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# The Australian Disability Rights Movement Lives

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**ABSTRACT** *The Australian Disability Rights Movement is surviving despite funding threats to advocacy programmes. The integral relationship of advocacy funding to the Australian Disability Rights Movement is outlined. A brief history of the Australian Disability Rights' Movement is given, and whether this is a new social movement, or not, is discussed. The role of Women With Disabilities Australia is outlined.*

## Introduction

The disability rights movement is widespread in Australia; it is pluralistic and articulate, rights-based and actively advocates on behalf of people with disabilities. A brief account of the Australian Disability Rights Movement is necessary to give the movement its social context. Just as it is difficult to define the Australian women's movement in any but the most general terms, it is equally hard to describe the Australian Disability Rights Movement. One can identify major events in a social movement, but different sections of the movement will be manifested at different times. Touraine described social movements as 'the expression of the collective will. These movements describe themselves as agents of liberty, equality, social justice or national independence, or even as appeals to modernity or to the liberation of new forces in a world of traditions, prejudices and privileges, and those who are interested in them feel themselves borne on to besiege the established order' (1981, p. 29).

The collective will of the Australian Disability Rights Movement grew from the numbers of people with disabilities surviving. We faced problems caused by great distances; treatment and accessible education facilities were, in the big coastal area cities, so that individuals often grew apart from their families and communities thousands of miles away. Disability services were, and still are, complicated by differing levels of responsibility, funding and service types run, or contracted out, by all governments from federal to state and territorial administrations, and including a multiplicity of local governments, and a plethora of regional co-ordinating bodies, all of which have the potential to conflict, wheel and deal amongst themselves.

Added impetus to the Australian Disability Rights Movement was caused by the reaction of people with disabilities to the world around us. Legislative actions had

outlined government and charitable policy towards disability. To reflect fundraising principles, and the earnest beliefs of concerned parents and professionals, agency services were often only available to people with specific medical diagnoses. People with disabilities were protected in asexual, congregated, work orientated, cradle to the grave care, in a time of increasing social freedom for others.

Australian activists heard via journals and international visitors, what was happening to their peers in other countries, particularly in America, where the University of Berkeley was funded in 1970 by the Federal agency of Health, Education and Welfare to establish the Ed Roberts' managed Physically Disabled Students' Program, then the 1973 federal Rehabilitation Act (with exemptions) was enacted, and in April 1977, when US Secretary of Health Education and Welfare Secretary Califano refused to sign section 504 of the Rehabilitation Act which dealt with discriminatory exemptions, 300 activists held the legendary 30-hour live-in in the HEW office (Shapiro, 1993). The past three decades have seen Australian disability activists advocate for a wave of action to overcome their felt oppression. People with disabilities were oppressed by poverty (Treloar, 1977), or as Abberley stated, 'the failure of society' to meet our needs thus causing economic disadvantage and disempowerment (1996, p. 111). Young succinctly described the sort of oppression disability activists delineated and targeted, writing about oppression as systemic constraints felt as 'vast and deep injustices some groups suffer as a consequence of often unconscious assumptions and reactions of well meaning people in ordinary interactions, media and cultural stereotypes, and structural features of bureaucratic hierarchies and market mechanisms' (1990, p. 41). The five faces of oppression could be explained via the study of 'categories and distinctions' of oppression as being exploitation, marginalisation, powerlessness, cultural imperialism and violence (Young, 1990, p. 42).

Is the Australian Disability Rights Movement a new social movement? Certainly, there was disability action prior to the International Year of Disabled Persons, mostly based around a medical diagnostic group or an issue. The Australian Association of the Blind was begun in 1896 (Wilson, 1987, p. 20), the Blind and Professional Guild was established in 1944 (Jeffrey, 1998), the West Australian and New South Wales Civilian Maimed and Limbless Associations formed in 1949 (Ewing, 1981, p. 41), the Victorian Disabled Motorists' Association came into being in 1954 (Lever, 1985, p. 10), the Victorian Paraplegic and Quadriplegic Association developed in 1962, and in 1967 the Australian Quadriplegics Association NSW was developed (Jones, 1992, p. 2). Older social movements were seen by Campbell & Oliver, as 'tended to campaign on single issues, were led by experts and saw parliamentary lobbying as their only tactic' (1996, p. 21).

