

Womenwithdisabilitiesvictoria

empowering women



Claiming Our Future

Women with Disabilities Victoria: Claiming Our Future.

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Women With Disabilities Victoria is an organisation made up of women with disabilities who support women with disabilities to achieve their rights in Victoria. Our vision is 'a world where all women are respected and can fully experience life'. Our Mission is to lead the way for Victorian women with disabilities and to improve women's choices by building partnerships and providing support, information and community education.

Cover photo: Members and friends of Women with Disabilities Victoria in the Melbourne office with Dr Marsha Saxton, research and policy analyst at the World Institute on Disability in Oakland, California (fourth from left). Dr Saxton toured Australia in May 2010.



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Contents

- 4 Introduction
- 6 'Nothing About Us Without Us': Early Days of Women with Disabilities Victoria
- 12 Empowering Women
- 22 Creating an Organisation with Clout
- 38 Building Networks
- 46 Influencing Change: The Core Business of Women with Disabilities Victoria
- 52 Building the Plan – Thinking Strategically
- 55 Selected References
- 56 Further Reading

Foreword

As with many aspects of the lives of women, the differences between men and women are not usefully understood. Not the self-evident differences of gender, but the lived experience difference, the health difference, the experiences of violence as well as disease, the experience of partnership as well as aloneness.

I remember distinctly the day that the Minister arrived to announce that Women with Disabilities Victoria would be funded, and that this funding would be ongoing. There was a big cloth banner in the background, and a room full of women. Some wept - for relief as much as joy - that finally their difference was recognised and that it would now be possible to focus on the policy, research, advocacy and service needs of women with disabilities across Victoria. And that the work would be done by them!

Governments don't often understand that when they fund advocacy, they strengthen their own work. The work that has been done by Women with Disabilities Victoria has made for a stronger response by government, and has added to the worth and value of support and opportunities for women with disabilities around Victoria. This booklet is an important opportunity, to remember and reflect, but also to be emboldened to demand more!



Dr Helen Szoke

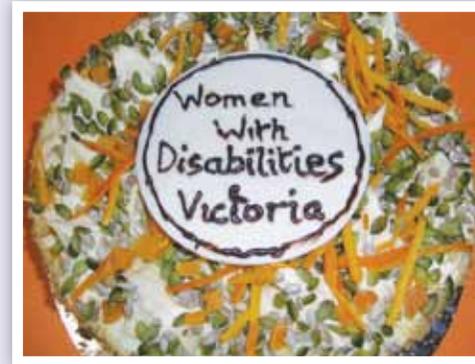
Commissioner
Victorian Equal Opportunity & Human Rights Commission

Introduction

On 19 August 2010, an exclusive group of women met in Melbourne to celebrate the birth of Women with Disabilities Victoria. Board members, general members, staff, partners, family and friends joined to acknowledge the 'passing' of the older entity it was replacing, the Victorian Women with Disabilities Network (VWDN), and to usher in a new era of advocating for women with disabilities in Victoria. 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 been stalwarts in the community at large. More than one inductee on the Victorian Honour Roll of Women was in attendance, and you don't get that accolade for working in a silo! Members and staff of Women with Disabilities Victoria have always been committed to empowering women in the communities they belong to. They just happen to have a disability.

For just over 15 years Women with Disabilities Victoria was known as the Victorian Women with Disabilities Network. In 2010, the general feeling amongst the members was that it was time for a name change, not only because the new version was easier to pronounce, but because it was a better reflection of what the organisation stands for in 2010. A reasonable argument, it would seem, however the proposed name change was not initially greeted with universal approval. As has been the case since the organisation was established in the early 1990s, discussion amongst members was 'open and robust'. The first name was born of contest (inaugural members contested the inclusion of the word 'feminist') and in 2010 the tradition of diversity from the floor and respectful consensus was alive and well. Some felt that a sense of tradition and history could be lost with the name change. A whole structure of identity is wrapped around a name. Why, therefore, change it?

Despite the obvious continuity, that this is a unique organisation run by women with disabilities for women with disabilities, Women with Disabilities Victoria is not the same, informal network of volunteers that, in 1994, 'met regularly on the first Saturday of every month to discuss anything



The cake served at the celebration of the new name.

relevant to the needs of women with disabilities and to develop strategies to advance the interests of the constituency'. In 2010, it is a fully incorporated, not for profit association managed by a Board of Directors that employs four members of staff. It has a well developed strategic plan and a focus on advocacy in three well articulated priority areas. The members are still

encouraged to be involved in deep discussion about their situation, although the hope is that they will take what is discussed to the 'mainstream', by representing the interests of women with disabilities in community and other organisations. What started as a network with an entirely justifiable inward focus on empowering its membership to learn their rights and find strength in unity has transformed into an organisation made up of empowered and passionate women with a single-minded determination to raise the consciousness of the community at large. VWDN is now Women with Disabilities Victoria.

The following pages describe this transformation, and celebrate the women who travelled with it. But before going back to the beginning, we need to turn and face the existing elephant in the room. Why is Women with Disabilities Victoria necessary? There are many disability advocacy organisations in Australia, some with a disability specific focus while others are focused on servicing national and regional interests and the interests of carers. Government has come a long way in passing equal opportunity legislation that protects the rights of people with disabilities. Public consciousness of the issues, while still inadequate, is on the rise. Why, then, do we need an organisation that focuses solely on the needs of women with disabilities?

Women with disabilities are amongst the most marginalised and disadvantaged people in Victoria because they are less likely to be educated, employed and well-housed than almost any other member of the community. Make no mistake; gender influences the disadvantage that comes with having a disability. **That's why we need Women with Disabilities Victoria.**

Women with disabilities are less likely than women without disabilities to receive appropriate health services, particularly breast and cervical cancer screening programs, bone density testing, menopause and incontinence management. It is ludicrous that people who almost certainly have health issues associated with their disability are less likely to receive health services than people without disabilities. **That's why we need Women with Disabilities Victoria.**



Wendy Brooks (Women with Disabilities Victoria Chair) and Keran Howe (Executive Director, Women with Disabilities Victoria).



Members and staff at the celebration of the new name.

Women with disabilities are more likely to have their human rights abused than women without disabilities or men with disabilities. Girls and women with disabilities are more likely to be unlawfully sterilised than their male counterparts. Between 1992 and 1997 at least 1045 girls with disabilities in Australia were unlawfully sterilised. Comparisons with other data sources suggest that the true number is much greater. **That's why we need Women with Disabilities Victoria.**

Women with disabilities, regardless of age, race, ethnicity, sexual orientation or class are assaulted, raped and abused at a rate of at least two times greater than non-disabled women. Statistics indicate that 90% of women with intellectual disabilities have been sexually abused. 68% of women with an intellectual disability will be subjected to sexual abuse before they reach 18. *This is a national disgrace.* **That's why we need Women with Disabilities Victoria.**

As long as that elephant keeps appearing at celebratory functions attended by women with disabilities, then we need Women with Disabilities Victoria. Perhaps the greatest celebration of all will be the day she doesn't turn up, because the Women with Disabilities Victoria vision of 'a world where all women are respected and can fully experience life' will have been achieved. But until that time, we cannot ignore her. She is blocking a view that women with disabilities have every right to share.

