Margaret Cooper: Feminist and Disability Activist

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Abstract: Margaret Cooper has been a leading figure in the disability rights movement since the 1970s. This paper describes aspects of her involvement, particularly the years when she was a member of Women with Disabilities Victoria.

Keywords: Margaret Cooper, Women with Disabilities Victoria, feminism, disability rights movement

Introduction

Women often start explaining an idea by describing how their own web of knowledge grew. That way others can check whether they have had similar experiences which may have led to similar conclusions and ideas which can be shared and developed.¹

Margaret Cooper

On 22 November 2010, a number of women gathered at Government House, in Melbourne, to launch a small publication. ‘Women with Disabilities Victoria: Claiming our Future’, documents the short, but important, history of Women with Disabilities Victoria (originally known as Victorian Women with Disabilities Network (VWDN)).² It was a momentous occasion, attended by a veritable who’s who of women who have not only been staunch advocates for women with disabilities across three decades, but have also been stalwarts in the community at large.³ Women with Disabilities Victoria has spent nearly twenty years supporting women with disabilities, advocating on their behalf so that they can lead ordinary lives and fulfil their own potential as leaders. There was much to be proud of as friends and members celebrated the history of an organisation that, despite significant changes, had always existed ‘to empower and support women with disabilities in Victoria to achieve their rights in the disability movement, the women’s movement and society in general by the provision of communication, information sharing, networking, advocacy, peer support and education’.⁴ Creating and sustaining ‘a web of knowledge’, as Margaret Cooper described it, has always been the top priority of Women with Disabilities Victoria.

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It was fitting that Margaret Cooper should be front and centre in the audience at the event. The daughter of a GP and a homemaker with a fiercely independent streak, Margaret Cooper grew up in the Melbourne suburb of St Kilda. After a family seaside holiday to Frankston when she was four, Margaret and her younger brother and sister came home unwell. The polio diagnosis was confirmed with the help of Dame Jean McNamara, who was developing an experimental vaccine for polio. Margaret’s brother and sister and some of the neighbouring children received the vaccine and their muscle weakness disappeared. Margaret was not so lucky. The general view was that she was going to die in any case, so treating her would be a waste of resources. Over 60 years later, it would appear that the doomsayers were wrong. Margaret is alive and well and continuing a life-long career in advocacy for people with disabilities, fighting for their rights to control their own lives.5

Margaret was a founder and inaugural member of Women with Disabilities Victoria and has been a leading light in the disability rights movement in Australia, more or less since its inception. She has been a social worker, advocate, volunteer, lobbyist and leader, taking on executive roles in feminist and other disability organisations since the 1970s. She was one of a group of women with disabilities from around the globe who were determined to bring attention to the special needs of women with disabilities and to highlight the inadequacies of both the disability rights and feminist movements’ responses to their needs. Her advocacy on behalf of women with disabilities has been enacted globally, on behalf of Disabled Persons International (DPI), nationally, as a leader in Women With Disabilities Australia, and locally, with Women with Disabilities Victoria. Her story and that of the disability rights movement in Australia are inextricably linked.

This paper will narrate some key features of the gendered development of the disability rights movement in Victoria and Margaret Cooper’s leading role in this process. Although the focus will be on Cooper, it will draw upon the experience of some of her contemporaries in order to round out the picture and to underscore her belief that leadership is only worth something if it is shared.6 It will start with a general discussion of the emergence of the feminist disability rights movement in Australia in the 1970s and 80s and move to a more focused discussion of Margaret’s important place within the movement.
Women, Feminism and the Disability Rights Movement

There is a photograph in Margaret Cooper’s collection of herself, Lurline Beeston and Lina Pane running a meeting in 1992 that, she thinks, was the first meeting of the network of women that was to become Women with Disabilities Victoria. The year 1992 may well be when this network officially came into being, but it was in the making for some years before then. Its antecedents can be traced back to the mid-1980s, when long-time activists came to understand that the disability rights movement was badly in need of a gender perspective. Others also became dissatisfied with the feminist movement’s lack of vision when it came to disability rights. And there were women working in health and allied professions who saw the lived experience of disadvantage at the intersection of gender and disability in the course of their professional lives. All these threads knitted together to create a network that came to meet every month on a Saturday in order to provide support and discuss the issues that confronted women with disabilities. The founding members were acutely aware that sharing experiences and ‘creating a web of knowledge’ was an important first step towards ‘taking hold of personal power’ and refusing ‘the role of victim’.

