

8. 'Part of the human condition': Women in the Australian disability rights movement

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People with disabilities form the largest minority in Australia and are amongst the nation's most disadvantaged people, with substandard outcomes on most indicators of community participation and *wellbeing*.² Despite this, most people tend not to think of disability rights as a political issue, as they do feminism or the struggle for Aboriginal self-determination. Instead, they tend to perceive disability as a personal problem to be overcome. Does this oversight stem from a collective fear of disability since everyone is a candidate for it? As Doris Fleischer and Frieda Zames observe, "[h]andicapism" ... is the only "ism" to which *all* human beings are susceptible'.³ We are all vulnerable and subject to the vagaries of accident, illness and old age. Yet, despite the likelihood that we will all be potential recipients of their hard-fought gains, the struggle of disability rights activists against 'handicapism' has failed to capture the imagination of historians.

There has been very little historical writing about the Australian disability rights movement (ADRM). The stories of Australian people with disabilities—out of sight and out of mind—have generally been overlooked by historians except where their experience is central to the topic (for example, the impact of war or the rise of the eugenics movement) or when they can be contained within narratives of exceptionalism in stories of people like Alan Marshall 'jumping puddles' or Tilly Aston 'overcoming' her vision impairment.⁴ Historians the world over 'have generally treated disability as a personal tragedy to be overcome, not a cultural construct to be questioned'.⁵ The individuals who

1 The University of Melbourne.

2 Productivity Commission (PC), 'Disability Care and Support', *Productivity Commission Inquiry Report* (54) (31 July 2011); PricewaterhouseCoopers (Australia), *Disability Expectations: Investing in a Better Life, A Stronger Australia Report* (Sydney: PricewaterhouseCoopers, 2011), <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>.

3 Doris Jame Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2001), xv.

4 See, for example, O. S. Green, 'Aston, Matilda Ann (1873–1947)', *Australian Dictionary of Biography Online* (Canberra: National Centre of Biography, The Australian National University), <http://adb.anu.edu.au/biography/aston-matilda-ann-5078/text8471>; Eileen E. Ewing, *'Can't I? Just Watch Me!': A Biography of Hazel Bedwin M.B.E* (Melbourne: Landvale Enterprises, 1981); and Alan Marshall, *I Can Jump Puddles* (Sydney: Penguin, 2004) (first published in 1955).

5 Douglas C. Baynton, 'Defectives in the Land: Disability and American Immigration Policy, 1882–1924', *Journal of American Ethnic History* 24(3) (2005): 41.

participated in the ADRM are therefore the ones who have been left with the task of communicating the transformative idea that it is not bodily impairment that disables people but socially constructed physical and attitudinal barriers.⁶ Since the movement took shape in the late 1970s, politicising the personal has been central to the task of breaking down these barriers.

Women have taken leadership roles in the struggle for disability rights in Australia. They've directed organisations, run businesses, headed families, assumed political office, played elite sport, published innovative academic research and advocated for their rights. They've done so in the context of a movement that encompasses a wide range of issues and includes activists with many different political perspectives, across the country and across eras: Tilly Aston in the late nineteenth century founded the Victorian Association of Braille Writers and later established the Association for the Advancement of the Blind (now Vision Australia); Elizabeth Hastings was appointed Australia's first Disability Discrimination Commissioner in 1993; Kelly Vincent in 2010 became the youngest woman ever elected to an Australian parliament and the first person with a disability elected to the SA Parliament. The leadership of women with disabilities, in disability activism and beyond, has been important to the development of public recognition and understanding of the issues confronting Australian people with disabilities and the ongoing challenge of eliminating discrimination.⁷

This chapter explores some of the ways in which Australian women have risen to this challenge. It refers to and builds upon their work through an analysis that describes women's leadership in disability activism over the past 30 years. It uses, in the main, oral testimony of activists themselves to highlight the issues they believed were most important, that best defined their styles of leadership and that characterised women's involvement in the movement. The focus will be on the period leading up to and immediately after the International Year of Disabled Persons (IYDP) in 1981 and the period in the early 1980s when a distinctly feminist consciousness began to inform activism. The chapter will explore the ways in which feminism influenced disability politics and will focus on the women who insisted that disability politics needed to be understood as a human rights issue of universal importance.

