

Tunnel Vision or Fine Tuning? – a focus on government & women with disabilities

By Sue Salthouse for Women With Disabilities Australia (WWDA) Paper presented at the ANU Conference 'Historical Moments: The View from the WNGOs', 29-30 November 2011, Canberra. © Copyright 2011.

Abstract

Women With Disabilities Australia (WWDA) is the peak national body representing close to 2 million women in Australia. Historically, neither feminist polemics nor disability activism have made room for women with disabilities. Yet understanding is emerging of the effects of multiple discriminations, primarily of gender and disability, on women with disabilities. WWDA has a short history of interaction with government and its small size has meant that it must be strategic in its systemic advocacy. This paper examines WWDA's use of international human rights instruments to advance an advocacy campaign nationally and internationally. Domestically, it considers the effect on WWDA of the current national evaluation of the not-for-profit sector; comments on WWDA's interactions with its funding body; and conjectures on the possible effects of social media on government interactions with civil society.

Before starting, I would like to acknowledge the Ngunnawal and the Ngambri people of the Canberra region and pay my respects to their elders past and presen.

Introduction - The historical context for women with disabilities

Historically women with disabilities in Australia have been ignored by governments and by the women's movement alike. As individuals, they have had to grapple with being treated as permanently childlike, subservient¹, trivialised, and locked out of feminist discourse. Learned passivity, coupled with a denial of woman hood, and the social or actual removal of reproductive rights, has kept women with disabilities in the shadows. Unable to be regarded as 'whole' women by their peers, women with disabilities were essentially invisible in the women's movement. Their collectives and organisations have been similarly treated by both governments and non-government organisations (NGOs).

Those women who have sought to become leaders have had to overcome stereotypical attitudes to women coupled with the stereotypically negative attitudes to the disabled. Over the past 2 decades, recognition of the multiplying effects of different discriminators has been increasingly researched. Intersectionality - the interacting effects of different socially constructed identifiers is a term first coined in 1989 to describe the

¹Barron, K. (1997, April). The bumpy road to womanhood. *Disability & Society, 12*(2), 223-240.

multiplier effects of race and gender^{2 3}. For WWDA, the primary discriminators are disability and gender which act together to reduce the life chances of women with disabilities. Race, religion, sexual preference, and class, along with poverty and the experience of violence, have compounding negative effects on the life experiences of women with disabilities.

Successive Australian governments have failed to recognise that women with disabilities are grossly overrepresented in the lowest socio economic groups or that there are structural and societal barriers that keep us there. I contend that WWDA has played a significant role over the past 15 years to draw attention to our collective plight and force the changes that we are now beginning to see.

WWDA began life as a group of feminists with disabilities who formed the National Women's Network within Disabled People's International (Australia) [DPIA]. DPIA itself began formal operation at about the time of the 1981 UN International Year of Disability⁴. Incorporated in 1995, WWDA began its relationship with government at this time when it first received operational funding from the Office for the Status of Women. The dilemma of intersectionality was resolved to the assumed satisfaction of government by denying the duality of WWDA's role. In 1995, the government re-defined WWDA as a welfare organisation and transferred the relationship to the (then) Department of Health and Family Services, thus effectively nullifying our womanhood in government considerations. By 1999, WWDA was grouped along with other national peak Disabled People's Organisations (DPOs), and funded under various programs and various iterations of the current Disability and Carers Branch of the Department of Family, Housing, Community Services and Indigenous Affairs (FaHCSIA). The inability of governments to simultaneously address both the gender and disability aspects of our advocacy continues to be problematic both for us and them.

Nationally and internationally there are emerging considerations of intersectionality. Women's studies entered into academia in formal coursework about 40 years ago, as part of a second wave of feminism⁵. Disability studies⁶ arguably began at approximately the same time, although the term may not have been coined on campus until much later. Courses which combine a study of both in a single unit, are scarce or do not formally exist. Individual academics, such as Meekosha⁷, Silvers⁸, Saxton⁹, and others, have focussed attention on different aspects of this gender/disability nexus and its effects on women with disabilities themselves.

This work at a research level is filtering across to civil society. Discourse on the complexity of the determinants which affect an individual's condition are now more commonly evident in the work of both government and NGOs. It is commonly accepted that a range of social determinants affect an individual's health status. Consideration of intersectionality of gender and disability is becoming more evident at an international level, for example disability is now integrated into Millennium Development Goals, and also in the deliberations of United Nations human rights treaty Committees and Commissions. I argue that WWDA's voice internationally has been one of those bringing about these changes.