Many of the early members of Women with Disabilities Victoria had been active in the disability rights movement in Victoria for several years. Lesley Hall, chief executive officer for the Australian Federation of Disability Organisations in 2010, for instance, was associated with protest action at the Melbourne Town Hall in the early 1980s. She and a group of other women climbed on stage at the Miss Australia quest to protest against the event, which was an important fundraiser for the charity then known as the Spastic Society. She was a founding member of the Disability Action Forum, a unique organisation of people with disabilities from around Victoria, united on a regional basis—not disability specific—to speak and act on behalf of themselves. And she was instrumental, in 1981, in establishing the state’s first Disability Resource Centre (DRC) in Brunswick.

The DRC, 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 consciousness raising. As Margaret points out, it was ‘really important because it was a step towards
people with disabilities managing their own advocacy on a more formal, funded level’. As such, it was a key place where people with disabilities developed organisational skills and explored their potential as leaders.

The DRC was one of many initiatives that grew out of the funding and atmosphere that accompanied the International Year of the Disabled Person in 1981, ‘a crucial year’, said Lesley, ‘for getting everyone to understand that people with disabilities needed to be involved and lead their own projects’. And indeed they did. In the early 1980s, grassroots organisations, led by women and men who had been radicalised by their own experiences of discrimination and marginalisation in school, housing and the workforce, began to blossom. People who had received an education, often against the odds, and been inspired by stories about what can be achieved by people with disabilities when they are provided with appropriate support, began to mobilise, establishing informal collectives where people could just meet and talk. The experience of tertiary student Natalie Tomas is typical of this early atmosphere of ‘a hundred flowers blooming’. Natalie started up one of the first grassroots disability organisations in Melbourne from her own flat. ‘I had no idea what I was doing’, she remembers 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’.

For many women with disabilities, this entry into the world of disability politics 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 over equity in education, housing, employment and accessibility, especially to public transport. An extraordinary amount of effort went into lobbying the government for better services and legislative changes. In particular, the deinstitutionalisation of people with intellectual disabilities was implemented in the mid-1980s, a policy shift that Lesley Hall fully supported.

There was slow and steady progress on the legislative front, as governments began to accept that they had a responsibility to protect the rights of people with disabilities, and to acknowledge that the current situation was a disgrace. At the federal government level, in 1981, the Australian Bureau of Statistics (ABS) conducted a survey of ‘handicapped persons’. In 1983, the Commonwealth Review of Handicapped Persons was accomplished and, in the same year, the Disability Advisory Council of Australia (DACA) was established. In 1985, the Home and Community Care Program formed the first community-based respite services and, in 1986, the federal government’s Disability Services Act recognised advocacy as a program area to be funded.
In 1988, a Social Security Review of Income Support for People with Disabilities was held. Gains were also made with respect to social rights during the 1980s, including anti-discrimination legislation. In 1991, the Commonwealth State Disability Agreement transferred the direct administration of disability services, except employment and some advocacy programs, from the Commonwealth to the states and territories.\(^\text{17}\)

While there were some important advances and responses from government and the community at large during the 1980s, some significant policy gaps remained. Many women with disabilities came to see that some of the worst of these gaps applied to the special issues confronted by those of their own sex. Many of these related to basic socio-economic factors. As Natalie Tomas discovered when researching employment prospects for women with disabilities in the 1980s, women were ‘doubly disadvantaged’. Compared to men with disabilities, they were more likely to be poorly educated, unemployed or in institutional care without access to adequate rehabilitation and health services.\(^\text{18}\)