6 Margaret Cooper, 'The Australian Disability Rights Movement: Freeing the Power of Advocacy' (MA thesis, School of Social Work, University of Melbourne, 1999); Margaret Cooper, 'The Disability Rights Movement Lives', *Disability and Society* 14(2) (1999): 217–26; Rhonda Galbally, *Just Passions: The Personal is Political* (Melbourne: Pluto Press, 2004); Joan Hume, 'Disability and History', *Radical Sydney* (2010) <http://radicalsdney.blogspot.com.au/p/on-disability-and-history.html>; Helen Meekosha, 'The Politics of Representation or the Politics of Presence: The Challenge of Disability', in *Speaking for the People: Representation in Australian Politics*, eds Marian Sawer and Gianni Zappala (Melbourne: Melbourne University Press, 2001).

7 See, for example, 'Kelly Vincent', *The 100 Leaders Project*, <http://100leaders.org.au/themes/your-dream/kelly-vincent/>; Green, 'Aston, Matilda Ann'; 'Obituary: Elizabeth Hastings', *Women With Disabilities Australia News* (15) (1998), <http://www.wdda.org.au/issue15.htm>.

The chapter does so somewhat arbitrarily; there has been so little written in the area that to condense the complete history of the ADRM into the space provided would be general to the point of meaninglessness. My aim is to provide examples of women's activism as a way of introducing readers to some people who should be better known for the impact they had on improving the lives of people with disabilities. I approach the task cautiously, given the ambivalence most women with disabilities have about the narratives of exceptionalism and 'courageous battles against the odds' that accompany stories of their achievement. Stella Young, editor of *Ramp Up*, a website for news, discussion and opinion about disability in Australia, provides an explanation for this ambivalence. She describes the worst of these representations as a form of 'inspiration porn', designed to make able-bodied people feel better about themselves when they are feeling down. ('Things could be worse, I could be one of *them*!') Images of unnamed disabled people depicted as objects of inspiration and accompanied by slogans like 'the only disability in life is a bad attitude' exceptionalise and objectify people with disabilities and are premised on the assumption that the disabled people depicted 'have terrible lives, and that it takes some extra pluck to live them'. This isn't the case, and she gets tired of being congratulated for simply existing.⁸

Furthermore, stories of courage against the odds can create a dangerous impression. They can signal that if people with disabilities can't 'defy the odds' to 'overcome their disability' then the social structures that discriminate against them are not to blame; rather it's their attitude. 'It says that if we fail to be happy, to smile and to live lives that make those around us feel good, it's because we're not trying hard enough.'⁹ What Young describes here is a form of marginalisation that seems to be singularly owned by the disabled. 'Unlike racial, ethnic, and sexual minorities', says historian Catherine J. Kudlick, 'disabled people experience attacks cloaked in pity accompanied by a widely held perception that no one wishes them ill'.¹⁰ Put-down by pity is an insidious form of discrimination

Young's view has its critics. For some people with disabilities the very act of making it through a day *is* an achievement.¹¹ Indeed, leading advocates such as Keran Howe, executive director of Women with Disabilities Victoria (WDV), acknowledge that their own stories of success and achievement can provide inspiration for other women with disabilities confronting discrimination in their daily lives. As individuals, they've been able to overcome obstacles, but

8 Stella Young, 'We're Not Here for Your Inspiration', *Ramp Up*, ABC Online, 2 July 2012, <http://www.abc.net.au/rampup/articles/2012/07/02/3537035.htm>.

9 Ibid.

10 Catherine J. Kudlick, 'Why We Need Another "Other"', *The America Historical Review* 108(3) (June 2001): 768.

11 See comments after Young, 'We're Not Here for Your Inspiration'.

they recognise that not everyone has the capacity ‘to keeping banging on about the issues’ in positional leadership roles.¹² So Howe and others will be role models but they don’t want their stories to be used to justify any argument that the social order doesn’t need changing. ‘One of the most challenging aspects of disability’, says Kudlick, ‘is to convince non-disabled people that ... disability is not always a tragedy, a hardship or a lack but in fact offers much of value’.¹³ One of the challenges of writing the history of disability is recognising and resolving that tension between honouring individual achievement and foregrounding the barriers that make that achievement so remarkable.

With the rise of the ADRM in the 1970s and the accompanying understanding of history as a source of empowerment for marginalised social groups, we have seen scholarship aimed at reconciling that tension by representing people with disabilities as ‘more than another Other to add to a list that scholars either indulge or decry as being “politically correct”’.¹⁴ As people with disabilities began to describe how social structures, not their impairment, were the source of their exclusion, theories of disability as a social construct, not a medical problem, provided a platform for approaching disability ‘not simply as the variations that exist in human behavior, functioning, sensory acuity, and cognitive processing, but more crucially [in terms of] the meaning we make of these variations’.¹⁵ Helen Meekosha, Christopher Newell, Gerard Goggin and Karen Solditac are internationally recognised Australian academics who have made significant contributions to the emerging field of disability studies. Through critical analyses of disability, they have helped us to understand that there are a variety of ways of understanding disability as a construct with a past that informs the present.¹⁶ They, like other women featured in this chapter, have fought for the recognition of the *value* of disability ‘as simply a part of the human condition’ and campaigned for the citizenship rights of people who ‘do not wish to “be included”’: they wish ... to be acknowledged that they already belong’.¹⁷

12 Keran Howe interviewed by Nikki Henningham, Melbourne, 24 June 2010, Personal collection [hereinafter Howe Interview].

