Physically Impaired Against Segregation (UPIAS) claimed that *disability* was: *'the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical*

2. The UN Convention on the Rights of Persons with Disabilities, 2007

3. For an overview of the global situation of disabled women, see Meekosha & Frohmader 2010.

impairments (a long term restriction) and thus excludes them from participation in the mainstream of social activities.' (p6)⁴

The 'social model' has been extended and developed by academics and activists in the US, UK and other countries, so that now, the term 'disabled people' encompasses a wider group.

In the UN Convention for the Rights of Persons with Disabilities (CRPD), Article 1 states that "(p)ersons with disabilities include those who have long-term physical, mental, intellectual or sensory *impairments*." *Disability*, however, "is an evolving concept" and "... results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others". (UN Enable 2007). These include physical barriers; stigma and prejudice; the failure to provide accessible information e.g. in Braille or spoken word; inappropriate medical treatment (such as forced electroshock therapy for people with mental health problems, or the institutionalization of people with intellectual disabilities). The UN CRPD draws upon a *Human Rights model*, focusing attention on the need to address abuse and discrimination. Interestingly, the definition of disability it offers is not a fixed one but recognises its changing nature.⁵

Disabled Women Organizing – the Challenges

The challenges disabled women face—of poverty, lack of opportunity, denial of political, social and sexual rights, violence and abuse – are achingly familiar to feminists, for they are challenges that confront women across the globe. So why is it that since the beginnings of feminist awareness and campaigning, disabled women appear to have been relegated to the lowest rungs of the feminist movement, left alone to find their own ways of organizing, and are only slowly beginning to be accepted as sisters in the struggle? Unwilling or unable to see that disabled women's lives are also marked by prejudice, discrimination and oppression, feminists have tended to view dis-

abled women's status as 'Other', as 'parai'⁶, or, worst of all, not to see them at all. While this has been the response of the feminist and women's movements, disabled women's invisibility to other progressive social movements has been as bad or worse. Marked out as different, separated through unquestioned social, psychological and physical barriers, disabled women have become the invisible axes against which many social and political movements are defined.

With the failure of others to see disability as political, and in the absence of hospitable openings for their participation, insights, strategies, and leadership in other movements, disabled women have had to build their own movements. The potential for them to meet, organize and build a movement rests on a number of preconditions, some of which disabled women share with other women, some of

4. For a discussion on the social model see http://en.wikipedia.org/wiki/Social_model_of_disability Male disability activists, working in the late 60's in the UK, had developed what they termed the social model. In adopting a fixed division between impairment and disability, they rejected the role of the body in disability, and saw the self as unconnected to the body. Feminist disability thinkers have brought the body back into disability politics, arguing that, e.g. the pain and tiredness felt by disabled people, the insults to their bodies from forced treatment, the way disabled people adapt their bodies to fit -or challenge- preconceptions of certain disabilities, are all part of an embodied political view of disability.

5. The broad social understanding of disability adopted by disability activists is, however, strongly situated, informed by local context, as shown by the inability of those negotiating the CRPD to reach a commonly agreed and specific definition of disability.

6. 'Parai' - Hindi term for alien or foreign

which present disabled women with greater challenges, and some of which are specific to particular to the situation of some disabled women. These are issues that have actually served as the starting point for political organizing.

1. Identification:

Disability is as much a bodily issue as a political one, in the same way that feminism has allowed us to see how gender is both political *and* embodied⁷, as not fixed but permanently ‘under construction’. But to recognize disability and gender as political entails a process of consciousness raising—one has to begin to identify as ‘a woman’, to recognize women’s oppression and to support other women facing gendered challenges. And one also has to identify as disabled, to understand one’s specific position within an excluded minority and to recognize how ‘disability’ draws together a commonality of experience, oppression and prejudice faced by other people with differing disabilities – i.e., a diversity rather than homogeneity of identity.

Maori do not use the word disability and many do not understand that to identify as disabled means there is the opportunity to get supports and equipment. There is a lot of ground work to be done before there can begin to be a chance to address the inequalities. (Hickey 2010)

Whilst the notion of discrimination against women is fairly widespread, the recognition of disability discrimination is completely the opposite. The popular view of disabled people in many countries is that they are ‘charity cases’, marked by fate, damned by god, and without recourse to rights. The UN ESCAP report *Hidden Sisters*, describing the lives of disabled women in Asian and Pacific countries concluded “the combined effect of .. barriers is the extreme deprivation and marginalization of women with disabilities.” (UN/ESCAP 1997: Part 5).

To have a Disabled People’s Movement in a country, the PWD (person with disability) must first identify inequality in the way they are being treated and be ready to stand against such oppression. (Aderemi 2010: Nigeria)

This politicization entails a major shift in disabled women’s understanding, not simply at a personal but at a social and state/global level (Meekosha 2002). It requires disabled peoples to move beyond practical projects to a recognition of strategic questions, which is often a cause of strife within mixed (male/female) disabled peoples’ organizations. And yet, in the absence of any public consciousness of the political struggles which disabled women face, making common cause is crucial. As Ndoya Kane of the Senegal disabled women’s organization *Vie Feminine et Handicap* argues:

Without solidarity, without an understanding that the fight that we lead is not done in the interest of a sole disabled people’s organization, but in the interest of all, we will never achieve any results. Each disabled people’s organization to understand that the fight that we lead outweighs the competition and that we have to go forward together to succeed in getting long lasting results (Ndoya Kane, Personal communication, 2010)

2. Access:

Disabled people face many barriers to communication, to movement, to contact with others, depending upon the local context of their disability. Major limits to interaction exist for Deaf people, for instance, both for those whose main language is Sign when outside of their language network, and in the absence of Sign-teaching to both deaf and non-disabled people. People who are blind or visually impaired require access to alternative forms of written material. For disabled people who have mobility impairments, who may use crutches or wheelchairs to get around, inaccessible public

transport, uneven surfaces, and unhelpful attendants at public buildings with access limits, all restrict movement. Disabled women’s limited access to education is a barrier that restricts them in multiple ways. Ensuring that access requirements are **fully** addressed is expensive—far more expensive that non-disabled people ever realize. But unless a start is at least made in establishing access, many disabled people—especially disabled women whose mobility may be further restricted in some societies because of their gender—will remain isolated, unable to participate socially or politically.⁸

3. Outreach

If disabled women are to meet and organize politically, they have to first make contact, and have to then find spaces/places/contexts in which they can find a joint way of expressing their presence. Local groups of disabled women have arisen where individuals with disabilities have taken the initiative or where non-disabled people have worked in concert with disabled women. stimulating ideas and analyses, as is beginning to happen widely e.g. through training for CRPD monitoring. Many groups run for disabled people have responded to the call ‘Nothing about us without us,’ and have switched the management to ensure disabled people, disabled women take over and direct the aims and organization themselves.