'Nothing About Us Without Us': Early Days of Women with Disabilities Victoria

Women with disabilities who had been involved in disability activist organisations in the 1970s and 80s, or were part of the feminist movement in that era, came together in the early 1990s to form Women with Disabilities Victoria because they were tired of the way their concerns were marginalised by both political movements. The cry of 'we have issues, you must listen to us,' was repeatedly ignored, so women from both streams came together to 'do something'. Sometime in 1992, word was sent out and a diverse group began to meet on Saturdays, to 'do something'.

From the outset, Women with Disabilities Victoria was a 'very member driven' network, building on the model of the feminist collectives of previous decades. It had an important internal focus as a social support group for empowering women with disabilities. Women came together to talk about issues and discuss the ways in which women with disabilities were discriminated against differently. They 'got involved', writing letters and making policy, focusing on health related issues, parenting issues and domestic violence. They lived the mantra of 'nothing about us without us'.

According to Natalie Tomas, an early member, after a week of work it was sometimes hard to get motivated and head into the Disability Resource Centre in Burnley or the John Pierce Centre in Prahran to meet. But it was worth it, because meetings were normally 'pretty interesting'. They were a bunch of women with different needs, political views, cultural backgrounds and family experiences. They had different ways of connecting with feminism (some of them hated the word – hence no mention of it in the original name.) But they all had one thing in common. They were all women with disabilities who wanted to speak about and for themselves.

Glen Tomasetti articulated the importance of women with disabilities taking responsibility for their own political and social activism. Although it was

tiring, even exhausting (and it was important to be aware of the fatigue that could cause pain and even further incapacity), she explained that 'activism on behalf of oneself and others in a group can give energy. A way of raising confidence and of making a change for the better, is to be a member, as active as possible, of the Victorian Women with Disabilities Network [as it was then known]. In a short time it has given me a sense of support in the solidarity of a common purpose'.

This foundational history as a member driven organisation for women with disabilities by women with disabilities is what makes Women with Disabilities Victoria unique and is the ultimate source of its strength. For Keran Howe, an early member of Women with Disabilities Victoria, it is the key source of its power as an effective advocacy organisation. 'If we don't have that,' she says, 'we might as well go home.'

As the network matured, the members began to look at how they could use this effective foundation to have a political impact that would place the issues that they thought were being ignored on a broader agenda for action. The 'big ticket' items, such as access to education, employment, and housing all share a gender dimension that must be addressed, but Women with Disabilities Victoria decided to focus on issues that were the exclusive problems of women with disabilities.

Problems associated with women's health, parental rights, expressions of sexuality (almost exclusively represented as a problem for men only) and the appalling prevalence of violence against women with disabilities were ignored by the mainstream disability organisations. Since Women with Disabilities Victoria came into being, members have been driving an organisation dedicated to ensuring that they can't be ignored.



(From Left) Lurline Beeston, Marg Cooper and Lina Pane at an early meeting in Richmond, to determine the viability of an organisation for women with disabilities, c. 1992.

*Women with disabilities
All women
Sisters
Listen
Share your anger, laughter and strengths
Reach out
It is time to make others hear us*

*For too Long we have remained in the
background
Isolated from each other
Behind the general thrust
of the Women's Liberation Movement
the Disabled Rights push for equality*

We have important things to say

A poem published as a preface to an undated early publication produced by the Women With Disabilities Feminist Collective, articulating the dissatisfaction with existing political movements.

Lurline Beeston

Determining when the Women with Disabilities Victoria story begins has not been as easy as one might think. Some sources say it would have been around 1993, others say it was as early as 1992. All of them say that if Lurline Beeston was still alive, she would know. Sadly, Lurline passed away far too young, in 1997, so we can't ask her. Nevertheless, it is Lurline who gives us as close to a definitive date as we are likely to find. In her report for the newsletter of the national organisation, Women With Disabilities Australia (WWDA), in 1994, she advised members that 'our group was formed in April '92' and that they met 'regularly on the first Saturday of every month to discuss anything relevant to the needs of women with disabilities and to develop strategies to advance the interests of our constituency.'



Lurline Beeston c. 1996.

Lurline Beeston was severely ill with polio as a child, and was hospitalised for several months. She had strong memories of her parents travelling hundreds of miles from their Gippsland farm to visit her as often as they could. Hospitals discouraged family from visiting too often because it was, allegedly, disruptive and upsetting to the children!

As a young woman in the 1950s, Lurline worked as a clerk travelling on trains at a time when there were no ramps or disability access plans. This experience politicised her and she was frequently involved in protests throughout the 80s and 90s over accessibility. She lived in a hostel for people with disabilities (there was no other accessible housing then) until she could no longer endure the restrictions and humiliation that came with the territory of hostel living and took a flat with a friend. She kept up her social life, met Nick and married him in 1961. They moved around a bit, including overseas, had their two children, and eventually settled in Laverton, Melbourne.

Margaret Cooper remembers meeting Lurline in 1964, after she had 'blown in from Malaysia'. They were both patients in the same orthopaedic ward. Says Margaret:

There were four of us under the age of 30, all separated by rows of very old women. It was physically impossible to talk with each other but I wanted to ask her so many things like 'How do you look after your babies?' or 'will I ever be as independent as you?'

I kept on hearing about Lurline's exploits through the polio grapevine, but I didn't 'meet' her until the early 90s when we both became involved in looking at disability issues from the point of view of women. I was actually a bit scared of her; Lurline's life seemed so much more exciting than mine.

Lurline's involvement with the disability consumer sector was extensive. She began work as the Administrative Officer for the Western Region Committee of Disabled Persons (WESTCOD) in January 1988. She was heavily involved with transport issues in Victoria and played a role on sub-groups for the State Transport Minister's Accessible Transport Consultative Council and other committees. She was a founding member of WWDA and Women with Disabilities Victoria.

Her friends remember her as an advocate and activist, who loved parties, endless chats and shopping. She spoke passionately about the importance of families, and the need for mothers with disabilities, and mothers of children with disabilities, to get the help they need. 'I'm not a feminist' she declared, but she believed in the rights of women to live and work how they wanted to.

Lurline Beeston died suddenly on February 8, 1997. A trailblazer all her life, 'she's gone ahead of us again', said her obituary writer and good friend, Margaret Cooper.