13 Kudlick, ‘Why We Need Another “Other”’, 769.

14 Catherine Kudlick, ‘Comment: Comparative Observations on Disability in History’, *Journal of American Ethnic History* 24(3) (2005): 60.

15 Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 2001), 2.

16 See, for example, Gerard Goggin and Christopher Newell, *Disability in Australia: Exposing a Social Apartheid* (Sydney: UNSW Press, 2004); Karen Soldatic and Helen Meekosha, ‘Disability and Neoliberal State Formations’, in *The Routledge Handbook of Disability Studies*, eds Nick Watson, Carol Thomas and Alan Roulstone (London: Routledge, 2012), 195–210.

17 Elizabeth Hastings, ‘Foundations: Reflections on the First Five Years of the Disability Discrimination Act in Australia’, Australian Human Rights and Equal Opportunity Commission website, http://humanrights.gov.au/disability_rights/hr_disab/found.html.

Women in the early disability rights movement

Space does not permit a comprehensive account of the rise of the disability rights movement in Australia in the 1970s and 1980s. There have been some partial accounts provided by those who participated, but a study comparable with Fleischer and Zames' analysis of the movement in the United States is yet to be written.¹⁸ Lifelong activists such as Margaret Cooper in Victoria and Joan Hume in New South Wales have commented upon the influence of activism from the United States, and the impact of national and international publications. They have also stressed the importance and influence of courageous individuals who showed them that being shut away in institutions, silently accepting exclusion and discrimination, was not the only option available to people with disabilities. People who asserted what little power they had over their lives by questioning the appalling treatment they received had a profound impact upon Cooper, who learned from them that an independent life was possible for people who 'took control and spoke up'.¹⁹ What this meant, in practical terms, was mobilising: a) to create social support networks for people with disabilities so they felt less isolated and discovered strength in numbers; and b) to advocate their rights for social inclusion on their own terms.

Women were prominent in the late 1970s and early 1980s in these efforts to mobilise. The late Lesley Hall, former CEO of the Australian Federation of Disability Organisations (AFDO), the peak body for disability organisations in Australia, was instrumental in establishing Victoria's first Disability Resource Centre (DRC), in Brunswick in 1981.²⁰ This, according to Margaret Cooper, was 'a radical and a vital step towards enacting what would become a basic priority for the disability rights movement, that there should be "nothing about us without us"'. Set up along the lines of the Independent Living Centres that were being established in the United States, where 'people with disabilities ran their own show', the DRC was not only important as a tool of empowerment and social support. As Cooper points out, it was also important because it was 'a step towards people with disabilities managing their own advocacy on a more formal, funded level'.²¹

18 Fleischer and Zames, *The Disability Rights Movement*; Cooper, 'The Disability Rights Movement Lives'; Hume, 'Disability and History'.

19 Margaret Cooper, interviewed by Nikki Henningham in the Women with Disabilities Project, 19 July 2010, National Library of Australia Oral History and Folklore Collection, ORAL TRC 6240/6, National Library of Australia, Canberra [hereinafter Cooper Interview]. See also, Nikki Henningham, 'Margaret Cooper: Feminist and Disability Activist', in *Founders, Firsts and Feminists: Women Leaders in Twentieth-Century Australia*, eds Fiona Davis, Nell Musgrove and Judith Smart (Melbourne: eScholarship Research Centre, University of Melbourne, 2011), <http://www.womenaustralia.info/leaders/fff/pdfs/cooper.pdf>, 261–73.

20 Lesley Hall, interviewed by Nikki Henningham and Rosemary Francis in the Women with Disabilities Project, 7 June 2010, National Library of Australia Oral History and Folklore Collection, ORAL TRC 6240/2, National Library of Australia, Canberra [hereinafter Hall Interview].