I had polio at the age of three and I have been coping very well after I recovered. I got the idea of starting an organization when I was a student at the University of Ibadan. While there, I was placed in a hostel reserved for female students with disabilities. My experience living there made me better appreciate the plight of women with disabilities. I also became more aware of people’s reactions towards them. So, I led a group that fought for the rights of people with disabilities in my school. After graduation in 1995, I got really involved with a women’s group in Nigeria. There, I found that women with

disability were constantly being excluded from their programs. This led me to help create the Family-Centered Initiative for Challenged Persons in 2000, for Nigerian women with disabilities. I serve as its director. (Umoh 2004 Nigeria)

Meeting physically continues to be a challenge for some disabled women, although such contact is vital for consciousness raising, sharing information and political planning. Access to the web and internet have provided some with a new route for contact and organizing politically with others, although ensuring web sites are fully accessible to those with visual impairments, and inexpensive enough for general access, continues to be a challenge.

4. Exclusion

As disabled women have developed a social awareness and political consciousness, there are two obvious ‘movements’ they have been drawn towards – the disability and the women’s movements. Yet so many disabled women have stories to tell about the difficulty of trying to raise issues about disabled women within these movements.

‘The issue of women with disabilities is excluded in two areas; there is a great oversight of disabled women’s issues within the women’s movement, they think it is a matter for disability movement, while the disability movement think it is matter for women’s movement. So, we are at crossroad and sometimes I am almost tempted to think that we are beginning to lose our gender because of a disability. (Umoh E. 2009, personal communication; Founder, Executive Director: Family Centered Initiative for Challenged Persons (FACICP) an NGO founded in 2000 in Nigeria, to promote the rights of women and girls with disabilities.)

Because these challenges have had both direct and indirect impacts on disabled women’s movement-building struggles, they are discussed in greater detail in the next sections.

7. The notion of embodiment rejects the idea of a split between the mind and body and is used, rather, to mean ‘the intertwining of mind and body, as well to express a dynamic interplay—a reciprocity—between the whole person and the external world’ (Einstein & Shildrick 2009:295). Embodied difference therefore includes not only physical disability but the whole range of sensory, mental health and intellectual disabilities. The embodied or material self is not simply constructed, as a one off event, but is ‘under construction’ because it is always in a state of flux in relation to people and things around it.

8. UNESCO estimates school enrolment for disabled children at about 2%, and even lower for girls; and that the literacy rates of disabled women and girls is about 1%. Invisibility of disabled girls and their absence from programmes committed to educational equity, the diversity of their requirements and the lack of access facilities and skills within the education sphere, and within the school environment e.g. accessible toilets, all serve to limit disabled girls’ attendance at school. Further, schools are one of the environments within which disabled girls face high levels of violence and sexual abuse, further reducing the likelihood that they will attend. (Rouso 2003)

Disability Politics and the Disability 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 of networking between their members marked the beginnings of the disability movement. For instance, the resistance to 'charitable' approaches saw the establishment of several international DPOs (Hans & Patri 2003:190), whilst the impact of organizations of veterans returning disabled after the Vietnam War in the USA, marked the rise of disabled people organizing together and campaigning for *Rights not Charity*. They drew strength from and were influenced by the rise of feminist, civil rights and anti-racist movements in setting their aims and in refining their tactics.

Giving further impetus to the rise of disabled people organizing and in recognition that this stretched beyond the minority world⁹, was the adoption by the UN General Assembly of The Declaration on the Rights of Disabled Persons, on 9 December 1975. The year 1981 was designated the UN International Year **for the Disabled**, changed after intense lobbying to the International Year **of Disabled People**.¹⁰ Established as a self-advocacy global organizations in 1981, Disabled Peoples International (DPI) 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 Rights Convention. Its mandate states:

Disabled Peoples' International is a network of national organizations or assemblies of disabled people, established to promote human rights of disabled people through full participation, equalization of opportunity and development. (Disabled Peoples' International www.dpi.org)

However, there are several aspects of disability organizing and politics that have worked against disabled women:

1. Male Domination of disabled peoples and of Disability Thinking

Disabled women tend to agree with Indian activist and scholar, Anita Ghai, that 'men and male concerns have dominated the disability movement' (2003: 51). Tom Shakespeare, a UK activist and theorist, suggests that this male bias has various rationales.

Male, instrumental, public, rational and material concerns were seen as more real and more pressing than domestic issues. Looking at some of the macho politics of disabled direct action, and at some of the confrontationalism and anger and bitterness displayed by activists also gives some clues as to

why relationships and intimacy and childrearing may not have been on the agenda. (2006:167).¹¹

The disabled people's movement, run predominantly by men, saw—and many women would argue, continues to see—disabled women's issues as a sideline, not of real relevance to disability. '...Disabled women are a nearly invisible element ...in the general disability movement...' concluded Asha Hans & Annie Patri in their introduction to the collection 'Women, Disability and Identity' (2003:14). And despite their battles around disability, disabled men often hold traditional assumptions about male supremacy and women's role within the home and domestic sphere. Consequently, male leaders do not regard disabled women's rights as worthwhile campaign issues. Even in taking on the fight against the medicalization of disabled peoples lives, they fail to recognize the specific impact on disabled women. And yet the consequences are devastating for many women. As Helen Meekosha argues in a paper on political activism and identity making:

The sphere of reproduction has been even more tightly regulated by society, where [disabled] women have been controlled in relation to their sexual desire, their sexuality, their right to motherhood, and their right to care for their children. The primary vehicle for this control has been the medicalization of the disabled woman, and the construction of an apparatus of surveillance and management under the control of the medical and caring professions, and the state. For instance, the mass sterilization of disabled women without their knowledge or consent has been a regular feature of Australian and US medical services. (1999:5)

Such assaults on disabled women's bodies through sterilization are not restricted to the North, and disabled women have had to resist such insults in countries such as India, Rwanda and Japan¹² where custom and law have dictated that disabled women are subject to a eugenic imperative. Further, there is evidence that men running disabled people's organizations resist women gaining power within and through them. The notion that women may campaign and organize together is disrupted and discouraged by some disabled men. And even without specific intention, societal power dynamics ensure that male leaders predominate—for instance, the majority of the senior officers in disabled people's organizations are male.