Though somewhat sceptical of setting aside class and labour analysis of society, Burgmann (1993, p. 5) saw the new social movements could claim 'alleged innovation in their non-productivist' analysis of society. Burgmann stated social movements were 'imagined communities of the oppressed, disadvantaged or threatened. A symbiotic relationship exists between movement and participants; ... this forging of a common self-identity that achieves for the group a political impact, that makes the collection a collectivity, a mass of people a coherent political actor' (1993, p.

19). The success or otherwise of a movement could be, according to Burgmann only tested by the extent the movement effected political change. The new social movement aimed at disability rights could be evaluated against three other criteria according to Campbell & Oliver (1996, p. 168), 'the extent of consciousness raising and empowerment' of people with disabilities, the extent disability issues are raised internationally, and the promotion of disability rights from human and civil rights perspectives. Both the national multidagnostic organisations controlled by citizens with disabilities, Disabled People's International (Australia) and Women With Disabilities Australia, and the single diagnostic organisations National Federation of Blind Citizens Australia and the short-lived People First, managed by people with intellectual disabilities, have carried issues to international arenas. I suggest the Australian Disability Rights Movement be considered as a new social movement according to all the above criteria.

Examples of Australian disability activism and advocacy for a different way may be seen in the successful battles against the Miss Australia quest, the adoption of fully subsidised attendant care under the still small In Home Accommodation Support scheme, deinstitutionalisation of many clients of intellectual disability services, closure of institutions, relocation of people with physical disabilities from hostels and nursing homes to community housing, the Home and Community Care Act, enlightened mental health legislation in various states, establishment of public advocates, and guardianship and administration boards in most states, and the proclamations of the Disability Services Act 1986 and the Disability Discrimination Act 1992. These waves of action are usually carefully run campaigns by major advocacy organisations, with the lead taken by the organisation closest to the sector wanting change. Always the actions address the felt need by people with disabilities for specific measures to remedy inequities.

Advocacy, the core business of consumer controlled disability organisations is under threat in Australia and, by definition, so is the Australian Disability Rights Movement. Derksen (1980, p. 113) warned of three service provider reactions to the Canadian consumer movement. 'The initial reaction ... has been to use such covert influence ... on government and private funding sources to deny resources to emerging consumer groups.' Derksen described a second reaction as the setting up by the service provider of 'artificial citizens groups' by the provider's community development worker which 'take the name of the consumer movement without incorporating the movement's fundamental values, philosophies and perceptions.' A third, and rare reaction found by Derksen was the acceptance of the right and value of the consumer perspective into the decision-making processes of the organisation. We have seen all these activities in Australia.

Funding for citizen groups advocating disability issues and strategies for the resolution of the same, has been difficult, and groups and organisations have traditionally relied on philanthropic trusts and government projects. The vast distances between cities greatly increase the expense of developing and maintaining national citizens with disabilities controlled advocacy organisations. This has led to a reliance on government funding which has serious consequences for our independence. After many years of lobbying, advocacy was recognised as a programme area

to be funded under the Disability Services Act 1986. Advocacy services were defined in the Act (1986, p. 2) as:

- (a) self advocacy services to assist people with disabilities to develop or maintain the personal skills and self confidence necessary to enable them to represent their own interests in the community;
- (b) citizen advocacy ... services to facilitate persons in the community to assist
  - (i) people with disabilities; or
  - (ii) the families of; and other persons who provide care for or assistance to, persons with disabilities, to represent their interests in the community; or
- (c) group advocacy services to facilitate community organisations to represent the interests of groups of people with disabilities.

In further explanation of the last category, the Department of Community Services and Health (1987, p. 2) stated the aim of funding this group was 'to raise awareness in the non-disabled population of the needs and special difficulties faced by people with a disability and where necessary to bring about changes in existing systems and services.' The target group, according to the same guidelines was 'across the whole range of disabilities. They should not be restricted to advocacy on behalf of a specific disability group or consumers of a particular organisation.'