21 Cooper Interview.

The DRC was one of many initiatives that grew roots out of the funding and atmosphere that accompanied the IYDP in 1981. It was 'a crucial year', said Hall, 'for getting everyone to understand that people with disabilities needed to be involved and lead their own projects'.²² The experience of academic Natalie Tomas is typical of this early experience of group formation. Living in East St Kilda in 1981, Tomas, a history student at Monash University, decided to start a disability action group. Their first meeting was held in her flat; subsequent meetings were held in the St Kilda Municipal Library. 'I had no idea what I was doing', she remembered nearly 30 years later. 'I was just a nineteen year old student who had never organised anything in her life. But I thought it was a good idea.' She met people, they networked and they talked about the things they could do and change.²³ Social support and affirmation were important steps in the activist's journey.

As it did for many women with disabilities, this sort of grassroots activism marked her entry into formal disability activism and politics.²⁴ Also, as with many women with disabilities, it was not marked by any sort of feminist consciousness. Early grassroots activism focused on advocacy to see that very basic, universal human rights were granted to people with disabilities: rights to education, housing, employment and accessibility, especially to public transport.

Women were at the forefront of many of the public protests about inadequate access to such services in the lead-up to the IYDP, especially protests relating to public transport. Whilst protests happened across the country in all major cities, one of the most publicised was in Sydney, because it was captured on film. In 1979, at the opening of the Eastern Suburbs Railway at Bondi Junction, a state-of-the-art transport hub designed to be replicated in other locations, a small group of protestors in wheelchairs and their supporters, including Joan Hume and filmmaker Genni Batterham, were jostled, spat at, told that they were 'spoiling the view' and that they 'should go home to their nursing homes'.²⁵ The behaviour is graphically captured in the internationally acclaimed documentary film *Pins and Needles*, about Batterham's coming to grips with her own disability.²⁶ Premier Neville Wran, who officiated, was deeply embarrassed as he proclaimed

22 Hall Interview.

23 Natalie Tomas, interviewed by Nikki Henningham and Rosemary Francis in the Women with Disabilities Project, 18 June 2010, National Library of Australia Oral History and Folklore Collection, ORAL TRC 6240/3, National Library of Australia, Canberra [hereinafter Thomas Interview].

24 Ibid.; Cooper Interview; Hall Interview. See also Cooper, 'The Australian Disability Rights Movement'; and Hume, 'Disability and History'.

25 Hume, 'Disability and History'.

26 Barbara Chobocky, dir., *Pins and Needles*, [film] (Sydney: AFI Distribution, 1980).

the station to be 'open to many'.²⁷ He acknowledged later, when announcing the establishment of the NSW wheelchair taxi subsidy program as one of a raft of IYDP programs in 1981, that his experience at the protest motivated him.

For women with disabilities like Hume and Batterham, mobilising support for basic human rights for all people with disabilities was an important first stage in their activism. 'From little things, big things grow', said Hume, as she reflected on the journey from Bondi Junction in 1979 to the passage of the Commonwealth *Disability Discrimination Act* in 1992.²⁸

Women and the International Year of Disabled Persons, 1981

Early in 1980 award-winning advertising executive Phillip Adams met with three consultants to get advice on an important government-funded project. Adams had just been appointed by a Commonwealth Government ministerial committee to devise the media campaign to accompany 1981's United Nation's International Year of Disabled Persons. His brief was to educate the Australian public and to help them to 'see ability within disability', and he believed he had the strategy sorted within 10 minutes of being awarded the contract. Filmed portraits of Stephen Hawking, Franklin Delano Roosevelt—'any of the mighty afflicted', he said—'would be grist to my media mill'. The approach was ratified by the ministerial committee with satisfaction and speed.²⁹

The consultants he met were three women with disabilities. When Elizabeth Hastings, Edith Hall and Rhonda Galbally came through the door using their wheelchairs and crutches, Adams knew he was dealing with people who would persevere until their message sunk in. Their presence 'was testament', said Adams, 'to their determination, given that our building ... ha[d] no disabled access'.³⁰ At the meeting, the three women explained to Adams, politely, that he was 'a buffoon', and that his campaign involving 'super crips' (Elizabeth Hastings' words) like Hawking and Roosevelt would do nothing for 'the tens of thousands of ordinary human beings who suffered everything from the fears and stigmatising of the "the able-bodied" to a comprehensive apartheid'. This year people with disabilities would claim the right to speak for themselves; 1981 had to be 'the year of disabled people, not the year for them'.³¹

27 Personal Correspondence with Joan Hume, 18 December 2012.

28 Hume, 'Disability and History'.

29 Chris Hosking and Phillip Adams, 'Brave, Sensual, Feisty, Warrior: The Passionate Spirit, the Enquiring Vigorous Mind, and the Steadfast Love, Our Friend and Colleague, Elizabeth Hastings Born 21.1.1949 – Dies 13.10.1998', *Australian and New Zealand Psychodrama Association Journal* 7 (December 1998): 17.