2. Class and Racial Biases:

Allied to the lack of gender awareness within disability politics are also profound class and race biases in many countries. Those who occupy leadership positions tend to be middle-class, educated, and from the dominant racial / ethnic groups, with the advantages this positioning brings and, too often, little awareness of their privilege. In India, for example, Anita Ghai says,

'In the fights for visibility in society, inclusion in the census, discounted rates in hotels, and other such contexts, one can clearly see the middle class, male-centric concerns that are guiding the development of the disability movement in India. (2003:51)

9. 'Minority world' (also termed the 'developed world' or 'the North') is used to indicate the proportion of the world which, whilst occupied by a smaller proportion of the population, utilises the largest share of the earth's resources. 'The majority world' (also termed the 'developing world' or 'the South') is used to indicate the converse, the share of the world with the largest proportion of the population which utilises a smaller portion of the resources available.

10. Rehabilitation International, a large charitable organization for disabled people, planned to publish its own charter, aiming to 'ensure the fullest possible integration of an equal participation by disabled people in all aspects of the life of their communities' (Oliver 1990: 116). A group of disabled people proposed to RI that it should become an organization run and controlled by disabled people, rather than one run by others for them. Unfortunately, RI saw such participation as being for others, but not applying to them as an organization. However, their rejection of a change in control led to the setting up of Disabled Peoples' International.

11. Drawing upon an 'ideology of masculinity' (Brittan & Maynard 1984) the British disability movement worked towards a social model of disability that failed to recognize the oppression that limited disabled women. There was no recognition of the ways in which their opportunity to fill productive roles was circumscribed nor of their

frequent exclusion from the traditional female roles of caring and mothering nor of the associated direct physical insults disabled women faced, e.g. though hysterectomy and sexual abuse. But this was a problem that went wider than the British disability movement. As more disabled peoples have risen in the majority world, in the decades since the UN Year of disabled people, the range of concerns addressed has widened, with a change of focus to reflect the poverty, the enormous access problems and the lack of employment that act as impassable barriers for many disabled people. But these issues, the prejudice and oppression faced by disabled peoples and their lack of rights have almost universally, in the first instance, been seen through a male lens.

12. A new law in Rwanda in 2009 proposes the sterilization of people who are mentally disabled. Human Rights Watch has mounted a campaign against it. (Kagumire 2009) In Japan, disabled women are fighting the Eugenic Protection Law which tries to prohibit the birth of children with disabilities through selective abortion. People with disabilities are sometimes forced to undergo sterilization to prevent them from having children. <http://www.mnddc.org/parallels2/one/video08/women.html>

The social model similarly displayed a lack of attention to other aspects of *intersectional* oppression¹³. Some organizations of black disabled people argued that institutional racism had to be understood as an aspect of discrimination that worked alongside disability discrimination such that,

...the able-bodied have now become white and the disabled people black (Confederation of Indian Organisations 1987:2)

The analysis commonly proposed, as with gender, was that of double or multiple discrimination. This has been widely critiqued for its 'additive' approach, meaning the idea that oppressions operate individually and can then be added up as "a + b + c". The recognition of the interdependence and interweaving of different forms of oppression that underlies the idea of *intersectionality* led to closer attention within activist groups to the differential impact of disability upon, for example, people of different ethnicities, ages and sexualities, amongst others. Huhana Hickey argues:

There are well-established disability movements in New Zealand. The problem with them is they do not easily embrace the diversity that exists within our disability community. Maori, Pacific Island, Migrant and GLBTTI¹⁴ peoples with disabilities are not easily embraced..... Basically the leaders in the disability movement are predominantly white with a small number of "other" identities within their communities. This is what needs to seriously develop if the disability community is to be relevant to all in this country. The problem we have is they are the predominant voices and influences of disability policy affecting everyone whether it is good or bad policy. (2010)

With the rise in strength of disabled peoples across the globe, new critiques of the implicit racism within the international disability movement have arisen. Helen Meekosha, an Australian based academic and activist, produced a powerful critique of disability studies and of its exclusion of Southern activists and academics at the 2008 Disability Studies Conference in Lancaster, UK. Although the focus of her questions was disability studies, they immense relevance and implications for any transnational movement:

- *The Major* question facing disability studies is how can we do it better? How do we include the Global South?
- *How do we* develop a Southern theory of disability that questions the implicit values and concepts of the urban / northern hemisphere?
- *Need to research* the processes of colonialism and neo-colonialism — the making of new social orders that included processes of disablement
- *How do we address* colonialism in scholarship?
- *Importance of acknowledging* work from the Global South and the colonized world (Meekosha 2008)

3. A seat at the policy table:

Campaigning by disabled people has led to the establishment of the most rapidly-negotiated and agreed International Convention that the UN has produced so far – viz., the UN Convention on the

Rights of Persons with Disabilities — and helped pull disabled people together in what could be termed a transnational disabled people's movement. Although there was a clear focus on reaching accord about disabled peoples rights, underlying this was disabled people's clear understanding of the necessity of ensuring that they were present and fully involved in every stage of the debates and decisions about the CRPD. The slogan that emerged and became a global rallying cry was '*Nothing About Us Without Us*,' which served to create the benchmark to which disabled people will now attempt to hold their country's politicians, judiciaries and civil society accountable. This process also resulted in a global cadre of skilled and politically motivated disabled people prepared to take forward the struggle locally. Amongst other initiatives, many of them will be involved in monitoring the implementation of the CRPD and of training others, raising awareness of the new rights that disabled people now have and of the extent to which these are being asserted and enforced within those countries that have ratified the Convention.¹⁵ It is yet very early days in assessing what sort of impact the CRPD will have upon disability rights and the disability movement, with the first reports just beginning to come in.

Disability in Feminist Politics and the Women's Movement

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. Disabled women have been excluded by most women's movements—through omission if not commission—and have struggled to find their space in feminism. Until recently, the non-disabled women who were prepared to stand alongside disabled women to campaign, research, theorize, protest, or participate in other ways in disabled women's politics, were rare exceptions. While feminist ideas were focussed around women's identity in the 1970s and 80s, feminists rarely addressed the issues of disabled women, and if they did, tended not to see them as having a group

identity, but rather as facing a disparate range of impairments—blindness, deafness, wheelchair-bound, etc—'tragedies' that had to be dealt with individually.

Given the male domination of the disability movement, disabled women who were politically active often drew upon feminism to aid their analysis of disability oppression. However, this was not a two-way process. Within both theory and research, disabled women noted their exclusion:

(T)he growing insistence of women with physical, sensory, or cognitive impairments that they are marginalized within feminist theory to an extent little different from how patriarchal society devalues them. (Silvers 1998: 82)

..both disability and feminist studies and research had left out the issues of gender related to disability...We believe these women are overlooked, disregarded and neglected as a group within majoritarian feminist strategies' (Hans & Patri, 2003:9,14).