Advocacy involves needs analysis. Fraser's (1989, p. 164) discussion over the political basis of needs analysis is particularly apt for examining the relevance of group or systemic advocacy to people with disabilities. 'the politics of need comprise three moments that are analytically distinct but interrelated in practice.' The first moment is 'the struggle to establish or deny the political status of a given need, the struggle to validate the need as a matter of legitimate political concern or to enclave it as a non political matter.' The Disability Discrimination Act 1992 might be seen as the establishment of the need of people with disabilities to be empowered by access to anti-discrimination legislation to enforce equal treatment with the rest of the community.

The second moment is the struggle over 'the interpretation of the need, the struggle for the power to define it and, so, to determine what would satisfy it.' The Disability Discrimination Act Standards Working Groups on education, employment, building access and transport are examples of work in progress to define reasonable standards to support the intent of the Disability Discrimination Act. The third moment is the struggle over 'the satisfaction of the need, the struggle to secure or withhold provision.' Many disability advocacy groups are immediately engaged in a struggle to retain inexpensive access to the Disability Discrimination Act, at a time when the Human Rights and Equal Opportunity Commission is under threat of further role reduction, and the Disability Discrimination Act Commissioner position has been abolished and there is a substantial fee for lodging a discrimination matter with the Federal Court. There is consequent concern from citizens with disabilities over the fate of the Disability Discrimination Act Standards Working Groups.

The full meaning of advocacy has been hotly defended and debated by

Australian disability activists. Atrill-Wheeler and Cassinides (1994, p. 9) saw advocacy as essentially involved in structural reform while 'change agency' must be included in any Australian government's disability strategy (Leipoldt, 1993, p. 23). Harding (1997, p. 8) argued about the inherent conflict of fitting advocacy, into a service model searching for an outcome which would fit the agency's purpose, 'the balance must always favour vigorous and partisan advocacy dedicated to identifiable political ends.' Meekosha & Dowse (1997, p. 21) was critical of the limited view of 'the discourse of rights driven by disability activists [which] rarely ventures into the difficult waters of responsibilities and contributions to civil societies by all people with disabilities' and has challenged activists to look at the full meaning of citizenship and work towards that end. Women With Disabilities Australia (1997, p. 5) saw 'Advocacy is integral to any social, economic and political advancement for people with disabilities. It is the nature of advocacy that its focus will shift as changes occur in the social and material conditions of those for whom advocacy takes place. Advocacy is not something which can be completed.'

Until 1991 the Australian government provided advocacy monies under the Disability Services Act 1986. Then the Commonwealth and States entered a new relationship under the Hawke Labour government's 1990 policy of New Federalism. Attridge (1991, p. 3) reported that Prime Minister Hawke 'mooted a "closer partnership" after redefinition of responsibilities between governments.' The Special Premiers' Conference endorsed Hawke's proposal in October the same year. Attridge reported there had 'been scant public debate and minimal consultation with service users and providers' apart from the Premiers' Conference communique. Attridge was quite critical of the proposal 'In social policy terms the shift of responsibility for key community services to the states and territories is a disaster. The historical credentials of the states to perform these functions is woeful.'

The Commonwealth States Disability Agreement was the first programme to be devolved, i.e. a major part of Federal Government's responsibility was transferred to the states. Given its importance to people with disabilities, and the disability industry, consultation with both sectors could have been considered important. The Commonwealth States Disability Agreement was approved in principle at a meeting of health and welfare ministers in Adelaide March 1991. Brian Howe (1991, p. 5), then Minister for Community Services and Health, disagreed with Attridge and stated in relation to the planned partial disability services transfer 'I believe that confusion of government responsibilities has been greatest in disabilities.' He assured readers that planning and evaluation issues would accompany financial arrangements and there would be no agreement until each state had enacted complementary disability related legislation. Howe implied there was an ongoing process of consultation with consumers by stating 'the input from consumers has played a critical role in the rationalisation process and the development of the Commonwealth/State Disability Agreement' and 'we are committed to a process of debate with the community sector on intergovernmental reform.' However, the then major citizens with disabilities controlled advocacy organisation, Disabled Peoples' International (Australia), was only invited to a Department of Health Housing and Community Services briefing session (Rosenberg, 1991, p. 1), and the major

disability industry peak body ACROD stated through their executive officer (Braithwaite, 1991, p. 6) they 'saw no evidence of this consultation.'