Lurline Beeston demonstrating about public transport accessibility.



Lurline Beeston - activist.

Margaret Cooper

Margaret Cooper has been an inspiring symbol of the disability rights movement in Australia, virtually since its inception. The daughter of a G.P. and a homemaker with a fiercely independent streak, Margaret 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 wasn't 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 sixty 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.



Margaret Cooper in relaxed mode.

'Life long' is not an exaggeration. From the age of ten, as a school girl, Margaret 'began her journey into advocacy'. Excluded from any form of schooling as a small child (apparently a child in a wheelchair would scare the other children in the local primary schools) Margaret attended the special school, Yooralla, from the age of ten. While she liked being at school, learning and socialising with other children and young people with disabilities, she didn't like the four hour round trip, every day, to get there. She was annoyed that she didn't get the opportunity to mix with local children, and that her academic excellence wasn't 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 that has made this journey effective.

It is as though every step of her journey towards adulthood and enjoying the rights of full citizenship has involved a struggle which has brought change for those that followed. While laid up in orthopaedic wards, she watched the mistreatment of patients, and 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 with a system, it doesn't 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. She 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'.

The 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. A key activity in which she took part was state planning for the International Year of the Disabled Person (IYDP) in 1981.

The lead up to this event was exciting but hard work. Many people gave up their personal lives to be involved in the planning for this. Margaret was on the state committee, representing the Victorian Council of Social Services, and was involved in a variety of other committees engaged in organising activities for the year. There wouldn't be a person she knew well who wasn't engaged in some way. It was a dynamic time and the planning was 'a very empowering process'. 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 twenty-five people with disabilities and their representatives, thrashing out the issues that needed to be addressed, making decisions for themselves. An important outcome of these meetings was the agreement that a Disability Resource Centre should be established, along the lines of the Independent Living centres in the United States, where people with disabilities ran their own show. This was an incredibly radical idea for the time. But it was crucial, in Margaret's opinion, to moving towards a situation where managing advocacy could be administered on a more formal, funded level.

After IYDP, Margaret took some time out from advocacy and activism. She was exhausted and needed some time to re-skill and recuperate.

She wasn't 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 that gender issues came to the fore.

Margaret was 'a generic equal rights person' with feminist sensibilities. She understood the constraints placed on women with disabilities as a result of their gender. These were some of the issues that women at this meeting said needed to be confronted. The general message was, 'We are not being treated fairly,' said Margaret, 'what are you going to do about it?' The response from the male members was disappointing, as they told the women that there were more important things to worry about.

The women persisted. 'Women with disabilities have less access to education and employment than their male counterparts,' they argued. 'They are less likely to be married and live a 'normal' family life. They are more likely to be abused. You must listen to us and confront these issues.' The outcome was a special meeting where it was determined that the main body of DPI would assist the women to establish a special women's group within the organisation. This group would develop policy which could be taken to the main Board for consideration. It was a 'highly satisfying' result, one which, in the fullness of time, would lead to the establishment of WWDA and Women with Disabilities Victoria. Margaret was a founding member of both organisations.

In 2010, Margaret 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'. She's 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, due to inadequate funding, training and changes in the general workforce. 'It's hard to get someone to help after 7:30 pm,' she says, which means that's 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'.

Natalie Tomas

Natalie Tomas, feminist, academic historian and public servant, has been active as an advocate for women with disabilities since the 1980s. She was a bright student who refused to be ignored and received a good secondary education, which enabled her to complete a PhD. In negotiating her own tertiary education she discovered the limitations that bureaucrats attempted to impose on people with disabilities, and experienced the practical limitations that confronted her as a woman with a disability. Limited access to public transport and to buildings where classes were held were challenges most other students didn't have to face as they negotiated their way around the university campus and work places.

Nevertheless, Natalie's lived experience demonstrated what could be achieved by people with disabilities when they are provided with appropriate support. She became part of a movement of people who began to establish informal collectives where people could just meet and talk. Living in East St Kilda in 1981, Natalie decided to start a disability action group. Their first meeting was held in her flat, subsequent meetings were held in the St Kilda library. 'I had no idea what I was doing,' she remembers nearly thirty 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.

Like many women with disabilities, this sort of grass roots activism marked her entry into disability activism and politics. Natalie was an early member of Women with Disabilities Victoria and WWDA, and was at the founding meeting of the latter organisation. She had been a member of the Women with Disabilities Feminist Collective which preceded both. She served on the Women with Disabilities Victoria Management Collective, resigning in 2006, when she felt that her current employment would create a conflict of interest.

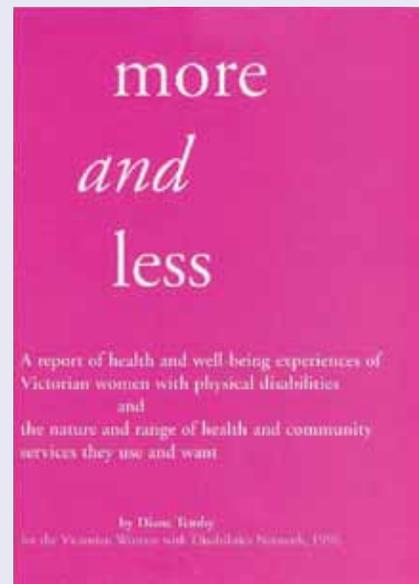
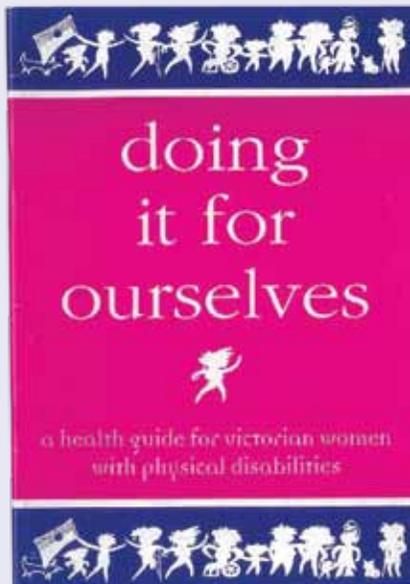
In the transition period of Women with Disabilities Victoria, Natalie served actively on the Partnership Governance Group and was earlier engaged in the discussions and negotiations which preceded the signing of the Partnership Agreement in 2005. She served on the Victorian Disability Services Council for three years.



Natalie Tomas (left) with Tricia Malowney and Keran Howe at the Australian Sign Language Interpreters Association (ASLIA) Awards in 2008.

Empowering Women

When the Victorian Women with Disabilities Network changed its name to Women with Disabilities Victoria it made sure that the words 'Empowering Women' were included in its new logo. Implicit in its activities and strategic direction, since formation, is a focus on, and commitment to promoting leadership opportunities for women with disabilities and fostering the empowerment and participation of women with disabilities.