Non-disabled feminists have also been wary of the image—of dependence, helplessness, vulnerability—that they fear disabled women might present, as they struggled to project a picture of women as strong, capable, and in control. In one of the earliest analyses of feminism's neglect of disabled women, Fine and Asch argue:

The popular view of women with disabilities has been one mixed with repugnance. Perceiving disabled women as childlike, helpless and victimized, non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent and appealing female icons. (Fine and Asch 1988:4)

Even when disabled women were included in the women's movement, it was more for the sake of political appearances, rather than through any understanding of or commitment to their issues—for instance, disabled women would be called on at the last moment to sit in front for a group photo, acting as a token or mascot. Instead of sisterhood, non-disabled women in high-income countries were ready to offer 'support' to disabled women around what were perceived as issues of care and

13. The theory of intersectionality grew out of feminist's growing awareness of the multiple different levels upon which women face oppression and of how the differing aspects of gender discrimination are interwoven and interact, simultaneously, with aspects of race, class, sexuality, age, and of course disability, amongst others. These axes of oppression act in materially, culturally and socially specific ways and a major challenge of intersectionality is in analyzing how the different dimensions impact upon each other to produce specific patterns of privilege, exclusion and discrimination. However, one of the strengths of intersectional theory is that it offers an approach to rights which embraces the prospect that, rather than being played off against each other as a zero sum game, different rights can be simultaneously addressed. (McCall 2005, Emmett & Alant 2006)

14. GLBTTI is meant to mean gay, lesbian, bisexual, transgendered, takaatapui and intersexed peoples. Takaatapui is the Maori term for those who sit outside the spectrum of what is considered straight and is more inclusive of all genders, not so divisive as some sexual identities can be. (Hickey H. personal communication 2010)

15. Up to early April 2010, 144 UN members had signed the UNCRPD and 85 had ratified it.

welfare. Much early feminist discussion was around the 'care' that disabled women would require, with the analysis focusing on the world of the 'carer' rather than on the disabled woman. They remained concerned at the impact that 'assistance' for disabled women had upon the lives of women working within the care sector, whether in people's homes or in residential institutions (Thomas 1993).

Jenny Morris critiqued the work of non-disabled feminists whose research focused on the excess care burdens placed on informal carers such as family members and the impact of UK government policies on community care. She suggested that in failing to identify with either disabled women or older women *receiving* care, or with the women *providing* care (often family members or those in low-wage caring roles, working class women, students and immigrants), both groups are presented as 'Other'. Portrayed as filling gender stereotypical positions, Morris argued that it was rare to find non-disabled feminists challenging these negative stereotypical depictions of disabled women's position within society (Morris 1991). Thus despite disabled women's desire to be a part of women's movements, most non-disabled women saw no necessity to campaign and advocate together with them around the issues disabled women faced.

These dynamics are ironic, given that from the earliest days of modern feminism – from Simone de Beauvoir's *The Second Sex* onwards – there was a feminist theoretical understanding of *otherness* and a challenge to the notion of biology as a *natural* basis for analyzing the world. Feminist theory has always deemed the body as a vital point of analysis and action, from the early explorations of women's health activists into the medicalization of women's bodies, to the development of theory about the role of women's bodies in structuring their place within society, culture and politics. The development of identity politics – not only in relation to women but further in understanding the politics of sexuality and race – served to help feminists see the body not as "natural" but rather as a constructed idea. But while these insights did not lead to feminism embracing disability within their analysis, the argument that biology was constituted through socio-cultural forces was taken up by disabled feminists in addressing the place of impairments in disability theory. It also provided a connecting point to feminist scholars theorizing the body, and issues of experience, meaning and identity.

So while the majority of those who took up and theorized the relevance of these issues to disability were disabled women, there were a few feminist activists who recognized that it was important to work alongside disabled women. Drawing on the example of Black feminism, Lloyd (1992) wrote of the simultaneity of oppression faced by disabled women—of gender and of disability. Based on radical feminists' belief that the personal is political, she argued for the need to integrate the experiences faced by disabled women, so that their concerns are seen as 'central to both disability and feminist agendas' (p219), thus challenging the difficulties of fragmentation and marginalization that occur when disabled women were pulled between two different movements. Most importantly, Lloyd argued that in working towards societal change, it was vital that the struggle for recognition and support of disabled women should not be left to disabled women:

In order that 'disabled people' should cease to mean, effectively, 'disabled men', non-disabled feminists must lend their strength to the naming of women's experience within any analysis of disability. For 'women' to cease to mean, effectively, 'non-disabled women' disabled men must lend their strength to the naming of disability within feminism (Lloyd 1992:219-20).

However, non-disabled women found it difficult to identify a way to begin to do this in practice. They invited disabled women to meetings but without ensuring that access conditions were fully met – or without providing information on access. They failed to recognize that disabled women had their own analysis of feminist issues that differed from mainstream views. And they failed to build and sustain partnerships with disabled women. (Personal Communication, 2005, India).

Apart from some rare 'special' initiatives, feminist life across the globe went on much as usual, with inaccessible or distant meeting halls and venues, lack of appropriately accessible information on issues of major concern to disabled women (such as violence), and lack of access to support services such as women's refuges and other safe spaces. Underlying this lack of engagement with disabled women was an atmosphere of anxiety, discomfort, embarrassment and fear. (Shildrick 2007)

....the fact is that most times we are always forgotten in the mainstream of activities. We simply

do not have any place within such a movement, except [when] they are reminded [about us]. (Umoh 2007: Nigeria)

By the early years of the new millennium, however, women's activists, especially those working on health issues in low-income countries, were beginning to explore political alliances with disabled women. The rise and spread of HIV/AIDS, across Africa in the first instance; the use of the

technologies of medicine to abort both female and disabled children in a new eugenic impulse, especially affecting India and the South Asian countries; the widespread violence against women, domestic, sexual and militarized; the resurgence of population policies against women's struggle for reproductive and sexual health rights – each of these issues, in their differing ways, placed disabled women firmly in the limelight.

Box 4: Moving from ignorance to partnership – Indian feminists working with Disabled women

A group of Indian feminist activists agreed to take on the role of organizing the 10th International Women's Health Meeting (IWHM), to be held in New Delhi, India in 2005. This is a non-affiliated initiative that takes place every 2-4 years, and draws together up to 1,000 women's health activists and feminist scholars from across the globe. The group were committed from the beginning to including disabled women in the meeting, both in terms of ideas, by addressing disability in the presentations, and in practice, by ensuring it was truly accessible to disabled women. The presence of disabled women in its organizing committees served to highlight issues to be addressed. Plenary presentations by disabled women and papers and posters by disabled and non-disabled activists about mental health, disabled girls' access to education, accidents from mining, the effects of conflict and more, ensured that disability wove through the agenda. In practical terms, the long negotiations with accommodation and venue providers that had attempted to ensure premises were accessible were not completely successful at turning round the partially inaccessible spaces. But there was a noticeable representation of disabled women at the IWHM, disability took a prominent place on the organizers' agenda, and it made an impact on the conference in general.