The broad aims of CSDA were, as reported by Yeatman (1996, p. xiii):

- to establish an initial framework for the rationalisation of the administration of disability services by the Commonwealth and the States; and
- to develop, on a national basis, integrated services to ensure that people with disabilities have access to appropriate services which meet their individual needs.

Yeatman found that while the former was largely achieved, there was a lot to be done on the latter. We agree. All disability activists involved in advocacy will have concurred with Yeatman's (1996, p. xvi) view that 'Advocacy, in all its forms, promotes, enhances and protects the rights of people with disabilities. This has been an area of some neglect under the current CSDA. Advocacy services should have the capacity to link with complaints mechanisms where they need to, and advocacy and complaints services must be guaranteed independence from the funder, purchaser and provider roles within the system.'

Some 80 disability advocacy groups, citizens with disabilities are not always in control, continued to be funded to some extent by the federal Department of Health and Family Services, which last year has conducted an as yet unreleased review of advocacy funding. The Office of Disability, which is part of the same Ministry, arranged parttime secretarial funding for the National Caucus of Disability Consumer Organisations. The Caucus is a loose network of 10 consumer-orientated national organisations, although not all the organisations could claim to be controlled by people with disabilities. Many activists with disabilities wish for non-disabled people to adopt the purist line of Drake (1997, p. 644) who questioned the legitimate roles a non-disabled person could play when working with the disability movement.

One of the members of the National Caucus of Disability Consumer Organisations, and currently funded through the Office of Disability, is Women with Disabilities Australia. Women With Disabilities Australia remains the only national multidagnostic organisation controlled by members from a variety of disability and geographic backgrounds. Women With Disabilities Australia is a coalition of state-based organisations and individuals. Its' philosophy is feminist in a non-separatist sense. Women With Disabilities Australia is not just a 'feminist offshoot' of Disabled People's International (Australia). The organisation began evolving in 1984 when women members of Disabled People's International (Australia) began a network to assist each other in educating their male colleagues on gender perspectives, and in engaging with women's organisations on aspects of feminist debate about the federal government's agenda for women to the year 2000. Women With Disabilities Australia has an extensive history which is currently being researched by the author, who was the first elected Chair.

The Women With Disabilities Australia steering committee members had expressed discomfort at working with the traditionally organised, hierarchical Disabled People's International (Australia). From the beginning, Women With

Disabilities Australia's leadership worked at developing feminist ways of working, for instance adopting 'the philosophy of collectivity' and participatory-democratic processes (Weeks, 1994a, p. 134), with a leadership style which could be described as close to Weeks' definition (1994b, p. 150) 'woman-focussed, shared and social-change-oriented, worked independently of Disabled People's International (Australia), although the two organisations shared office premises until early 1995. Women With Disabilities Australia was originally funded by the Office for the Status of Women, Department of Prime Minister & Cabinet in 1995, to enable both a move to separate premises and more work on cross-disability feminist issues.

Women With Disabilities Australia advocates on issues which affect its members, and publishes views of members in public fora, disability arenas and feminist circles. Major issues so far canvassed have included the UN Beijing Conference on the status of women in relation to women with disabilities (Pane, 1994), feminism and eugenics (Hume, 1996) difficulties women with disabilities have in accessing adequate women's health care (Cooper & Temby, 1996) and domestic violence (Wilde & Scerih, 1996; Strahan, 1997a). Representatives went to the International Leadership Forum for women with Disabilities held in the USA 1997, and have participated in various Australian conferences on issues such as social security, violence against women, the national women's health programme, workplace diversity programmes and equal employment opportunity. Women With Disabilities Australia is a member of the Australian National Training Authority's Disability Forum, the annual Round Table Conference with the Minister for the Status of Women, the national telecommunication users' council, the Australian Institute of Health and Welfare data reference committee, and various national Disability Discrimination Act Standards working groups.