30 Ibid., 1.

31 Ibid.

Adams required no convincing but was obliged to advise the ministerial committee of the change in tack. The members took some persuading to adopt the new, assertive slogan 'Break Down the Barriers'. Said Adams: 'They could see a campaign leading to demands for new legislation.'³² But he prevailed and 'the Government's hopes for a sweet year of sloganism came to naught'.³³ Adams, accompanied by Galbally, Hall or Hastings, travelled the country, taping interviews with hundreds of ordinary people with disabilities. Their stories formed the platform of an advertising campaign that won the 1982 Golden Lion Award at Cannes for the best advertising campaign in the world.³⁴ It was the first time advertising had been used as an effective tool to fight for the rights of people with disabilities. 'With Phillip's ads, and with our media and speaking campaigns', said Rhonda Galbally, 'we put disability rights on to the agenda and helped break down the institutional walls'.³⁵ Importantly, remembers Adams, 'by the end of the year, the disabled people of Australia had joined [Elizabeth, Edith and Rhonda] in speaking out for themselves'.³⁶

To say that Hastings, Hall and Galbally influenced Adams' thinking on how to understand disability is understating the extent of their impact. He claims that no-one taught him more about human rights than they did.³⁷ 'They made me realise that they [human rights] weren't merely an issue in Burma or Afghanistan', he said. 'They were missing here every time our bigotry, our buildings or our institutions placed a barrier in a disabled person's path.'³⁸ Indeed, one of the most important outcomes of the IYPD was the impact on communities of people with disabilities and those who were 'not yet disabled (NYD)'³⁹ of hearing people with disabilities taking control of events and speaking for themselves. Those in the former group were inspired to join the campaign for their rights; those in the latter began the slow process of transforming their understanding of the 'problem' of disability from a medical concern to a social problem.

Not everyone was as quick as Philip Adams to comprehend disability within the framework of human rights. But after a year of exposure to the advertising campaign there were many more 'NYD' people starting to make that transformative journey. The leadership role taken by women at this time was crucial in creating the platform to successfully advocate for important structural changes and legislative measures that would follow, such as the

32 Ibid.

33 Galbally, *Just Passions*, 16.

34 Hosking and Adams, 'Brave, Sensual, Feisty, Warrior', 18.

35 Galbally, *Just Passions*, 16.

36 Hosking and Adams, 'Brave, Sensual, Feisty, Warrior', 18.

37 Ibid.

38 Ibid.

39 NYD was a label used by Elizabeth Hastings to describe the 'able-bodied' population in Mark Ragg, 'The Quiet Enabler: Elizabeth Hasting, Australia's First Disability Discrimination Commissioner', *The Bulletin*, 15 March 1994: 42.

1981 survey of people with disabilities conducted by the Australian Bureau of Statistics (ABS), the 1983 Commonwealth Review of Handicapped Persons and the establishment of the Disability Advisory Council of Australia (DACA), also in 1983. A decade later, in 1992, the *Commonwealth Disability Discrimination Act* was passed, paving the way for the establishment of the office of the Disability Discrimination Commissioner.⁴⁰ It wasn't until there seemed to be real action on some of these basic human mechanisms to protect the rights of all people with disabilities that women in the movement began to form a view that disability politics' interactions with gender politics led to women with disabilities being 'doubly disadvantaged'.⁴¹

'Doubly disadvantaged': Disability and feminism intersect

While there were some important advances and responses from government and the community at large throughout the 1980s, there were still some significant blind spots. Many women with disabilities came to see that some of the worst of these related to the special issues they confronted. Some related to basic socioeconomics. Compared with men with disabilities, women were more likely to be poorly educated, unemployed, in institutional care and without access to adequate rehabilitation and health services.⁴²

Additionally, many activists began to express concerns that there were aspects of gendered discrimination that lay, quite literally, in the bodies of women with disabilities. They battled the pervasive and discriminatory notion that they had imperfect, unattractive, asexual bodies, which, in Hall's words, 'excluded them from society's norm'.⁴³ The fact that women with disabilities had a right to a sex life, the shape and boundaries of which should be determined by them, was a taboo subject that was taken on with candour and passion by the young New South Welshwoman Genni Batterham in *Pins and Needles*.⁴⁴ Diagnosed with multiple sclerosis (MS) at the age of twenty-three, Batterham and her husband documented her life with MS in a series of films over eight years.⁴⁵ Sex and

40 For a comprehensive list of legislative measures, see Mary Lindsay, *Commonwealth Disability Policy 1983–1995*, Background Paper 2 (Canberra: Australian Parliamentary Library, 1995–96), <http://www.aph.gov.au/library/pubs/bp/1995-96/96bp06.htm>.