Activist organisations have also taken disability on board. One example is TARSHI (www.tarshi.com), a Delhi-based group working around sexuality, sexual health and rights, which has arranged meetings with disabled people and with parent-carers to discuss specific aspects of sexuality and concerns disabled people and carers have e.g. masturbation, pleasure, marriage. They have initiated the audio translation of basic books for young people on adolescent sexuality to ensure they are accessible to deaf people. Just completed in early 2010 is a working paper, *Sexuality and Disability in the Indian Context*¹⁶.

The Indian Academe has also moved on. Although Disability Studies is not yet established as a separate discipline, disability has found a place within some disciplines and within feminist spaces e.g. the Centre for Women's Development Studies, New Delhi, India has appointed a disabled researcher who has produced both journal issues and books on women and disability (Addlakha 2008, 2009) thus strengthening the knowledge base about disabled women in India and offering activist scholars a chance to bring their concerns to a wider feminist audience.

Anita Ghai, feminist scholar and activist, and psychology lecturer has also found herself in a leading elected role. 'I am a part of the IAWS Indian Association of Women Studies. It took me some time to get in as a disabled person though at times it is more tokenism. However I am the president, so it isn't as if I will not be able to include disability issues.' (Anita Ghai, Personal Communication, 2009)

16. http://www.tarshi.net/publications/publications_reports_papers.asp

In the new millennium, there have also been signs that non-disabled women's research and writing is increasingly taking issues of disability on board. The growth of Women's/Gender and Cultural Studies as inter-disciplinary fields has led to many students being introduced to the thinking of disabled feminist academics. As the feminist activists of the future, involved not just in thinking and writing but in actively campaigning against women's oppression, disability has been raised as both an intellectual and a political issue for these students.

They, in turn, have taken up new areas of interest e.g. new genetics and eugenics, cyborgs¹⁷, new health technologies, intersectional identities, welfare, liberalization and globalization, and have served to influence the growing recognition of disability as an important focus of analysis for young feminist activist scholars. Within the aspects of identity that so frequently appear in feminist writing – gender, race, class, age, etc. — disability is at last emerging from the 'etc' and is taking its own place in the list.

Box 5: From scholarship to activism

More recent feminist writing on disability and assistance in the context of a globalizing world introduces a clear analysis of the dilemmas faced by poor women from the majority world. Many are leaving behind family, children, home and culture to act as assistants for disabled people, for elders, for those in residential homes in the minority world. The analysis of global inequity, poverty and the breaking down of international borders in the face of increasing privatization of welfare services demonstrates how majority world women are forced to migrate to ensure their families' economic survival. Again, this is often analysed as a one-sided equation, with no attention paid to the existence of those receiving assistance except by those with a long history of disabled scholarship and activism (Shildrick & Price 2005, Rioux 2009). But activists have fought to show that there are points of common interest, battles that can be jointly fought by assistance receivers and providers, as an alliance they formed in the USA demonstrated (Robinson M. Personal communication, 2005, USA Disability Activist.)

Disabled Women's Organizing and Movement Building

To organize and campaign for their rights, disabled women face all the difficulties that non-disabled women face, but mediated by disability. Yet change is in the air, locally, nationally, and globally. Day by day, disabled women fight to maintain their links to family, to survive abuse, to hold down jobs, to move through a world that is strewn with barriers – both physical and attitudinal, to manage the difficulties, discomfort and pain that can accompany some disabilities. 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. 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.

17. Cyborgs are organisms, not necessarily human, with both natural and artificial or cybernetic systems. Within disability culture, they have been explored as representing people with prosthetic devices. The potential of cyborgs has been addressed in the fields of medicine, sport, technology and art, amongst others.

1. Establishing connections

Disabled women's organizing challenges and strategies are in many ways similar to other feminist movement-building efforts. The differences arise in the details of how problems affect disabled women's lives, in the wider array of strategies they have to employ, and in the specific requirements they have to negotiate to mediate the barriers of disability. They also lie in the ways access and assistance measures have to be addressed at every level, to ensure that as disabled women they are not excluded from meeting and communicating, from wider debates and organizing spaces, from obtaining information, or from meeting political or legal representatives. Linked to access is the need for appropriate technology and aids, designed to meet individual disabled women's requirements. And these access considerations have to be thought

about *constantly* while building their campaigns, mirroring issues that will ultimately need to be addressed by all societies as their populations age.

Organizations of disabled women established at a national level have played a vital role in supporting the strategic and practical interests of disabled women across their countries. As coalitions, pulling together smaller local disabled women organizations, they offer potential capacity to undertake broader initiatives, drawing on the skills and experience of the local groups and simultaneously offering contacts, research and insights gained from negotiating with government officials, funding organizations, and international bodies' representatives at national level. However, many start small and are working in a context where there is limited if any state support for disabled people, never mind a recognition that disabled women might face particular issues of concern.

Box 6 : Formation of Union nationale des femmes handicapées de Côte d'Ivoire

The National Union of Handicapped Women of Cote d'Ivoire (Union Nationale des Femmes Handicapées de Côte d'Ivoire) is an NGO started in 1996, by a group of women who broke away from a mixed disabled peoples organizations. Anne-Cécile Konan the disabled president of the Union, says: "Society has to listen to us...we're not going to turn back...." Another member, Fatima Kone, insists "Even if we don't get benefits, what's important to us is our rights." Working initially without any state support, the members were concerned about a range of issues – employment, income, education – but particularly about sexuality, reproductive health and the absence of health care for disabled women (Zamblé 2006). By 2009, the disabled women's Union had grown in stature, presenting awards to NGOs for high quality work with disabled women and girls. They were also making an insistent attack upon the lack of recognition of their place in the electoral system. They had taken up a campaign to ensure that disabled women knew their entitlement to vote, how to do it, and that booths and voting papers were accessible for all disabled women. (Kei 2009)

Alongside such independent disabled women's organizations (DWOs) at national level, there are also a large number of disabled womens groups that are affiliated to larger disabled peoples organizations. For example, Disabled People International (DPI), one of the largest self-advocacy groups, functions at national, regional and international level, and it has women's groupings at each of these, running with more success in some countries/regions than in others. Their success depends in part upon the degree of support or opposition to their indepen-

dent functioning shown by the disabled men active locally within the organization. The following exchange in the context of Disabled People International (Australia) is typical of some of the resistance disabled women face when attempting to create solidarity with other women:

'You're not going to find it easy getting on with the other DPI (A) women—they're serious, don't say much, don't believe in women's lib, and are definitely not fun people', said an apparently

experienced male member to me in 1964 when I joined DPI (A). His mixed message took me back to the days when I kept my good school marks hidden from boyfriends..... But somehow I wasn't seen by this [man], a close friend, as a feminist. My questions to myself were 'Am I still covering up my skills, knowledge, and experiences so I can be part of the DPI(A) boys' team? Aren't women's issues really people issues?