More and Less and Doing it for ourselves

A very important first step in empowering women with disabilities was to consult them formally on matters of great concern to them. In 1996 Women with Disabilities Victoria, with support and funding from the Victorian Health Promotion Foundation and a number of partners, including the Healthsharing Women's Health Resource Centre, now Women's Health Victoria; La Trobe University School of Nursing (Centre for Social and Environmental Health Nursing) and the Royal Women's Hospital Social Work Department published two important reports. These reports documented the challenges confronting women with disabilities in their every day lives and the impact these challenges had on their health and well being. The project was a unique opportunity for women with disabilities to represent themselves and discuss, in a formal context, their experiences.

More and Less: A report of health and well-being experiences of Victorian women with physical disabilities and the nature and range of health and community services they use and want, written by Diane Temby (La Trobe University), with help from Keran Howe, Lina Pane, Pam Menere and Deb Peitch (Healthsharing Women's Health) summarised the consultative process and provided preliminary research data for the development of an information resource for women with disabilities in Victoria.

Doing it for ourselves: a health guide for Victorian women with physical disabilities, compiled by Fiona Strahan and published in November 1996 sought, in the words of the author, 'to empower women by using the voices and writings of women with disabilities'. Implicit in this aim was the notion that 'knowledge is power'. The women of Women with Disabilities Victoria were determined to support women with disabilities in Victoria by alerting them to their rights; by 'putting information into the hands of women with physical disabilities about the types of services available, their location and how to use them.'

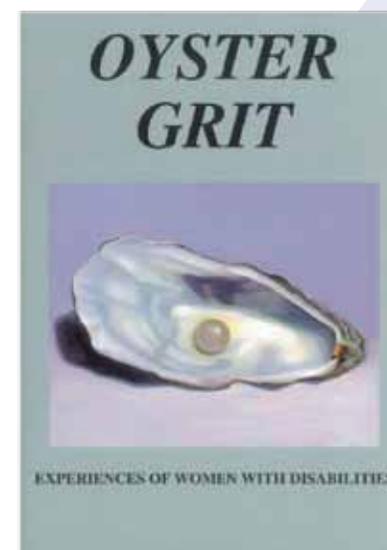
Women's Writing Circle and *Oyster Grit*

Consistent with its aim to empower women through the sharing of life stories and experience, Women with Disabilities Victoria took the initiative to produce and publish *Oyster Grit* in 2000. It was a number of years in the making. A notice in the October 1997 newsletter explained the proposed publication, suggesting that:

[O]ur writings could cover survival strategies, or how did some women achieve what they wanted. We might want to tell about leadership experiences, becoming part of a local community group or working with others to win a battle. Ways we have kept healthy and strategies to improve our strength and endurance might be interesting and helpful to other women with disabilities. Our history is very important, where we came from, who were the early female disability activists and where do we think we are going to - what would you like to tell the next generation of girls with disabilities? There's so much to tell – how will we select the poems, the stories and true tales? How will we get funding for a book? Would you like to work with us?

Glen Tomasetti held a series of four workshops at the State Library of Victoria to assist women with their writing. The book group members who managed the project were Betty Bone, Margaret Cooper, Mary Eves, Karen Hanson, Janny Ryan, Diane Temby and Bernadette Zen.

Launched in February 2000, *Oyster Grit* remains an important publication because, in the words of Rhonda Galbally, Women with Disabilities Victoria member and then manager of the Australian International Health Institute, it not only provided an opportunity for women with disabilities to speak frankly about their 'acute immediate experience', but it 'opened up the life of women with disabilities...for all to see'. In a very practical sense, *Oyster Grit* has an additional value; it helped to keep the organisation in the black when times were tough in the early 2000s.



Oyster Grit also represented an early attempt to provide an historical and social context to the lives of women with disabilities. In her contribution 'Disability rights movement revisited – the role of women', Lesley Hall rearticulated for the twenty-first century, the mantra 'nothing about us without us':

Moving into the year 2000, I want my voice to be heard. I want to be heard as a person. I want to be listened to because I have expertise – expertise that has been gained through a lifetime of having a disability. I want to be listened to, respected, regarded as the person who knows what is best for myself. I do not want other people to talk on my behalf – unless they have my permission. I do not want to be patronised. I do not want to be treated as unequal because of my disability or because I am female.

Women With Disabilities Australia Leadership and Mentoring Workshop

The year 2000 also saw Women with Disabilities Victoria involved in an important initiative that was to provide the model for subsequent activities. In June 2000, WWDA ran the first ever national workshop to increase leadership and mentoring skills for women with disabilities in Australia. Twelve women from around the country met at the Hotel Y in Melbourne over two days to participate in a course based upon a resource kit developed by Carolyn Frohmader and Ann Storr of WWDA.

Described as 'an invigorating and inspiring experience for the women involved', the workshop covered numerous themes as women discovered that they all had leadership qualities lurking within, just needing encouragement to be released.

Women with Disabilities Victoria and Women With Disabilities Australia Dinner

A highlight of the two day Leadership and Mentoring Workshop was the dinner jointly hosted by WWDA and Women with Disabilities Victoria, held in the function room at the Hotel Y on the last night. Guests were greeted by an art show in the foyer, which was converted into a gallery for displaying the art, jewellery and writing of women with disabilities. Between courses at the dinner, Weave Movement Theatre presented a dance and movement piece. At the end of the night, Women with Disabilities Victoria member, Samantha Jenkinson, provided musical entertainment, singing songs by and for women with disabilities.

'It was a very powerful feeling to be in a place where the organisation, entertainment and speeches were all done by women with disabilities, and those who would normally assist us were our guests.'

The post workshop dinner provided the inspiration for later 'gala events'. Members quickly saw the capacity for networking that they provided. 'Ordinary Women, Extraordinary Lives' (to be discussed later) was held in December 2001.



Samantha Jenkinson and Amira Pylotis performing at the Leadership Forum Dinner.

Women With Disabilities Leadership Project



Weave Dance Theatre performing at the Leadership Forum Dinner.



Weave Dance Theatre performing at the Leadership Forum Dinner.

In 2004-5 Women with Disabilities Victoria received funding to conduct the Women with Disabilities Leadership Project. The Project Officer, Sarah Waters, consulted with women with disabilities who had diverse experiences of leadership, in order to identify and document the leadership needs of women with disabilities in disability advocacy organisations and local government disability advisory committees. The experiences of five Women with Disabilities Victoria members with leadership experience (Margherita Coppolino, Norma Seip, Lesley Hall, Natalie Tomas and Ria Strong) were documented as part of the process.