41 Tomas Interview. See also Natalie Tomas, *'Double Disadvantage': Barriers Facing Women with Disabilities in Accessing Employment, Education and Training Opportunities—A Discussion Paper* (Disability Employment Action Centre, Melbourne, 1991).

42 Ibid.

43 Hall Interview.

44 Chobocky, *Pins and Needles*.

45 See also Hugh Piper, dir., *Riding the Gale*, [film] (Canberra, Ronin Films, Independent Productions International & Stormbringer Films); *Where's the Give and Take?* [film] (Sydney: Stormbringer Film Productions, Creative Development Branch, Australian Film Commission, NSW Department of Youth and Community Services, 1981).

sexuality were documentary focal points that, as one reviewer suggested, 'forced the viewer to reassess attitudes about the disabled and challenge historical value judgements about their needs'.⁴⁶

The idea that women with disabilities had bodies that they were entitled to manage in ways they saw fit was confronting. That the reviewer acknowledged the NYD community's need to respond to this by adjusting *their* thinking indicates that some people were starting to understand that although impairment is real, it is how we respond to it that makes it disabling. In other words, they were beginning to see the plasticity of disability as a social and cultural construction. Helen Meekosha has unpacked the social and cultural constructions of disability in Australia, and the complex web of meanings and relationships embedded in those constructions in order to underline the centrality of the politics of representation to the disability rights movement and to the women within that movement. She has argued that understandings of disability are fluid and no more fixed in biology than understandings of gender and race, and points to the historical dimensions of that constructedness, noting that almost from its foundations Australia preferred to lock disabled people away in institutions, preventing the 'pollution' of the wider population with 'defective' genes.⁴⁷ In the Australian colonial context, where development of a new society relied on the labour of the strong and the fit, where physical prowess became a measure of manhood while beauty and fitness to bear children were the cultural markers of femininity, the bodies of people with disabilities were regarded as defective and 'valueless'.⁴⁸

Women with disabilities, however, had been highlighting the relationship between real bodies and the warped meanings attached to them as a central plank of their feminist activism several years before Meekosha articulated this theory. Hall, for instance, became increasingly frustrated by the way traditional, patriarchal, gender hierarchies were played out in disability organisations and the apparent lack of concern for the needs of women with disabilities in the

46 'Review of Pins and Needles', *The Age*, 23 June 1988, 14; See also Chobocky, *Pins and Needles*.

47 Helen Meekosha, 'A Feminist/Gendered Critique of the Intersections of Race and Disability: The Australian Experience', Paper presented to the Faculty of Education and the Department of Educational Studies, University of British Columbia, Vancouver, 23 June 2005, <http://www.wvda.org.au/gendis2001.htm>, 5; Carolyn Frohmader and Helen Meekosha, 'Recognition, Respect and Rights: Women with Disabilities in a Globalised World', in *Disability and Social Theory: New Developments and Directions*, eds Dan Goodley, Bill Hughes and Lennard Davis (Hampshire: Palgrave Macmillan, 2012), 287–307; Helen Meekosha, 'Contextualizing Disability: Developing Southern/Global Theory', Keynote paper presented at the Fourth Disability Studies Conference, Lancaster University, Bailrigg, 2–4 September 2008, <http://www.wvda.org.au/meekosha2008.htm>, 9.

48 Baynton ('Defectives in the Land') and Kudlick ('Why We Need Another "Other"') have both explored these themes in the North American context. Jane Sherwin has argued that this understanding of disability still governs many contemporary attitudes towards people with disabilities. See Jane Sherwin, 'Leadership for Social Inclusion in the Lives of People with Disabilities', *The International Journal of Leadership in Public Services* 6 (Supplement) (September 2010): 84–93.

feminist movement. She was a founding member of the Women with Disabilities Feminist Collective (WDFC) that formed in Victoria in response. The WDFC was a social support organisation that engaged in overt political action. One of its earliest and best-known actions was its opposition to the Miss Australia quest, a beauty contest that raised funds for what was then called the Spastic Society, a charity that raised money on behalf of people with cerebral palsy. Hall and her group challenged the concept of the quest as a particularly objectionable form of fundraiser for people with disabilities, given its focus on physical perfection 'as the norm all must attain if they are to be fully accepted into society'.⁴⁹