With great trepidation I approached these awful women of DPI(A), one by one, and found each to be unique, with amazing humour, insightful and very caring of all people around them. The informal networking of DPI(A) women helped me meet many fantastic people. Women with disabilities living in poverty while raising happy children, women who have been institutionally abused still able to look at the needs of carers, women who have meekly but persistently nibbled away at transport agencies until accessible transport has been developed, women coping somehow with increasing disabilities while giving most of their energies to unpaid disability activism, and articulate and academic women whose writings or speeches don't seem to be widely recognised yet within the disability movement. (Cooper 1992)

Advocacy and awareness raising, particularly in relation to UN Rights agenda, are an important part of strengthening disabled women's networks. Often disabled peoples will send out only men to conduct advocacy work, thereby reinforcing many of the negative perceptions about disabled women and limiting their potential for participation and access to empowerment opportunities. But where women have developed the skills and confidence to advocate and lobby, major progress can be made.

The Network of South Asian Women with Disabilities is one of a burgeoning number of groups that are being formed by disabled women to try and establish more clearly what the situation of disabled women is, for data is markedly lacking and, crucially, to offer disabled women support and training in leadership and advocacy skills, operating within a rights based framework. Women from Bangladesh, India, Nepal, Sri Lanka, Bhutan, Afghanistan and the Maldives came together for workshops during 2008 and 2009. As Kuhu Das, the Director, Association of Women with Disabilities (India) said of the project,

Currently our rights are not understood or heard. We need to mobilize our girls and women to take

the challenge and responsibility to make our presence felt. A new generation of leaders is essential to make change happen. (2007)

Working on the issues raised above, national level disabled women organizations have recognized the importance of lobbying work on relevant international initiatives and strategies such as The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), human rights and the Convention on the Rights of Persons with Disabilities (CRPD), gender mainstreaming and the Millennium Development Goals (MDGs), all of which are or should be integrated into planning at a national level. They have a role to play in encouraging different government departments to adopt a disability-aware approach in their work programmes. Hellen Asamo of National Union of Women with Disabilities Uganda (NUWODU) addresses some of the challenges faced by disabled women and their organizations in ensuring that equality strategies such as gender mainstreaming are made relevant to and enhance equality for disabled women, creating the space for them to gain skills and confidence, and challenging prejudice and discrimination:

The biggest challenge for women with disabilities in Uganda is making disability-specific gender concerns central to policy formulation, legislation, resource allocations, and planning and monitoring of programmes. Surprisingly even in the disability movement itself, nothing much has been achieved in regard to gender mainstreaming into the movement's programmes. Furthermore, NUWODU is faced with a challenge of developing a knowledge base on the linkages between disability-specific gender equality and the substantive issues and processes. This would not be very difficult if funds were secured but there is a tendency of both government and donors not considering disability-specific gender equality issues as a priority on their agenda. ...

2. Strategies and Issues

Analyzing disabled women's campaigns, the most recurrent strategies are exemplified by initiatives proposed by disabled women in Papua New Guinea in 2006, viz.,

- Building self-esteem, leadership and capacity

- Advocacy
- Coalition building – with disabled and non-disabled women
- Access requirements: physical, especially to transport, to government services – health, education, local council, judicial
- Access to information: format, style, distribution of info; individual communication
- Development of assistance aids and technology
- Training in disability equality for public sector staff (and all those with whom the public comes into contact) e.g. health workers, development workers, teachers, civil servants
- Community rehabilitation
- Consultation at community level
- Quotas for government departments
- Bringing about legal change and protection
- Research

(Papua New Guinea National Network of Women with Disabilities, Statement, 17–19 July 2006)

Issues of major concern include (in no particular order):

- Sexuality, sexual and reproductive health,
- Violence, particularly sexual violence, in domestic, institutional, educational and other contexts
- Inclusive education for girls and women
- Transport
- Equal rights in women's employment, earnings and income-generation
- Housing
- Financing and public-private service provision
- Euthanasia, eugenics and bioethics

(Radtke 2007)

3. Challenges to movement building

Local level challenges:

Local level initiatives by disabled women, whilst being the most vital in directly offering a political space for action, can sometimes be the hardest

of all to form. This is the level at which they are often the most isolated, knowing no-one else who identifies as disabled or who has a political awareness of how it might be possible to challenge and change their situation. At this individual level, poverty's impact strikes disabled women particularly hard when they are in the period of trying to meet with other disabled women for the first time. Without the supportive structure of an organisation or movement behind them, they have few if any resources to draw upon and although there is much they can achieve without financial support, some difficulties, particularly access ones, need money to metaphorically and practically open doors. Many disabled women also have to struggle with minimal literacy and lack of access to education and, together with limits on familial support, these affect self esteem, job opportunities and the ability to navigate the social world. All of these are factors that can contribute to the difficulties of organizing and raising awareness.

Since girls are usually not sent to school in some parts of Nigeria, the education of a disabled girl is simply seen as an even greater waste of time and resources. So naturally, girls with disabilities bear a major share of the burden of poverty; lacking an education, they can't get jobs. Most times, a girl with a disability is seen as a social embarrassment to her family because she is not seen as marriageable. She is often considered unable to be a 'good wife' or a 'good mother' and therefore may be forced to remain in her paternal home for the rest of her life.

This, in turn, is a source of shame for the family, which leads the family to discriminate against her and hide her away from public view. She has no place in society. In addition, she usually has a poor self image because of the emphasis society places on women's physical beauty. Meanwhile, the access needs of girls with disabilities are being ignored. For instance, reproductive health information is not produced in a format accessible to blind girls (e.g. Braille). (Umoh 2004)

Over and above the social limitations facing disabled women, **physical and environmental concerns** play a large role in many disabled women's lives. In rural areas, lack of accessible transport, combined with poverty and prejudice, can result in disabled women being unable to leave their homes. Bumpy, muddy, potentially waterlogged roads serviced by unhelpful transport providers may act as impassable

obstacles. Life may be no easier in towns and cities. In La Paz, Bolivia, disabled people found:

The area with greatest isolation and lack of employment opportunities for a person with disabilities is the city of La Paz, due to the type of terrain and the geographical location (altitude, cobblestone streets, steep hills). The lack of accessibility to transportation is striking. (COBOPDI & DRPI 2009 p70)

It is not just transport, but overall communication strategies that can act as a major challenge to ongoing initiatives amongst disabled women. To connect, they have to take into account distance, language (including Sign), phone and postal connections and web access. They also want contacts to be made available in appropriate form for deaf and visually impaired women and women with intellectual disabilities, raising the need for interpreters, audio-describers, alternative font layouts of written material and other expensive and time consuming initiatives.