² http://en.wikipedia.org/wiki/Intersectionality

³ Crenshaw, Kimberlé W. (1991). *Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color*, Stanford Law Review, Vol. 43, No. 6., pp. 1241–1299.

⁴ Frohmader, C, There's no Justice, There's just us: the Status of women with disabilities in Australia, WWDA 2002

⁵ http://en.wikipedia.org/wiki/Women%27s_studies

⁶ Finkelstein, V (2004) *Disability Studies: Putting theory into Practice (Phase 3: Conceptualising new Services)* Lancaster University 2004

⁷ Frohmader, C & Meekosha ,H (2010) *Recognition, respect and rights: Women with disabilities in a globalised world*, WWDA 2010

⁸ Silvers, A, *Feminist Perspectives on Disability*, The Stanford Encyclopedia of Philosophy (Summer 2009 Edition), Edward N. Zalta (ed.), http://plato.stanford.edu/archives/sum2009/entries/feminism-disability

⁹ Saxton, M *Disability Rights & Selective Abortion* [Excerpted from: Abortion Wars, A Half Century of Struggle: 1950 to 2000. Rickie Solinger (ed) Berkeley, CA: University of California Press, 1998.

A direct relationship with politicians

In order to examine how WWDA has influenced policy change over time it is important to look further at context. In comparison to the other organisation represented at this conference, WWDA is a miniscule organisation with a short history of operation. WWDA lays claim to a staff of 2, a membership of over 2000 individuals and organisations and informal affiliations with the 4 existing sister organisations in the states (WWDWA in WA, WWDSA in SA, WWDACT in the ACT and the Women with Disabilities Network in Victoria).

WWDA recognises that its ability to influence policy through direct representation to politicians is limited. Direct lobbying strength naturally resides with big corporations. The policy effects of their influence on governments can be readily seen, especially in the instances where their operations affect tax revenue and Gross National Product! Larger Not-For-Profit (NFP) organisations have similar capacity to maintain policy pressure through direct discussion with politicians. In contrast, a small NGO such as ours has little ability to influence policy in this way.

Over the past 5 years WWDA has developed a relationship with Women's NGOs (WNGOs) through its association with the Women's Alliances. However, we only have capacity to be a member of two of the 6 Alliances - the Equality Rights Alliance (ERA) and the Australian Women Against Violence Alliance (AWAVA). Each of these alliances organises its own form of direct lobbying which involves their membership. ERA conducted an intense consultation process prior to the 2010 election to develop a series of position papers. WWDA also took part in this and in a day of direct lobbying at Parliament House, in which women, in groups of 2-3, met with participating politicians. The degree to which this form of lobbying goes beyond 'awareness raising' for the politicians involved is questionable. In contrast there is a considerable valuable transfer of skills to the more novice members of delegations, so that the exercise is valuable in itself. WWDA regularly participates in these activities, and is heartened to see more frequent consideration of disability issues included on the agendas.

In contrast, the Australian Federation of Disability Organisations (AFDO), of which WWDA is also a member, does not organise in this collaborative way, and it is more difficult to ascertain the degree to which gender is included.

In fact, WWDA does not regularly meet with politicians. Our practice is to ensure that we keep all parliamentarians at federal, state/territory and local level informed of our activities through efficient and wide distribution of our materials. This technique carries a risk of over exposure and a risk that the gatekeepers in the politicians' offices filter the material so that little reaches the decision-makers themselves. WWDA supplements this with strategic face to face meetings with politicians and departmental officers in key portfolio areas. Our limited capacity to meet regularly with those key players is a continuing challenge. The WWDA campaign to change the Australian sterilisation laws is an example of one in which we are using direct lobbying in conjunction with a sustained, targeted campaign of disseminating written information. Currently, this campaign is escalating at an international level. WWDA's work on sterilisation has international status and recognition. International pressure is building to prohibit the practice of forced and non-therapeutic sterilisations; to compensate those who underwent this procedure in the past; and to instigate support measures to assist primary carers where the procedure might be under consideration.