Feminist activists and lobby groups for people with disabilities protested outside the national finals throughout the 1970s. The IYDP in 1981 provided the catalyst for sustained opposition to the quest. Hall was among a group of feminists and disability activists who managed to gain access to the Melbourne Town Hall, where the event was being held, and reach the stage—a challenging act in itself given her restricted mobility. The protests received significant press coverage and provoked a range of responses, from strong support from people within the Spastic Society and other disability charities to criticism from conservative people with disabilities, who believed the protestors were 'ungrateful spoilsports'. This was an attitude that angered activists even further, due to the patronising 'charity model of victimhood' it represented.⁵⁰ In Sydney in 1983, Hume and her colleagues found it particularly galling when there was not a single person with cerebral palsy in sight during the red carpet arrival to the event—an event that women with disabilities themselves were not encouraged or permitted to enter. Says Hume, 'They were not considered beautiful or socially acceptable enough'.⁵¹ These protests were, arguably, the first public acts to place disability as a feminist issue on the agenda.

Attitudes towards the bodies of women with disabilities began to drive the activism of many women in the ADRM as they began to understand the extent of the human rights abuses that were committed because of them. The forced sterilisations, child removals and appallingly high rates of physical and sexual violence were problems that were barely acknowledged, and remain at the heart of much activism today.⁵² On the one hand, women with disabilities were represented as asexual beings who weren't expected to form loving relationships, bear children of their own or establish families. On the other, their sexuality was

49 Hall Interview.

50 Ibid.; Hume, 'Disability and History'.

51 Hume, 'Disability and History'.

52 For a summary, see Frohmader and Meekosha, 'Recognition, Respect and Rights'. Also, Carolyn Frohmader, *There is No Justice—THERE'S Just US. The Status of Women with Disabilities in Australia* (Canberra: Women With Disabilities Australia, 2002).

recognised and exploited by the hundreds of people who abused them at rates substantially higher than those experienced by women in the community at large.

Women disability activists began talking about these problems in public forums and felt that their voices on these important human rights issues were being ignored by men in the disability rights movement and many women in the feminist movement. Cooper experienced the hard edge of this ignorance from both quarters in the mid 1980s. The first time came at an international meeting of Disabled People's International (DPI) in the Bahamas in 1985. It took a threat from all the women delegates to withdraw from the organisation for the men to take them seriously. The second time came at the hands of the feminist movement. In 1985 Cooper returned from the euphoria of the moment in the Bahamas to attend a National Agenda for Women Conference in Canberra. Broken promises over funding saw her at odds with some of the 'mainstream' feminist organisations. The constant glossing over of the issues confronted by Indigenous women, migrant and refugee women and women with disabilities promoted discussion and coalition amongst those marginalised groups.⁵³

In response, a formal Women's Network was established within the DPI. This translated into the formation of the National Women's Network (NWN) within the DPI in Australia in 1985. Cooper, Tomas and Hastings were all early members of the network, and they found that they had much in common with several members of the WDFC, like Hall, especially with regard to prioritising the problems of access to women's health services and domestic violence. Working as an unfunded network with little support from the male-dominated leadership of DPI(A), these women decided in the mid 1990s that they would be better off going it alone. In 1995, the network incorporated and changed its name to Women With Disabilities Australia (WWDA), a new organisation with the aim of providing a 'national voice for the needs and rights of women with disabilities and a national force to improve the lives and life chances of women with disabilities'.⁵⁴ As the peak organisation for women with disabilities in Australia, WWDA's establishment marked an important phase in the evolution of women's leadership within the ADRM. The politics of representation was always a central feature of disability activism, and throughout the 1990s its feminist edge solidified as women insisted that it was not enough for men to speak out on their behalf. 'Nothing about us Without Us' was a gendered mantra.⁵⁵

53 Cooper Interview; and Cooper, 'The Australian Disability Rights Movement'.

54 Women With Disabilities Australia, Webpage, <http://www.wwda.org.au/background.htm>.

55 Sue Salthouse refers to the use of the phrase as a slogan by people with disabilities in 'Brave New World: Is the Convention on the Rights of Persons with Disabilities a Blueprint for Utopia?', Paper presented at the Australian Federation of Disability Organisations Conference, Melbourne, May 2009, www.wwda.org.au/afdopapermay09.doc.