National and International hurdles:

At the national and international level, disabled women tend to look to their aware and politically motivated peers to more successfully connect and project their concerns. Yet the additional costs of access requirements, the extra energy and personal resources disabled women have to deploy, greatly affects the pace of growth of cross-national formations.

A good example is the African Network of Women with Disabilities (ANWWD). The Network notes the growing desire and awareness amongst disabled women in pockets across the continent to meet, share ideas and campaign. A meeting in Saly, Senegal in 2005 saw 44 women from 17 countries come together. There was great enthusiasm and a really strong drive to develop an ongoing network to address the many problems they

perceived in common as disabled women. A small group of 6 later met as an interim steering committee to develop a constitution, objectives and mission statement. However, its further development has been halting, taking place in fits and starts. In 2007 there was an appeal for more members:

Unfortunately, the work of the network has been slow and cumbersome as a result of a weak membership structure and steering group. All of us who have been involved see the network as a crucial forum where women with disabilities work together to ensure that issues specific to them are recognized and considered. However, without a stronger and more vibrant membership and leadership, the NAWWD will not be able to empower women with disabilities to exercise their rights and positively influence their life situation. (Samuels 2007)

So despite being held up as a sign of hope and progress by a number of African disabled women, the Network's development is an exemplar of the struggles of disabled women organizations to become established.¹⁸ Similarly, it has taken disabled women in the Asia and Pacific region a long time to come together. The regional UN Economic and Social Commission (UNESCAP) had declared 1993–2002 the Decade for Disabled People, but disabled women had been singularly uninvolved in these activities. The end of the decade in 2002 saw the decision to formalize a network of disabled people's organizations with a recommendation that disabled women should be a priority.

In the past, it has been difficult to mobilize WWDs [women with disabilities] in the Asia Pacific region in the same manner as WWDs in Europe or the United States. We would like to change this paradigm by using the network to support each other's activities. With good collaboration and communication, the network will be a success. (DPI 2005)

As some researchers have observed, 'Many disabled people's organizations have low capacity and face governance challenges, at least partly due to resource constraints and insufficient capacity of

18. In September 2009 the Secretariat of the African Decade of Persons with Disabilities (SAdisabled peopleD) commissioned Disability Action Research Team (DART) and CBR Education & Training for Empowerment (CREATE) to strengthen the Network of African Women with Disabilities (NAWWD). The brief included development of this e-library. <http://disabledfeminists.com/2010/03/12/quickpress-e-library-for-women-with-disabilities-in-africa/>

volunteers' (DFID, 2005). And even larger organisations like DPI face difficulties. But despite the challenges, disabled women in some contexts have been able to build strong organisations.

4. From Organizations to Movements

Some disabled women's groups have evolved over time into established, committed, campaigning groups with clear political agendas and constituencies, and so can probably be termed movements, though they may still call themselves organizations or networks. Both Disabled Women's Network Ontario (DAWN Ontario) and Women with Disabilities Australia (WWDA) are examples

of emerging movements, organizations, and networks directed and organized by disabled women, and committed to developing women's leadership. They have launched a number of campaigns, noticeably violence against disabled women, as well as intervening in issues such as education, health, sexuality, and parenting amongst others. They have also produced resources for disabled women, campaigned and consulted on potential legal improvements, worked to influence government policy, and built coalitions with other groups of both disabled and non-disabled people. Some, such as DAWN-Ontario, are also avowedly feminist in ideology, principles, and agenda, as can be seen from their description of themselves on their website:

Box 7: DAWN Ontario: Who we are¹⁹

DAWN Ontario is a progressive, volunteer-driven, feminist organization promoting social justice, human rights and the advancement of equality rights through education, research, advocacy, coalition-building, resource development, and information technology.

Our mission is to generate knowledge, information and skills to advance the inclusion, citizenship, and equality rights of women and girls with disabilities.

We work to illuminate the causes and multidimensional consequences of the growing inequality of wealth, income, power & opportunity in Canada; and to move this critical national problem onto the front burner of Canadian politics and public discourse.

We seek to bring forward the distinctive perspective of women and girls with disabilities in the campaign for full equality both for women, and for persons with disabilities.

We do this by facilitating ongoing debates on fundamental and provocative issues as well as by building the individual and organizational capacities of those working for women's empowerment and social justice

Cross-sectoral networks are our strength— We believe that powerful, proactive networks can create change: We work at the grassroots level to generate knowledge, information and skills to secure the inclusion of women and girls with disabilities.

DAWN-Ontario is an exciting example of what can be achieved by a disabled women's movement when it broadens its agenda to non-disability issues, and works in alliance with a broader women's movement. In response to the growing

anti-feminist right wing politics within Canada in 2006-07, DAWN-Ontario became very involved in the campaign against funding cuts and against the anti-feminist voices that advocate them (DAWN www.dawnontario.ca/). For disabled women in the Ontario

19. <http://dawn.thot.net/>

province, the Network has been a source of support, hope and ongoing political challenge to the inequality that affects disabled girls and women. Their hope is gradually to spread their networking and organizing more globally.

The WWD Australia's movement agenda covers a range of disabled women's rights: preventing involuntary sterilization of disabled women, parenting, homelessness, health, employment, eugenics, and web-access – all of which have an immediate and very real impact on disabled women's lives. Some of their strongest work has been around violence against disabled women. They have collected and collated information, aware that disabled women face violence at approximately twice the rate of their non-disabled peers. Working with local disabled women's organizations and other disabled peoples, they have produced a Resource Manual under the supervision of a group of disabled women, which incorporates work on increasing access to Women's Refuges, a booklet on facing domestic violence for disabled women, a service directory, the stories and artwork of disabled women affected by violence, and analysis of global research papers and reports (WWDA 2007). The Manual was produced in a variety of formats with the aim that it would be accessible to ALL women, and information about it was distributed very widely, through disability, government, women's and other networks.

5. Global movement building

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. A number of disabled people organizations, including representatives from international organizations for deaf and blind women, and from Disabled People International, formed a cross-national women and disability network. 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 for disabled women who

would participate in the main conference²⁰. They lobbied for a number of areas of policy concern that were eventually accepted as part of the Declaration and Platform for Action. In recognizing that women faced specific barriers to equality and full participation due to discriminatory factors which included disability, the Declaration established a basis for action which responded to disabled women's specific concerns. There were commitments to promote, amongst others:

- Employment of women with disabilities and reduction of discrimination in the work situation
- The reduction of illiteracy amongst disabled women
- The promotion of health services supportive of disabled women
- Removal of barriers in Social services for disabled women
- A drive to reduce violence against disabled women
- The abolition of negative stereotyping of disabled women by the media
- The acceptance of the Standard rules of the Equalization for Persons with disabilities (UN Enable 2003-04).