Government policy changes - examination of the Not For Profit sector

In any review of the Australian Government relationship with NGOs, it is necessary to look at the actions undertaken since 2007 to review the NFP sector. In 2008, The Hon. Senator Dr Ursula Stephens, Parliamentary Secretary for Social inclusion and the Voluntary Sector, and Parliamentary Secretary assisting the Prime Minister for Social Inclusion, was charged with undertaking wide consultation to develop a national compact with the sector. Linked to this activity is the thrust for improving social cohesion through the Social Inclusion agenda. Government acknowledges that the NFP sector is a major player in addressing

disadvantage and poverty. WWDA's experience of this process is that the Government did not come to grips with understanding the diversity in the sector. There are over 700,000 NFP organisations ranging from multi-million dollar operations such as sporting groups and some charities, to small advocacy organisations such as WWDA. Twenty-five per cent are large NFPs which generate \$43 billion to GDP (over 4%) and employ 8% of the workforce. Volunteers contribute an estimated additional nearly \$15 billion to the economy¹⁰. The role of small systemic advocacy groups and the voices of women's organisations calling for changed structures to address gender inequity were drowned out by the imperative of larger cashed-up NFPs with a need to maintain their power base and status. How the sector can be organised so as to enable meaningful interactions at both ends of this spectrum is not yet clear.

For WWDA, a good-fit *modus operandi* comes from a definition of NGOs coined at the 50th Disabled People's International/NGO conference:

"A non-governmental organization (NGO) is any non-profit, voluntary citizens' group which is organized on a local, national or international level. Task-oriented and driven by people with a common interest, NGOs perform a variety of service and humanitarian functions, bring citizen concerns to Governments, advocate and monitor policies and encourage political participation through provision of information. Some are organized around specific issues, such as human rights, environment or health. They provide analysis and expertise, serve as early warning mechanisms and help monitor and implement international agreements. Their relationship with offices and agencies of the United Nations system differs depending on their goals, their venue and the mandate of a particular institution^{"11}.

Whilst it was identified during consultation that closer NFP-government relationships were wanted, the nature of this relationship was never really defined. The National Compact under development as a result of these consultations was heralded as a mechanism for closer government-NFP working. However the gestation period has been long and a change of prime ministers and ministers mid-stream perhaps blurred its focus. In a flurry of publicity, NFPs were urged to sign up to the National Compact in 2011.

The Compact¹² is an agreement setting out how the Government and the sector want to work together to achieve their shared vision:

The Australian Government and the not-for-profit sector will work together to improve social, cultural, civic, economic and environmental outcomes, building on the strengths of individuals and communities. This collaboration will contribute to improved community wellbeing and a more inclusive Australian society with better quality of life for all.

WWDA has been reluctant to sign up on the grounds that we cannot yet see how the aspirational commitments in the policy might be manifested in practice.

Australian Charities & Not-For-Profit Commission

In an associated 2009 action to examine the nature of the NFP sector, the Rudd government commissioned the Productivity Commission to undertake appropriate research. At the same time the Henry Taxation Review was underway culminating in the report to government on *Australia's Future Tax system*¹³. As a result of the PC work, the Australian Charities and Not-For-Profit Commission (ACNC) is being set up to oversee changes to the sector. The ACNC will initially be responsible for determining the legal status of groups seeking charitable or other status; look at better targeting of the not-for-profit tax concessions; implement a more rational reporting framework for charities, educate and inform the sector; reduce red

¹⁰ Productivity Commission (2010) *Contribution of the Not-for-Profit Sector* – Research Report, February 2010

¹¹http://www.ngo.org/ngoinfo/define.html

¹² Australian Government (2011) National Compact – Working together – part of the Social Inclusion Agenda, 2011.

¹³ Henry, K et al (2009) *Australia's Future Tax System,* Commonwealth of Australia Department of Treasury, 2009, http://taxreview.treasury.gov.au/content/Content.aspx?doc=html/pubs_reports.htm

tape, and devise a consistent, comprehensible definition of not-for-profit. WWDA has little capacity to participate in or monitor these developments. To date, they remain peripheral to our work, and have not yet affected departmental dealings with us. However, the cost of not being engaged in the ACNC brief could have drastic consequences for WWDA in the long term.

Social media

It is expedient for the Government to examine the relationship between governments and NGOs at this time. The need to create "participatory, transparent and collaborative" ¹⁴ government has become evident with the emergence of the Internet. Greater citizen participation in government is now possible through the use of social media such as blogs, twitter, Wikis, Facebook, live streaming of events and webinars. It could be that the existence of this direct way of interacting with government will also significantly change the role of NGOs. As yet, Web2.0/Gov2.0 strategies are not well understood by parliamentarians, with some notable exceptions¹⁵ or by the majority of NGOs. The government-funded portal, "RampUp", is an example of these new strategies. Run for and by people with disabilities, it is a public on-line forum for sharing ideas, giving feedback and venting spleen (albeit carefully moderated). The emergence of non-leader-driven movements such as the current "Occupy Wall Street" demonstrations which has spawned actions in numerous cities worldwide is not yet understood, and will also affect the way NGOs operate.