Over the past two decades the organisation has developed from one concerned primarily with building individual confidence and self-esteem to an internationally recognised human rights organisation. WWDA leaders continue to reinforce the message that disability is not a medical problem but a human rights issue, so the work of WWDA is grounded in a rights-based framework that links gender and disability issues to the full range of civil, political, economic, social and cultural rights.⁵⁶ WWDA has taken a leading role in creating this framework at an international level, a prime example being its work to ensure that a specific article on women (Article 6) was included in the UN Convention on the Rights of Persons with Disabilities, a treaty ratified by Australia in 2008.⁵⁷

Conclusion: Activism in the twenty-first century

Cooper has been involved with the ADRM since she was living in hostels in the 1960s and has had plenty of opportunity to watch it evolve over the past 40 years. From gaining inspiration from courageous individuals who refused to be patronised and infantilised, and supporting others through conversation and coffee to mobilising direct action, lobbying those in power with the capacity to make changes and working to establish organisations to give people with disabilities a voice—all this while managing work, study, relationship and other family obligations—Cooper has seen people and ideas come and go but she has never lost sight of what, for her, is the most important thing a leader must have: a passion for the issues.⁵⁸

Add to that a mechanism by which people can formulate ideas and communicate their passion and you get a sense of how Cooper understood effective leadership amongst women in the ADRM. She maintains that it was the feminist collective model of leadership that WWDA insisted upon that made it successful. She enjoyed participating in feminist organisations that were structured in ways that enabled information to be shared. They were 'circular' in shape rather than hierarchical, with leaders more like 'spokes in a wheel' who facilitated communication than figures sitting on high disseminating information as they saw fit. 'We did some amazing things', she says, 'acknowledging each other's point of view ... listening to everyone's opinion ... practising consensus decision making, thinking up ways by which other women could receive assistance to

56 Women With Disabilities Australia (WWDA), *Annual Report 2009–2010* (Hobart: Women With Disabilities Australia, 2010), <http://www.wwda.org.au/wwdarepts.htm>.

57 Sue Salthouse interviewed by Nikki Henningham in the Women and Leadership in a Century of Australian Democracy Oral History Project, 20 May 2011, National Library of Australia, Canberra, <http://nla.gov.au/nla.oh-vn5197761> [hereinafter Salthouse Interview]. For an account of the successes of WWDA at an international level, see also Frohmader and Meekosha, 'Recognition, Respect and Rights', 298–303.

58 Cooper Interview.

reach their goals'. Of course, this leadership model was time-consuming and very hard work, but, as Cooper indicates, it was 'infinitely more empowering than the old ways'.⁵⁹

Likewise, Sue Salthouse, WWDA president 2009–12, believes the effectiveness of WWDA nationally and abroad has come about not because of a focus on individuals but because individuals were, by and large, able to put their egos to one side for the sake of the group.⁶⁰ This has made interviews with women recognised by their peers to be leaders in the movement a challenging but interesting exercise. Most are reluctant to talk about themselves as leaders, except in the context of how they worked within a group to influence change. Understanding what constitutes good leadership matters, it matters enormously, but not as a position so much as a process resulting in change. What it achieves and how it does so are what count.

This is not to say that as individuals, these women don't recognise what it is they bring to the table. They rate themselves highly on their commitment, their strategic vision, their ability to share knowledge effectively and their use of networks to maximise their efficiency as facilitators. But what they are insistent upon is the importance of a leadership model that allows for a form of 'sharing'. They stress that it is impossible for any one person to carry all the traits required to be an effective leader, so the context in which they operate is all important. They almost always describe what they do in relation to how they connect with the group, with the issues and with the fight for social justice and human rights, without a hint of the 'heroic model' informing their processes. They conceptualise leadership within the 'hub and spokes' model of the collective, where knowledge is shared and the leader is the person who facilitates that sharing, within and beyond the organisation. A leader knows when to call in expertise from people at the rim of the wheel when required, and when to allow someone else to be added as an additional spoke. But, according to Sue Salthouse, she also knows when to rely on her own good judgment. 'While needing to be inclusive and consultative, prepared and hard-working', she says, 'you can't be self-effacing. A good leader has to have presence.'⁶¹

A good leader also has to be present. Says Salthouse, 'they must have a seat at the table', not only because it is vital that the voices of women with disabilities be heard but also because there is enormous symbolic importance attached to women with disabilities being seen to be leaders. They need to be able to demonstrate to themselves and the able-bodied people around them 'I look

59 Ibid.; Margaret Cooper, *Empowerment and Women with Disabilities* (Hobart: Women With Disabilities Australia, 1995), <http://www.wwda.org.au/empow.htm>.

60 Salthouse Interview.

61 Ibid.

like you, only sitting down'.⁶² Then, as Hastings hoped, we may proceed to a position where it is fully acknowledged that women with disabilities don't need to be included because they 'already belong'.⁶³

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⁶² Ibid.

⁶³ Hastings, 'FounDDAtions'.

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This text taken from *Diversity in Leadership: Australian women, past and present*, edited by Joy Damousi, Kim Rubenstein and Mary Tomsic, published 2014 by ANU Press, The Australian National University, Canberra, Australia.