On top of this, many activists began to express concerns that there were aspects of gendered discrimination that lay, quite literally, in the bodies of women with disabilities, and that these were forms of prejudice not experienced by men. Women with disabilities battled the pervasive and discriminatory notion that they had imperfect, unattractive, asexual bodies that ‘excluded them from society’s norm’.\(^\text{19}\) 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 constantly challenged by the rate of forced sterilisation and sexual violence that they experienced. There were also significant concerns about their lack of access to women’s health services, and the impact of that on wellbeing and life expectancy. The fact, for instance, that women with disabilities, regardless of age, race, ethnicity, sexual orientation or class, are still likely to be assaulted, raped and abused at more than twice the rate of non-disabled women, even after the important advances made to improve the lives of people with disabilities over the last two decades, gestures towards how critical the situation was then.\(^\text{20}\)

Women with disabilities felt that their voice on these matters was being ignored, by both the disability activist movement and the feminist movement. Margaret Cooper experienced the hard edge of this ignorance from both quarters in the mid-1980s. The first time came at a meeting of Disabled Persons 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 when they said, ‘We have issues, you must listen to us’.\(^\text{21}\) The
threat grabbed the men’s attention, ‘a highly satisfying result’, according to Margaret, and resulted in the establishment of a Women’s Network within the DPI. This translated into the formation of a National Women’s Network (NWN) within the DPI in Australia in 1985. Eventually, after several frustrating battles with DPI(A) over funding for women’s issues, the network decided to go it alone. Women like Margaret Cooper, Natalie Tomas, Lurline Beeston and Lina Pane were all early members (or founding members) of the NWN, which then became Women With Disabilities Australia. These women were also early members of Women with Disabilities Victoria.

Margaret came to Women with Disabilities Victoria through her frustration with sexism within the DPI(A) but she experienced further frustration at the ignorance of the mainstream Australian feminist movement. In 1985, she returned from the euphoria of the moment in the Bahamas to attend a National Women’s Consultative Conference. Broken promises over funding saw her at odds with some of the ‘mainstream’ sisterhood, many of whom persisted in glossing over of the issues confronted by Indigenous women, migrant and refugee women and women with disabilities.

Other women with disabilities also experienced this frustration. Lesley Hall had been active in the feminist movement and, exasperated by the lack of understanding of the issues confronting women with disabilities in that context, joined with some of her peers to found the Women with Disabilities Feminist Collective (WDFC). As Natalie Tomas, an early collective member, noted, it was an informal, but important, organisation, made up of women with a feminist perspective, who in their own lives had experienced discrimination based on their disability, and ‘wanted to get something done’. It organised consciousness-raising activities and was a vital forum for such women to come together and discuss matters of importance to them.

The WDFC also engaged in political action, like the Miss Australia protests, which were arguably the first public acts to highlight disability as a feminist issue. Throughout the 1980s, the WDFC continued to draw attention to these issues. Like the women from the DPI(A) women’s network, they began to develop a more theorised perspective on the issues confronting women with disabilities, especially when it came to their health and the problems of domestic violence. By the early 1990s, there was some crossover between the two streams. A decade of networking and consciousness-raising had created an environment in which women with disabilities in Victoria knew they needed to do something.
Sometime in 1992, the word was sent out by Margaret Cooper and her friend, Lurline Beeston, and a diverse group began to meet on Saturdays. According to Natalie, after a week of work, it was sometimes hard to get motivated. But the effort proved worth it because meetings were stimulating. The collective brought together women with different needs, different political views and different ways of connecting with feminism (some of them hated the word—hence no mention of it in the original name, the Victorian Women with Disabilities Network). They ate different lunches, spoke different languages, and had different family experiences. But they all had some significant features in common. They were all women with disabilities who wanted to speak about and for themselves. Unless they took control, things would not improve. From here on in, they said, there was to be: ‘Nothing About Us Without Us’.