It was an important initiative because it analysed the impact of disability and gender on leadership for women with disabilities, thus highlighting the double disadvantage that arises from that intersection. Margherita Coppolino was typical of those who participated when she stressed the importance of women with disabilities not only moving within their own circles, but finding the confidence to move in different sectors to 'expand the support available to them' and to 'discover that they are really quite progressive'.



Ria Strong (left) was consulted for the Women with Disabilities Leadership Project. She is pictured with Rebecca Maxwell.

Banner Painting On International Day Of People With Disabilities



The 2007-2008 Board in front of the Banner that was painted in 2000.
Back: Deb Humphris, Delia Portlock, Margaret Bayly, Tricia Malowney (Chair) and Sharon Granek.
Front: Effie Meehan, Danielle Chaffey and Margaret Stevens.

An important part of empowerment is celebrating achievement. Management Collective members recognised that this needed to happen alongside the important advocacy work that members were doing. A symbolic activity to mark that thinking was the creation of a new banner to represent the organisation. Members met to do so on the day of the AGM on 3 December 2000, at the Peacock Inn, Northcote. They enjoyed a glass of champagne as they discussed the role and future of women with disabilities in Victoria. Community Services Minister, the Honourable Christine Campbell and her advisor, Claire Thorn, were present for lunch. Said Co-Convenor Samantha Jenkinson, 'It was a great day and a great way to celebrate the International Day of People With Disabilities.'

Leadership Forum 2009

In September 2009 over 100 women attended a Leadership and Disability Roundtable, held in conjunction with Leadership Plus, a community sector initiative that promotes people with disabilities as leaders. Guest speakers were Charlotte McCain Nhlapo, from the World Bank, Maryanne Diamond, President of the World Blind Union and Effie Meehan and Wendy Brooks from the Women with Disabilities Victoria Board.

The event was universally praised as 'one of the best forums I've been to' as attendees listened to 'incredible speakers and inspirational advocates for women'. Marianna Codognotto, from Jesuit Social Services, felt privileged to attend:

What a gift to be surrounded by so many fabulous women willing to share their lived experience – the ups, downs, laughter, struggles and triumphs. Their vision and enthusiasm to work towards positive solutions was both humbling and inspirational. I wasn't going to stay for the leadership forum (many piles of work left behind at the office), but felt I couldn't leave as I didn't want to miss out on a second of all the conversations occurring all around me.

The event confirmed in the minds of all who attended that:

'Women and girls with disabilities are the solution, not the problem.'



A panel of speakers at the 2009 Leadership Forum.

Peer Mentoring and Support

A major breakthrough for Women with Disabilities Victoria in its quest to empower women and encourage leadership potential came when funding was obtained in 2010 to support a position for someone to perform this task. Lauren Hayes began work as Project Officer for Peer Mentoring and Support in March 2010. Her job entails supporting members in their representation work, for example those who sit on committees and boards, and who write submissions, by providing them with accurate information. Her role also involves increasing membership capacity, forming partnerships and collaborating with other women's services. Lauren is developing a peer mentoring program to enable members to gain the skills to become effective representatives in mainstream organisations.



Charlotte Mclain Nhlapo (left) was a guest speaker at the 2009 Leadership Forum. She is with Keran Howe.

Young Women's Health Forum

Women with Disabilities Victoria is aware that young women do not identify with traditional representation practice such as participation on advisory committees, submission writing and meeting with politicians. In order to identify ways that young women would like to engage in the work, in 2010 Women with Disabilities Victoria conducted an information sharing session for young women with disabilities on improving access to health care. Feedback was extremely positive. One participant made the following comments about the session:

I think you had a brilliant cross section of the disability communities and of women in general, it was fantastic witnessing women from vastly different disability backgrounds sharing and caring about each other's stories, then more importantly being able to relate personally to these stories with common themes coming through. It was actually an extremely moving experience for me. I left feeling really inspired and empowered about my own place in life, after hearing people's comments and stories.

As if completing a full circle, it was a forum asking young women with disabilities to talk about health issues and their experience of access to services that got them involved. The more things change...



Attendees at the 2010 Young Women's Health Forum.



Information for members at the 2010 Young Women's Health Forum.

Lesley Hall

Born in the Victorian country town of Port Fairy in 1954, Lesley Hall started her schooling at the local primary school. She then attended a special school (Yooralla) and completed her secondary schooling in Altona. She graduated with a BA and Dip Ed from La Trobe University in 1978.

Lesley's political evolution started at school, when she became aware of the equity (or inequity) issues associated with 'special' schooling. The process of being segregated and institutionalised as a young teenager was limiting, indeed, harmful, on many levels. Not only was the education sub-standard, it was socially inadequate. People in so-called 'special schools' often did not develop the interpersonal skills they might otherwise have developed in mainstream schools.

Lesley began to develop a theoretical perspective on the experience of oppression when she became involved in disability politics in the late 1970s. She met Richard Berger and Eddie Ryan, who were involved in the newly forming disability activist movement, around 1979-80 and immediately clicked with the group. They were radical in their thinking and their perspective matched her own, which was that people with disabilities should not be segregated, but should be encouraged to be part of the broader community. Very importantly, they must be able to speak for themselves.

An important step towards empowerment was the establishment of the Disability Action Forum (DAF) of which Lesley was a member. The DAF was a unique organisation of people with disabilities from around Victoria, united on a regional basis – not disability specific – to speak and act on their own behalf. As a member of this forum, Lesley was instrumental, in 1981, in establishing the state's first Disability Resource Centre (DRC) in Brunswick, a place run by people with disabilities, where people could go to find information about services and their rights under law. It was one of her first jobs in the disability advocacy sector.



Lesley Hall protesting at the Miss Australia Quest.

This activity took place in 1981, the International Year of the Disabled Person. According to Lesley, this year was 'crucial for people understanding that people with disabilities needed to be involved in and lead projects'. There was a lot of energy, and intense focus on organising and activism.

This was also a time when people with disabilities were gaining the confidence to speak for themselves in more radical, publicly confronting ways. Historically, disability support services had come under the auspices of charities, such as the Spastic Society (now Scope). This was a bone of enormous contention for disability activists, who objected to the charity

perspective of support on a number of fronts. Firstly, support offered by charities was generally provided in the form of segregation, in the guise of institutional living, sheltered workshops and special schools. The charity perspective oppressed people, says Lesley, because it 'focused on people's deficits rather than their strengths' and treated people as 'objects of pity'. So an important platform of political action for disability activists was to cut the nexus between charity and service provision. Their views on the matter were highlighted in the late 1970s in Victoria by a successful campaign of public protests aimed against the Yooralla Telethon and its depiction of children with disabilities as objects of pity rather than humans with agency.