There is concern that in the immediate future all advocacy may be funded by and through the states under the CSDA. One state government refused to establish a Joint Advisory Body of state and commonwealth representatives and appointed citizens with disabilities, and advocates for people with disabilities, required under the Commonwealth States Disability Agreement, and also recently cut funding to regional advocacy services funded under the CSDA by \$651,000, effectively shutting them down. In a letter sent to the advocacy agencies concerned, and quoted in a major state newspaper (Pegler, 1997, p. 6), the disability services director stated 'the Victorian Government requires all departments to rigorously assess the priority of all services and to examine ways to achieve similar outcomes in a more effective and efficient manner. Agencies that provide a broad range of general disability related information or who are providers of 'regional information and/or advocacy will no longer receive funding.'

A press release from the state Minister's office stated that \$190,000 was allocated to 'fully equip 22 specialist information service providers for access to the Internet and to help them establish home pages' \$240,000 'will be spent on an Information Clearing House to pass information onto the 22 agencies[to] enable the specialist agencies to access and pass on to people with disabilities up-to-date information from anywhere in the world' (Naphine, 1997, p. 1). This, of course, did nothing to address the cross-disability issues such as public transport access.

The sacked regional advocacy groups had of course grown out of local disability activism and were loosely allied through a network. Their remaining budgets and equipment were liquidated to pay out workers. After much representation by people with disabilities and their organisations, the same state government has sought to establish a state wide disability advocacy service (Victorian DHS tender, 1997, p. 1) to provide citizen advocacy. One must heed Derksen's warning of pseudo-citizens' structures which do not encompass the values of the disability movement. Part of the brief specifies the successful tenderer must maintain and develop regional advocacy networks. This example of action by one state government demonstrated the difficulty of translating programme intention by one set of policy makers, the Australian government, to implementation by another government level, the states. Weil (1996, p. 480) studied the welfare funding changes in the USA and warned that devolution of central government's responsibility may mean 'policy concepts of equality of access and equity of treatment are at risk.' With the reduction in federal government responsibility by the transference of block grants, rather than tied grants, to states and local governments, the decisionmaking about welfare and services may become dominated by the thinking of lower levels of government.

Although there are major funding difficulties confronting citizens with disabilities controlled national advocacy organisations, to claim the movement is 'fragmented ... operating without any national cohesion' after the 1995 collapse of Disabled People's International (Australia), as did Newell (1996, p. 430), is a failure of political imagination. Newell may be confusing social movements with the visible entities of pressure groups. This inclines the observer to focus narrowly and miss seeing the underlying movement (Burgmann, 1993, p. 8). The pressure group approach, described by Burgmann as 'American pluralism', rests on an assumption that all pressure groups have equity of status. This is clearly not the case in Australia. Disabled People's International (Australia), a federal Labour government funded national disability advocacy organisation, set up in 1983 to be controlled by people from a variety of disability and geographic backgrounds, is relevant in the lessons to be learnt by other community developers. Unless people with disabilities feel the structure they are building is responsive to their needs for assistance in surviving within an often hostile society, their interest in the group will wane. Recognition and incorporation of this essential point, is one of the reasons behind the success or failure of citizen controlled disability rights organisations. Events leading to the 1997 deregistration of the company Disabled Peoples' International Australia, was due to many factors yet to be researched.

Newell (1996, p. 429) also asserted the 1995 demise of Disabled People's International Australia, has been central to 'a lack of political power ... and a lack of positive media stories by and of people with disability.' Positive or negative media stories should not be confused with the issue of political power. Media coverage should be the subject of further research. Current stories may reflect the Murdoch media preoccupation with sensationalism, rather than reflecting a realistic sampling of community concepts of the roles of people with disabilities.

To summarise, the Australian Disability Rights Movement is alive, albeit in financial difficulties. Each issue is met by a groundswell of activity usually spear-



headed by an activist group or organisation who grasps leadership for the moment and focuses change efforts. Women With Disabilities Australia is possibly unique in dictating its own agenda of issue raising, and consequent policy formulation and presentation. While the political power of people with disabilities is most easily seen in national specific disability organisations debating issues with government policy makers, a greater power is with the myriad of individuals and small groups, working mostly without funding, but armed with anti-discrimination legislation, and engaged in access battles. Maybe this is how our diverse society works best.

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