Margaret Cooper, Feminism and the Disability Rights Movement

To describe Margaret Cooper’s career in advocacy for people with disabilities as ‘life long’ is not an exaggeration. From the age of ten, as a school girl, Margaret has been fighting for the rights of people with disabilities. Excluded from any form of schooling as a small child (apparently a child in a wheelchair would have scared the other children in the local primary schools) Margaret attended the special school, Yooralla. While she liked being at school, learning and socialising with other children and young people with disabilities, she did not like the four-hour round trip every day to get there. She was annoyed that she had not been given the opportunity to mix with local children, and that her academic excellence was not recognised in the way that of her siblings, in grammar schools, was. She was really annoyed when authorities visited Yooralla and argued for it to become a primary school because secondary schooling would be wasted on people with disabilities. She knew how empowering a proper education could be, and wanted equity for all. Her experience of inequity at school set her on a political journey that has lasted a lifetime. Tertiary training as a social worker gave her the qualifications, and helped her to develop the networks and framework of understanding, that has made this journey effective.

It is as though every step of Margaret’s journey towards adulthood and enjoying the rights of full citizenship has involved a struggle that has brought change for those who follow. While laid up in orthopaedic wards, she watched the mistreatment of patients and applauded the courage of those who spoke out and succeeded in getting some things changed. It helped her to understand that, even though you may have to work within a system, it does not mean
you have to become a victim of it. ‘You don’t have to accept what is dished up … you have to be active’. Hostel living, the only option for people with disabilities living away from families in the 1960s, was often an infantilising and humiliating experience for people at the mercy of inquisitive and controlling supervisors. Margaret lived what she describes as a contradictory existence. At home, she battled hard to have control over her own life. ‘But at work, I was the expert, the mentor, the teacher, the authority figure’. One good thing about hostel living, however, was meeting people who refused to be controlled. People like Helen McKeon, for instance, demonstrated by example what was possible. She was a member of the Communist Party, she had a boyfriend and she had sex—all behaviour that was way too independent for the hostel supervisor, who eventually asked Helen to leave. But Margaret was inspired. ‘It was fascinating to see what people could do’, she says.

Margaret was heavily involved in disability activism throughout the 1970s, 80s and 90s, a time when the political and legislative framework was evolving and there was a real feeling that things were changing. Her involvement in state planning for the International Year of the Disabled Person (IYDP) in 1981 was an all-consuming activity. The lead-up to this event was exciting but gruelling with people giving up their personal lives to assist in developing the program. Margaret was on the state committee, representing the Victorian Council of Social Services, and was involved in a variety of other committees active in organising activities for the year. There would not have been a person she knew well who was not engaged in some way. It was a dynamic time and the planning was ‘a very empowering process’, she recalled. IYDP made a ‘huge difference’ to the lives of people with disabilities. And things seemed to gel particularly well in Victoria, where the networks created by people in schools and other services operating in a concentrated environment, seemed to spring into life. A highlight for her was sitting at a table of 25 people with disabilities and their representatives, thrashing out the issues that needed to be dealt with, making decisions for themselves.

After IYDP, Margaret took some time out from advocacy and activism. She was exhausted and needed to re-skill and recuperate. Work in the advocacy sector was becoming far more complex, and her advice was called upon more and more frequently after the sex and racial discrimination acts were passed. As a social worker at the Preston Community Hospital, she was moving into areas unfamiliar to her, such as domestic violence and sexual abuse, for which she needed to develop skills. Furthermore, she was living on her own, in her own unit for the first time, and needed to adjust to everything that entailed. She was also in a relationship with someone and wanted to commit time to that. So, in many respects, the 1980s were a time of consolidation and re-
skilling, a time for her to step back and see what the next generation could do. ‘Things were moving’, she said, so she felt quite confident in the capacity of younger people to continue the task of advocating on behalf of people with disabilities. Going back to university made her realise just how much things had changed. Still not enough, mind you, but the platform was established for people with disabilities to expect full citizenship rights. ‘Everyone was saying “I want a life, I want a family”…it was great’.