There was a feminist thread to this activism. Lesley was involved in feminist politics in the 1970s which took her to the disability movement at the end of the decade. Her interest in both streams, however, reinforced in her mind the inadequacies of both. There was 'a lot of sexism around' in the disability movement in the early 1980s. But the feminist movement's response to the particular needs of women with disabilities was inadequate and unsatisfying. A significant number of women with disabilities shared her frustration.

They established the Women with Disabilities Feminist Collective (WDFC) which offered a space where women with disabilities could go and talk about their experiences and gain strength through doing so. It was also a political action group, involved in organising protests. The Anti-Miss Victoria Quest working party was one activity, but there were others organised around housing, employment and transport. WDFC was busiest in the early to mid 1980s; less so in the late 80s to early 90s, although this was a time when other organisations with a gender perspective, such as Women with Disabilities Victoria and WWDA were beginning to take shape.

Lesley was involved in a set of direct action protests that highlighted the gender perspective in the critique of public representations of people with disabilities. The Miss Australia Quest was a beauty contest that since 1954 had run as a fundraiser for the Spastic Society in Victoria. Feminist activists and lobby groups for people with disabilities had been protesting outside national finals throughout the 1980s.



The Long Leg of the Law: Women with disabilities protesting outside the Miss Australia Quest. (Photo courtesy of *The Age*)

The International Year of the Disabled put the spotlight on opposition to the quest. As Lesley explained, the beauty quest as a form of fundraiser for disability charities was particularly odious, given its focus on physical perfection 'as the norm all must attain if they are to be fully accepted into society'. Lesley was among a group of feminists and disability activists who got into the venue for the 1981 event. 'The media sprang to life as soon as soon as we got on stage,' she says.

The protests received significant press coverage and provoked a range of responses, including strong support from people within the Spastic Society and other disability charities, and also criticism from people with disabilities. There was still a very conservative group that believed segregation, and therefore, the charities that supported segregated services, to be the best way of providing for people with a disability. Despite the objections from this camp, the protest marked a symbolic shift in the mode of public thinking about the place of people with disabilities in Australian society. This was accompanied by a major policy shift in Victoria, initiated by some very progressive people in government, who were listening to disability activists and beginning to 'get' the issues.

The 1981 protest action was, arguably, the first public act to place disability as a feminist issue on the agenda. Throughout the 1980s, the WDFC continued to highlight these issues. Like the women from the DPI (A) women's network, they began to gather a more theorised perspective on the issues confronting women with disabilities especially when it came to women's health and the problems of domestic violence. By the early 1990s, there was some crossover between the two streams. A decade of networking and deep discussion had created an environment where women with disabilities in Victoria knew they needed to do something.

Lesley became involved with Women with Disabilities Victoria in the late 1990s. Her professional work as an advocate in the development of attendant care action and planning brought her into contact with members of the network, such as Keran Howe. Lesley was a member of a working party that was examining the issues associated with women with disabilities gaining access to women's refuges, a problem that Women with Disabilities Victoria and WWDA were researching at the time. She lent her support to Women with Disabilities Victoria at a time when the organisation was on shaky ground, to help them return to a stable and sustainable position. She also lent her writing skills to *Oyster Grit*, the breakthrough publication of stories about women with disabilities, written by women with disabilities.

Lesley Hall is currently the Chief Executive Officer for the Australian Federation of Disability Organisations.



Effie Meehan (left) with Keran Howe and Wendy Brooks.

Effie Meehan

Effie Meehan has spent more than thirty years advocating for women with a disability, especially for those from a non-English speaking background who are parents. Effie became aware, once she had children, of a lack of information or support for parents with a disability. Coming from a Greek heritage and living in Melbourne's western suburbs seemed to complicate matters further.

In 1982, in recognition of the need for an organisation to work for people with disabilities and their families within non-English speaking communities, she co-founded the organisation, Action on Disability in Ethnic Communities (ADEC). She advocated on behalf of migrants with disabilities and at the same time helped them to become leaders and advocates. She served as a Chairperson and remained on the committee for ten years.

Consolidating her work in that area, in 1990 she established a women's disability support group in the Western Region and in 2005 worked for three years as an advocacy coordinator at the Migrant Resource Centre.

In 1996 she established a parent disability community project at Yooralla to support women with disabilities who were parents. The aim was to advise them of their rights, especially mothers with an intellectual disability, thus challenging the authorities who held that parents with disabilities were unable to care adequately for their children and empowering mothers to resist the attempts of the child protection authorities to remove their children.

In 2006, in recognition of her work for women with disabilities, Effie Meehan was inducted to the Victorian Honour Roll of Women. She has been a member of the Women with Disabilities Victoria Board since 2007.

Margaret Stevens

Margaret Stevens has been active in Women with Disabilities Victoria since 2003, when she joined members of the collective at a meeting at the Maj Café, next door to Her Majesty's Theatre, in Exhibition Street, Melbourne. She has witnessed and participated in the evolution of Women with Disabilities Victoria from being a group of women who were meeting and forming their ideas, to looking at issues surrounding women with disabilities in the community. Margaret was briefly Convenor before becoming Treasurer. She relinquished the role of Treasurer before Women with Disabilities Victoria changed its structure, in the belief that a person with accounting qualifications should hold the position. Margaret valued being part of the Women with Disabilities Victoria team when its governance changed. For her, the best part of Women with Disabilities Victoria was the team and the commitment of the women and the good policies that Keran Howe put in place. In her view the level of commitment of these women arose out of the fact that 'everyone has a disability, some more obvious than others'.

She is glad to be a member of a Board where meetings are conducted respectfully with all members encouraged to express their views or ask questions. As a member of the Women with Disabilities Victoria Board, she brings her personal experience to the table and is fearless in her advocacy of the rights of women with disabilities to access the built environment and to protection against domestic violence. Her own experience of domestic violence when living in a country town informs her perspective on the issue when she meets with representatives of the Department of Justice, or when she participates in forums focusing on the issue.

The projects, in particular, the Violence Against Women with Disabilities Project and the Parenting Project, have kept her active and she believes that Women with Disabilities Victoria are trailblazers in this area. The quality of the people involved is also important. As she says, the capacity of women such as Tricia Malowney to 'get the message across' makes the organisation effective.



Margaret Stevens at the 2005 AGM.

Margaret Stevens and Margaret Bayly, with Keran and Tricia's help, took on the production of the newsletter in 2005 as a means of building up the membership base. In addition, she was actively involved in the establishment of the Advocacy Information Service, an important initiative which aimed to get information to government and other disability groups which should have been, but were not, focused on issues relating to women with disabilities. The AIS provided statistical evidence to help support the arguments of members participating in representation activities.

For Margaret, the next step for Women with Disabilities Victoria is to become an even stronger voice in Victoria within government as it represents women with disabilities. She sees this happening out in the community as Women with Disabilities Victoria is respected for the strength of its knowledge base. She hopes, too, that more young women will become involved with Women with Disabilities Victoria.