Operational considerations

Notwithstanding all the above-mentioned 'big-picture' consultations, WWDA views a relatively unchanging landscape in day to day interactions with government. WWDA continues to be reliant on government for operational funding. The recent FaHCSIA change to a 3-year funding cycle from an annual one is definitely an improvement. (In the ACT, accreditation processes are in place to move to a 10-year funding cycle for some NGOs, and in particular service provider organisations which support people with disabilities.) However, like other government-funded organisations WWDA is a victim of a government fixation on accountability. Funding Agreements seem unable to cope with advocacy organisations. Standard Agreements are written for service provider organisations which we fundamentally are not. During the Howard era, contracts had a fixation on countable Key Performance Indicators, and it was tempting to furnish reports which simply cited Section and Paragraph of the contract, and provide a numeric against each, e.g. the KPI asks for "Number of contacts with constituents", the final report reads: "53"! Amongst the changes which have manifested after the 2007 election, are a return to more meaningful KPIs and scope for more descriptive reporting. Nevertheless required policy papers are submitted into an abyss, with no acknowledgement and little evidence of their having been read, let alone absorbed into policy.

WWDA believes that its interactions with government and its effectiveness are directly affected by the Efficiency Measures being applied. Departments are constantly restructuring in an endeavour to find savings, and this results in a game of "musical chairs" played by public servants, such that a funded organisation can deal with different desk officers sometimes from one phone call to the next. In WWDA's case, corporate knowledge of the disability sector or of significant players within it, is lost. A much higher level of personnel continuity is found within the disability and WNGO sectors.

Also lost with the frequent personnel changes, is any sense of trust in an NGO. There is no mechanism to properly acknowledge any NGO which consistently delivers on-time, on-budget, and beyond the requirement of a funding agreement. Nevertheless, WWDA does fulfil a role as a key informant to government in areas where it has recognised expertise, e.g. on sterilisation, or violence against women with disabilities.

¹⁴ US Government White Paper (2010) *Gov 2.0: Promoting Inclusive, Open and Transparent Government through Technology Transparency*, Microsoft Corporation and Hi Software Inc., 2010

¹⁵ The Hon. Sen. Kate Lundy won the 2010 International eDemocracy award, conducted by the World e.Gov Forum & Politics Online, for her work conducting 3 Public Sphere events: http://www.katelundy.com.au/category/campaigns/publicsphere/

Moreover, attempts to rationalise the number of NGOs funded in either the disability or gender portfolios has been frequently subsumed into the political agenda. Departments can sink into a catatonic state in which the status quo is maintained in lieu of making any change which may bring about a political backlash. Over the past several years WWDA has participated in a series of meetings of all the disability peak bodies, both FaHCSIA-funded and not, called by the Department. These have mostly been billed as "finding ways to reduce red tape". The unspoken agenda is to find ways of reducing the number of organisations. Governments still wish to deal with a single voice. Suggestions are given and submission written, but the usual outcome is to increase the number of deliverables in the contract. This is not confined to FaHCSIA alone. A neo-liberal trend across Australia, United States and Britain is to ask greater involvement in consultation processes and greater accountability whilst simultaneously reducing the resources available¹⁶. The inherent difficulty of the concept of a single voice for any sector, is that such a thing is a figment, and the art of governing is to listen to disparate voices and choose a best-fit set of compromises.

Consultation and other evidence collection

Currently governments operate under a consultation imperative. High level discussion papers arrive in the email Inbox. Often the gestation of the paper has taken so long within government circles that the response time dictated to the NGO is so short as to preclude any consultation with constituents. This is especially true for organisations which rely on the input of volunteers. At an individual level, WWDA finds itself furnishing feedback from Advisory Group appointees who have to give personal opinions rather than input informed by constituents. Even though these *ad hoc* opinions are based in the lived experience of disability or committed feminism and being steeped in the daily conversations with similar colleagues and friends, the responses do not constitute *bona fide* evidence.

Since 2007, there has been a federal government desire for NGOs to support any systemic advocacy with evidence. Yet, there are scant resources to undertake national research. Access to information from government surveys, such as those conducted by the Australian Bureau of Statistics (ABS), is limited by inability to pay for the needed reconfiguring of data. Admittedly, the ABS itself is taking positive steps to make survey data available through automatic online publishing spreadsheets. In addition the Gender data portal (Topics@ a Glance¹⁷) enables much greater and easier access to gender disaggregated data. But for groups wanting information where two or more characteristics intersect, such as for women with disabilities, the portal does not furnish sufficient information for our purposes. Any additional disaggregated data itself. WWDA's contribution to building the evidence is through its 2011 Policy Paper¹⁹, which contains a comprehensive dossier of information collected in Australia about women with disabilities, even though not all of this information is publicly available. This Paper also contains a comprehensive summary of additional evidence which needs to be collected to gain a true picture of the situation for women with disabilities in this country.