Cooper was not totally out of the loop, however. She attended the Disabled Peoples’ International (DPI) Asia Pacific regional assembly in Adelaide in 1984, and went overseas to the DPI World Assembly in the Bahamas in 1985. It was here, as mentioned above, that gender issues came to the fore. Margaret was instrumental in placing women’s concerns firmly on the agenda, and was involved in the early committees that eventually led to the establishment of Women With Disabilities Australia and Women with Disabilities Victoria. She would be a founding member of both organisations. They were great times and 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’ facilitating 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 reach their goals’. Of course, this leadership model was time consuming and very hard work, but, as Margaret indicates, they were ‘infinitely more empowering than the old ways’.

They were perplexing times as well, as Margaret began to see the impact of her leadership on some of the men she moved with in the disability rights movement. As well as being involved in feminist disability organisations, she served as vice president, policy, of DPI(A) in the 1980s. She had no mentors from whom to learn leadership skills and so found the experience a challenging one of learning on the job. She was proud of the work she did in policy development, although disappointed that no one in the organisation practised the affirmative action policy they developed. She was hurt by the people who attacked her personally, instead of criticising her work. As a leader who saw her role as one of sharing knowledge, she found it surprising how many times men would listen in silence to her proposals, perhaps criticise them, and then repackage them as their own. This led her to offer the following advice to other women intending to take up the challenge of performing leadership roles. Never ‘underestimate how much marginal males
will do to keep control … divest yourself of negative relationships … and build up a team of trustworthy advisors’ 29

After helping to establish the organisation, Margaret chose not to have a huge, on-going involvement in Women with Disabilities Victoria. For one thing, her workload was enormous and she was in danger of spreading herself too thinly. Furthermore, she was worried about being perceived as a ‘Queen Bee’, running the show in all women’s advocacy groups. She was acutely aware that new blood needed to be injected into the movement, if it was to survive. Her view was that the organisation had to be strong enough to do survive without her leading it. Her instincts were correct; after a short lull in activities, the network received an injection of energy from other sources, like the Women with Disabilities Feminist Collective, which included Lesley Hall and Natalie Tomas, as well as women such as Keran Howe and Di Temby, who came from the social work and women’s health sectors.

Whilst the issues of inequality of opportunity in education, employment and housing were (and are) important to Victorian Women with Disabilities, members believed that they were being attended to by other advocacy organisations. They decided that they would take on the issues others had ignored, and thus developed a health and violence and abuse orientation. Margaret herself was particularly involved in a large women’s health project, which was an important step in getting the community at large to recognise that disadvantage brought about by disability is not so much a health issue as a social problem and an abuse of human rights. 30 She was also connected to an important project run by WWDA, but including input from Victorian Women with Disabilities, which represented the first steps towards analysing the experience of physical and sexual abuse among women with disabilities. Like most women with disabilities, Margaret had buried her own experiences of harassment and abuse, and had not realised the extent of violence against women with disabilities in the community. Statistics indicate that 90 per cent of women with intellectual disabilities have been sexually abused and that 68 per cent of such women will be subjected to sexual abuse before they reach the age of 18. 31 It is a hidden problem that must be exposed and Margaret supports the on-going efforts of women’s disability advocacy organisations to do so, leaving the ‘big ticket items’ to the mainstream disability organisations.

Conclusion

Since 1992, when the first meeting was held, Women with Disabilities Victoria has been one of a handful of feminist organisations in Australia
defending the rights of women with disabilities in Victoria to speak for themselves and to advocate on their own behalf. From the very first days, they were about ‘Empowering Women’ to share and grow their ‘web of knowledge’ and become leaders of their own lives. Their effectiveness has been acknowledged by government and central departmental agencies and, according to Dr Helen Szoke, Victorian Equal Opportunity & Human Rights commissioner, they have had ‘a critical role to play in ensuring that the voice of women with disabilities is heard in government, law reform, policy development and service delivery’. 32

Margaret Cooper has been involved in this historical journey in some capacity, every step of the way. She has no doubt that life, on the whole, is better now for most people with disabilities than it was in the 1960s. The problems still exist, but they are at least recognised now. Appropriate national leadership, combined with active local organisations, can only serve to see continued improvement. Women with disabilities now expect that they can have a home, a family and a career. They demand to be treated equally and are better equipped to deal with discrimination when they experience it. Women with disabilities simply cannot be left off the national agenda.