Creating an Organisation with Clout

The members are the strength of the organisation, but good governance builds the capacity to grow and succeed. Beyond its members, another key to the success of Women with Disabilities Victoria has been its ability to get its structure right and to adapt to changing times and needs. Women with Disabilities Victoria's ability to evolve from a volunteer social support organisation to an effective advocacy organisation employing paid staff is predicated on the firm organisational foundation it was built on.



Margaret Bayly and Kim Ling Chung at the 2006 AGM.



Marilyn Beaumont (Women's Health Victoria) and Mary Owen (member Women with Disabilities Victoria) at the 2005 AGM.



Board Member Brenda Gabe.

1992 First meetings.

1995 Constitution.

1995 First AGM June 1995.
1995 Women with Disabilities
Victoria affiliates with WWDA.

1995 Funding received for two projects examining access to health services, from Vic Health Foundation and Health and Community Services. Important first steps in an on-going engagement with health issues.

The First Constitution

The First Constitution aimed '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.' Its fourteen objectives were:

- To enable women with disabilities to achieve their rights;
- To advocate for research into the relationship between disabling conditions and gynaecology;
- To work for appropriate health care;
- To promote the fullest education of women with disabilities;
- To work for women with disabilities to have full control over all aspects of their lives;
- To critique and develop social legislation and surrounding regulations so as to ensure women with disabilities have equality of opportunity;
- To use and develop ways of empowering members to participate in the functioning of the network;
- To work in conjunction with any other organisations whose purposes include the advancement of women with disabilities;
- To educate the community about the rights and needs of women with disabilities;
- To develop a resource library of material for use of all members;
- To encourage the development of innovative projects relevant to women with disabilities;
- To be a human resource development vehicle working with gender issues from the perspective of women with disabilities;
- To develop consensus philosophy and sharing of responsibilities;
- To ensure that disability organisations factor gender in their responses to government discussion papers and policies.

These early aims have been prioritised consistently throughout the life of Women with Disabilities Victoria.



Member Lesley Hall at the 2009 AGM.

1996 Incorporation.

1997 Woorarra Women's Refuge Project leads to ongoing work in the area of family violence.

2000 Leadership Forum co-hosted with WWDA.

2001 Department of Human Services fund *Women With Disabilities Affected By Family Violence* Project.

2001 Ordinary Women, Extraordinary Lives Dinner offers networking opportunities with potential funders.

2002 Chris Jennings begins work at DVRC on *Women With Disabilities Affected By Family Violence* Project.

2003 First Paid Staff Come On Board.

Paid Staff Come On Board

As Women with Disabilities Victoria made the transition from volunteer, grassroots social support organisation to a funded advocacy service, there was opportunity, at long last, to fund paid employees. Where possible, the policy was to employ women with disabilities.

Sarah Waters was employed in 2003 by Women's Health Victoria (WHV) as Project Officer, Strategic Consumer Advocacy Project for Women with Disabilities. In this role, she was employed to develop a model of advocacy appropriate to address the needs of women with disabilities. She was also involved in the Women with Disabilities, Advocacy in Leadership project that was developed over 2004-5.

Jane Watson-Brown was employed in 2005 as the Advocacy Administration Officer with responsibility for developing policies around resource collection, management and access.

Karen McQuigg was employed in 2005 in the role of what was then called the Victorian Women with Disabilities Network - Advocacy Information Service (VWDN-AIS) Development Manager, charged with the task of supporting the service and assisting with the organisational development of Women with Disabilities Victoria. Karen was also a member of Women with Disabilities Victoria.

Vanessa Simpson was employed in the position of Network Resource Officer in 2005, a role that focused on supporting the activities of Women with Disabilities Victoria. She supported the membership and Management Collective, produced newsletters and issues papers and assisted in some of the consultative processes on the issues of women with disabilities and domestic violence.

Melanie Thomson was employed in 2006 by WHV to set up the information service for the VWDN-AIS. She had responsibility for developing the Clearinghouse, continuing the work that Jane Watson-Brown started. She also worked on a literature review for Vic Health and identified groups of women who had experienced violence and demonstrated the prevalence of the issue. Melanie also had responsibility for the Women with Disabilities Victoria newsletter at a time when it was being transformed, not entirely to the satisfaction of all members. As a funded advocacy organisation, there was an expectation that it be more than a 'social page'. It needed to articulate the three priority areas. Not everyone initially understood those tensions.

Lucy Healey was appointed to the position of Research Coordinator, *Building the Evidence Project*, VWDN-AIS in 2007. Primarily Lucy was employed by the University of Melbourne in this position and based at Women with Disabilities Victoria. During this time, she worked closely with Melanie Thomson to develop the Clearinghouse collection on violence as well as supporting the project team that produced the report.

Kate Hood worked as Policy Officer for Violence Against Women with Disabilities for Women with Disabilities Victoria from November 2008 until July 2009. It was a steep learning curve for her, requiring an enormous amount of education. While she is certain that significant steps have been made, she feels there are still huge blind spots in the Disability Services sector. For instance, when the Respectful Relationships Program was rolled out in schools, special schools were excluded! Supposedly well informed people saw no need for the program in schools for people with disabilities, despite women and girls with disabilities being in the group most likely to be on the receiving end of 'disrespectful behaviour'.

2003 Application for funding to explore a model for advocacy for women with disabilities in partnership with WHV.

2004 Tricia Malowney becomes Convenor.

2004 Report on Advocacy Project released.
2004 Funding for an ongoing Advocacy and Information Service sought.
2004 Co-location with Women's Health Victoria in their premises.



Norma Seip addressing the crowd at the 2005 AGM.

Tricia Malowney as Convenor

Women with Disabilities Victoria was very lucky that Tricia Malowney retired from her paid position at Victoria Police in 2000. Had she not done so, they would not have been able to rely on her to drive their agenda after she joined the organisation in 2004. Tricia arrived at a time when, for a variety of reasons, other members were unable to devote much time and energy to the organisation. Given the amount of work demanding attention, this could have proven catastrophic, if not for Tricia's commitment, leadership and preparedness to muck in and 'do what needed to be done'.

As she acknowledged herself, when she attended her first AGM, Tricia 'was not planning on becoming the Convenor.' After a year in the job, she had 'the deepest respect and admiration for those who have undertaken the task before me.' The Women with Disabilities Victoria Convenor has always had a demanding job, but during the period 2004-2007, a period described by one member as 'the banging your head against a brick wall period', things were particularly demanding.

This is partly because it coincided with the time when the organisation was making the transition to a funded service working in partnership with WHV. The amount of work Tricia did to assist this transition is widely acknowledged.

'It wouldn't have happened without her,' asserts one party to the partnership. 'Her insistence that it should, kept things on track when the going got tough.'