International instruments for domestic policy change

Over the past 15 years, WWDA has been realistic about the size and strength of its voice at home. However, we have also been realistic about the need for engagement in international human rights processes. Over the past 4-5 years, the Australian Government has better supported NGO participation in UN processes, by providing minimal funding for compilation of NGO Shadow/Parallel reports. WWDA has contributed to compilation of all Shadow/Parallel reports during this time and has had input to the official

¹⁶ACOSS 2005, Cheverton, J Past their peak? Governance and the future of peak bodies in Australia, viewed online 19 November 2011 at: http://findarticles.com/p/articles/mi_hb3359/is_3_40/ai_n29223324/pg_7/?tag=content;col1

¹⁷http://www.abs.gov.au/websitedbs/c311215.nsf/web/gender

¹⁸http://www.abs.gov.au/ausstats/abs@.nsf/mf/4533.0

¹⁹ Frohmader, C (2011) Assessing the situation of women with disabilities in Australia: A human rights approach WWDA 2011

Government reports to UN Committees. Because of the strong WWDA input to the Shadow Report, in 2006, the CEDAW Committee's Concluding Observations²⁰ to the Australian Government contained a number of references to women with disabilities. In 2010, a WWDA internal report to Government on the status of women with disabilities in Australia was accepted by the CEDAW Committee as an official NGO Shadow Report. This was an important step in having issues for women with disabilities in Australia considered by the Committee. Of parallel importance was the inclusion of WWDA member, Christina Ryan, in the NGO delegation to CEDAW. The 2010 CEDAW Concluding Observations²¹ to the Australian Government contained a greater number of specific references to women with disabilities. In 2011, the Government selected Christina Ryan as one of the Community Representatives included in the Government Delegation to the 55th Commission on the Status of Women (CSW). Thanks to strong lobbying, the Agreed Conclusions from CSW55 recognised the multiple discrimination and disadvantages faced by women and girls, although falling short of use of the term intersectionality. The communique called for improved and systematized collection, analysis and dissemination of sex-, age- and disability disaggregated data.²².

Meeting Australia's CEDAW obligations has led the Government, among other actions, to develop the National Plan to Reduce Violence against Women and their Children²³. WWDA representative, Annie Parkinson, was a member of the Violence Against Women Advisory Group to Government, and the Plan contains specific actions which should change the current situation for women with disabilities.

WWDA had input, along with many other feminists with disabilities, to the writing of the Convention on the Rights of Persons with Disabilities (CRPD). Significantly the CRPD contains a specific article (Article 6)²⁴ which acknowledges the multiple discriminations experienced by women with disabilities. The implementation of this convention, in conjunction with implementation of CEDAW, will mean that issues of gender and disability start to be routinely included in policies and programs.

Conclusion

At a macro-level, WWDA acknowledges that the Australian Government is striving to have a more open and transparent relationship with individuals, and is putting a fairer structure around the operation and tax regime of non-government Not-For-Profit organisations, whilst recognising their contribution to the economy. In the last decade, WWDA has come of age as an organization, and built a reputation as a significant contributor to dialogue on human rights and women with disabilities. WWDA's interactions with politicians and government are more frequent, and there is a noticeable improvement in consideration of intersectional issues, and of the need for both targeted and mainstream measures to improve the status of women with disabilities. At an operational level, there has been little change in WWDA's interaction with government over the last 10 years, and little change in level of funding despite marked increases in the scope of our work. WWDA's motivation remains consistent and we are committed to our vision to improve the lives and life chances of women with disabilities.

²⁰ http://www.unhchr.ch/tbs/doc.nsf/0/5864389fbe4047a9c1257245003e0bdf/\$FILE/N0623798.pdf

²¹ http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-AUS-CO-7.pdf

²² UN Economic and Social Council, (201) Commission on the Status of Women 55th Session: *Draft agreed conclusions submitted by the Chair of the Commission on the Status of Women on the basis of informal consultations: Access and participation of women and girls in education, training and science and technology, including for the promotion of women's equal access to full employment and decent work,* E/CN.6/2011/L.6, 2011

²³ http://www.fahcsia.gov.au/sa/women/progserv/violence/nationalplan/Pages/default_new.aspx

²⁴ http://www.un.org/disabilities/convention/about.shtml