Beijing marked a watershed 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). It was a major step forward in disabled women's organizing and visibility at the international level, and most importantly, laid the ground for a growing group of disabled women activists who would become involved in campaigning about the rights for women to be established through the CRPD. But this has been a slow and difficult journey: 'Women with disabilities did not get on the United Nations development agenda overnight,' Mathiason (2003-4) argues in a detailed history of disabled women's struggles to become a recognized group within UN processes. Nevertheless,

.....the truth is that women with disabilities are beginning to see the need to organize themselves

20. Their meeting is recorded in a powerful video at <http://www.mnddc.org/parallels2/one/video08/women.html>

more formally to form a strong network around the world to improve the lives of women with disability globally. (Umoh E. 2009, personal communication; Founder, Executive Director: Family Centered Initiative for Challenged Persons (FACICP) an NGO founded in 2000 in Nigeria, to promote the rights of women and girls with disabilities.)

However, it was the swell of activity and awareness that has been raised by the planning and campaigning towards the establishment of the UN Convention on the Rights of Persons with Disabilities (CRPD) that led to greater clarity about the breadth of possibilities for disabled women to build movements within and across countries within the majority world. Convention activities have had a big impact upon the contacts that women have been able to make with each other and have led to wide ranging discussions upon the specific problems disabled women face, over and above those faced by all disabled people²¹.

6. Connecting and Mobilizing on and through the Web

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 mentioned earlier—challenges faced in travelling, with physical access, and communicating. Disabled women are slowly discovering that the net can act for them as a political tool, enabling contact, building communities, and enhancing political action. Rebecca Finn, a tutor from the USA says:

Whether it is awareness raising, providing/connecting resources, or pushing for political activism, online provides many free and effective tools. Who knows, one might even spark an international effort..! To me, this is a route to building community and a critical mass of informed and passionate citizens. Furthermore, it can also do a lot to ease isolation. (2010)

One of the first virtual networks to establish itself followed the Beijing Conference in 1995. Some disabled women participants at Beijing set up the disabled women's web-based network, *d-WILD*, and soon drew in many other members (currently about 91). Today, we find a growing web of disabled women's net-based groups. The characteristics they hold in common seem to be that they have a clear political identity as women and disabled, and that they are committed to ease of use by **all** disabled women—so for example, the user interface will ensure ease of access to and for women with visual impairment. The web is used in multiple ways:

- For general discussion and information sharing
- To address and accumulate knowledge about issues faced by disabled women e.g. INWWD²² is currently addressing violence and its impact on disabled women's lives
- To prepare and comment on reports
- To petition the UN and other international/national bodies
- To build awareness and solidarity and to run campaigns
- To offer personal support

Some are locally based – such as the group linked to DAWN-Ontario—whilst others are nation-wide, such as WWD Australia, or regional, such as the Network of South Asian Women with Disabilities—but because of their web-base, they all have the potential to be global. The degree to which they control membership varies: some welcome anyone committed to rights for disabled women, whilst others screen members or are open only to those who identify as disabled women. This latter is a difficult process on the internet, since people can and do change identities on-line.

These networks have the potential to build a powerful set of links between different groups of disabled women. However, there are the inevitable pitfalls that befall such groups, some of which are

21. Much of the official debate on the Convention is documented on Women Watch run by the UN (<http://www.un.org/womenwatch/enable/index.html#convention>). From across the globe, disabled women were involved in debates about the content and structure of the developing Convention to protect the rights of disabled people.

22. International Network of WWD at <http://groups.yahoo.com/group/inwwd/>

enhanced because of the nature of online communication: personal misunderstandings and disagreement; global and political differences over terminology, attitudes and forms of expression; the silencing and eventual withdrawal of those members who are not speakers of the primary language used by the group; the dominance by a small number of individuals who have met and worked together politically, whose confidence and familiarity with issues and with each other can intimidate or silence newcomers. Many of these are issues that any online organizing process must confront, but within the context of users with disabilities, a whole new set of social norms and practices have to be developed and followed. This is a process that is currently taking place, tentatively and with scope for much new learning.

Such web groups cannot be the answer for all disabled women, so many of whom must struggle with poverty and non-literacy – but they can serve as a powerful tool to share ideas, experience and skills, to build solidarity and to engender support and input to campaigns for disabled women's rights locally, nationally and globally.

Looking to the Future: disabled women's movement building

Building on discussion with politically active disabled and non-disabled women from across the globe, I have tried to draw out some of the issues that disabled women face in trying to build Disabled Women's Movements. There is already a substantial and highly organized group of disabled women who have influenced the structure and form of the CRPD, ensuring that women were included and their rights addressed in a clear and comprehensive manner. This task has been vital for establishing disabled women's rights. Yet, disabled women's movements cannot depend

only upon links to major international bodies like the UN. Any disabled women's movement has to grow from its base, from our diversity as women, from the variety and creativity of our widely differing lives, through the embodied changes we face and from the responses and reactions of both those who work with us and those who resist the changes we seek. The constituencies on which we build, 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. I wonder whether we are coming to a time when the notion of living with firmly fixed identities will begin to open out, as we become more fluid in ourselves, more inclusive in our campaigning. Our lives as disabled women can grow as, stronger in ourselves, we look to strengthen coalitions with a diversity of others, groups that can open up new spaces – with those campaigning around climate change; those who address militarization; those working to end violence against women; with those who struggle for sexual rights and sexual health. We need to acknowledge the impact of these and of much else upon the lives of women, already disabled and potentially disabled in the time to come²³. I look to a time of widespread recognition of the place of disabled people, 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. As Sian Maseko of Zimbabwe says:

I think the most effective movements are those that acknowledge and encourage diversity and celebrate difference and yet are able to work together towards one particular goal. movements are crucial and I think that movement-building is key to the realisation of human rights for all groups. (Personal communication, 2010)

23. We may find a time coming where we can move out, each from our own carefully constructed positions, our safe identities. Working with an understanding that we are all vulnerable, and that we all live with unstable, potentially out-of-control bodies, could we dare to displace the able-bodied/disabled binary, drawing on the recognition that we are all, at best, temporarily able-bodied. For we will at least all get old, if nothing else. An acceptance of this inevitability breaks down some of the great divides that have been instituted through identity politics and brings us all to a recognition of the temporary, and highly contextual nature of our identities, and of the embodied self.

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