Cooper is living proof of some of the changes that have occurred over her lifetime. In 2010, Margaret is a postgraduate student, completing her PhD, while caring for her elderly father and remaining connected to the disability activist movement as a member of a variety of boards and consultative committees. She remains a member of Women with Disabilities Victoria, although she is more active in other areas and organisations, for example the Telstra Disability Forum. ‘The digital divide is real’, she observes, and ‘it’s an economic issue that inevitably impacts upon people with disabilities in discriminatory ways’. 33

There are still, however, some major problems with services that seem to be worsening rather than improving. Cooper is very concerned about issues affecting Attendant Care, a service she has used since 1966 and one that has been steadily deteriorating over the past decade, owing to inadequate funding and training and to changes in the general workforce. ‘It’s hard to get someone to help after 7:30 pm’, she says, which means that is when she goes to bed these days. ‘You can manage your own bank account’, she says, ‘you can write a PhD but you can’t choose the time you want to go to bed. We’re back in the 60s’. 34
4 The aims were restated in VWDN updates and newsletters, e.g. Newsletter of the Victorian Women with Disabilities Network, October 2000, 2, Archives of Women with Disabilities Victoria.
5 Margaret Cooper, interviewed by Nikki Henningham in the Women with Disabilities Project, 19 July 2010, National Library Oral History and Folklore Collection, ORAL TRC 6240/6, hereafter cited as Interview with Margaret Cooper; Cooper, ‘Empowerment’.
6 Interview with Margaret Cooper; Cooper, ‘Empowerment’.
7 Francis and Henningham (comp.), 7.
9 A note written by Sarah Waters in 2004 found in electronic archives indicates that she thought it was established in 1993. The bulk of evidence suggests 1992 is correct. Sarah Waters’ memo, 8 June 2004.
11 Cooper, ‘Empowerment’.
12 Lesley Hall, interviewed by Nikki Henningham and Rosemary Francis in the Women with Disabilities Project, 7 June 2010, National Library Oral History and Folklore Collection, ORAL TRC 6240/2, hereafter cited as Interview with Lesley Hall.
13 Interview with Margaret Cooper.
14 Natalie Tomas, interviewed by Nikki Henningham and Rosemary Francis in the Women with Disabilities Project, 18 June 2010, National Library Oral History and Folklore Collection, ORAL TRC 6240/3, hereafter cited as Interview with Natalie Thomas; Interviews with Margaret Cooper and Lesley Hall. See also Cooper ‘The Australian Disability Rights Movement’; Margaret Cooper, ‘The Disability Rights

15 Interview with Natalie Tomas.

16 Interview with Lesley Hall.


19 Interview with Lesley Hall.


21 Interview with Margaret Cooper.

22 Ibid., and Cooper, ‘The Australian Disability Rights Movement’.

23 Interviews with Lesley Hall and Natalie Tomas.

24 Interview with Lesley Hall.

25 Interview with Natalie Tomas.

26 A collection of writings by women with disabilities that reinforced this can be found in Betty Bone, Margaret Cooper, Karen Hanson and Glen Tomasetti (eds), *Oyster Grit: Report on the Book Group Project for the Victorian Women with Disabilities Network* (Melbourne: VWDN, June 2000).

27 The following section is written mainly through reference to the above cited interview with Margaret Cooper.

28 Cooper, ‘Empowerment’.

29 Ibid.


31 Frohmader.

32 Written Communication with Dr Helen Szoke, Commissioner of the Victorian Equal Opportunity & Human Rights Commission, October 2010.

33 Interview with Margaret Cooper.

34 Ibid.