On top of this, however, Tricia was doing the bulk of the work to maintain Women with Disabilities Victoria's public profile. She attended countless forums, meetings and conferences, ensuring that Women with Disabilities Victoria was acknowledged, 'mainly making a nuisance of myself by throwing myself in front of people and asking 'what about us?'' No one at the Magistrate's Court, the Police Force, the Department of Human Services, Department of Justice or Office of Women's Policy was safe. But she was absolutely determined to ensure that Women with Disabilities Victoria was a continuous blip on the mainstream radar. Whenever any policy was designed or legislation was drafted, not just policy affecting the disability sector, she wanted to know that the public servants would ask

'how will this impact upon women with disabilities?' During this period Tricia relied heavily on the support of Margaret Stevens and Margaret Bayly, who tirelessly did whatever was asked. Whether it was helping with the newsletter development, or stuffing envelopes, they always came when called.



Tricia Malowney and Margaret Stevens at Tricia's first AGM as Convenor in 2005.

2005 Women with Disabilities Victoria provides sponsorship to the Australian Women's Health Conference.

2005 Women with Disabilities Victoria obtains a seat on the Statewide Steering Committee on Family Violence.

August 2005 Partnership (WHV) document signed.

Whilst Tricia Malowney was Convenor, in conjunction with the collective management team, she oversaw the following significant achievements. Note well that the list is NOT comprehensive!

- The formalisation of the Partnership Agreement with Women's Health Victoria.
- The implementation of the Women with Disabilities Advocacy Service.
- Sponsorship of 21 women to attend the Australian Women's Health Conference in Melbourne in 2005. Also sponsorship of Professor Carol Thomas from England as a Plenary Speaker. Presentation of a paper, with Natalie Tomas at the conference entitled 'Disability Advocacy in Action'.
- Completion of a significant capacity building 'Leadership' project funded by DHS.
- Ongoing discussion in the mainstream about the problem of violence for women with disabilities. Significantly, she was Convenor when Women with Disabilities Victoria was included as members on the Statewide Steering Committee to Reduce Family Violence, and also represented Women with Disabilities Victoria on the Statewide Steering Committee to reduce Sexual Assault.
- Formation of a working party to oversee their major project on Parenting Rights for Women with Disabilities.
- Development and release of a Statement on Abortion.
- Consultation with the Federation of Community Legal Centres on issues relating to cognitive disabilities and sexual assault.
- Participation at the following events and Board meetings:
 - DHS Active Participation Strategy Disability Reference Group,
 - Equal Opportunity Commission of Victoria Disability Reference Group,
 - Royal Women's Hospital Consumer Advisory Council.

Partnership – the Advocacy Information Service

Women with Disabilities Victoria reached a stage in its development when it was clear to everyone that the organisation needed to find a more sustainable funding model, one that enabled the employment of permanent staff to do the work that volunteers hitherto had taken on. The organisation 'had a fragility' about it, because it was heavily reliant on volunteer labour and the influence of one or two 'charismatic' individuals. The innovation and passion was there amongst the members, but the time and energy they could commit waxed and waned. Something needed to happen.

Keran Howe took a major role in making something happen. She had developed a good relationship with the then Minister for Community Services, Christine Campbell, and had become aware of funding available from within this portfolio for supporting advocacy programs. There was a real possibility that a women's service would be funded, a possibility that gained momentum when the policy officer for Women's Health Victoria approached Keran to discuss how they might collaborate with Women with Disabilities Victoria to provide a service for women with disabilities.

This was an extremely important move. In 2003 Women with Disabilities Victoria was not strong enough, in terms of governance, to manage funding as they did not have the organisational capacity. WHV began to think about their role as 'incubators' for women's programs and saw this as a perfect opportunity to broaden their role to one of providing support to women who were disadvantaged in terms of access to health services. The opportunities afforded to both were too great to resist. Effective partnership would enable WHV to advance its strategic direction to work with more disadvantaged and marginalised groups, while affording Women with Disabilities Victoria the opportunity to develop its advocacy role in a sustainable fashion.



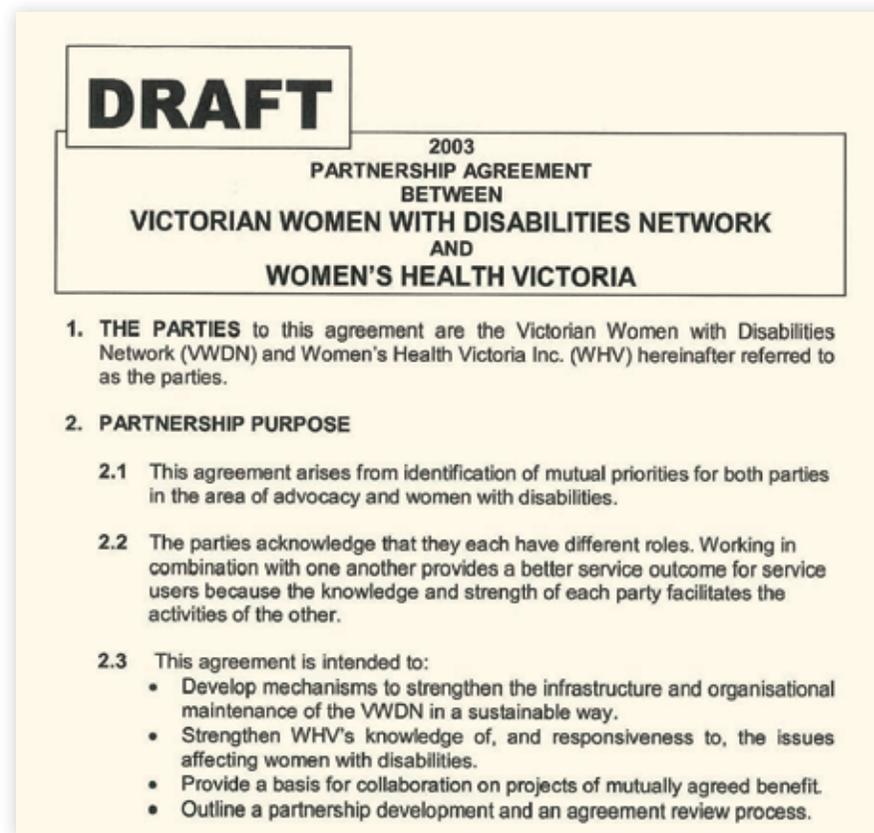
Marilyn Beaumont (Executive Director WHV) and Keran Howe have worked as partners since 2006 when Keran was seconded to work for Women with Disabilities Victoria.

In 2003, Women with Disabilities Victoria joined forces with WHV to mount a successful case for funding a pilot Advocacy Information Service. On Good Friday 2003, Karleen Plunkett, Lesley Hall and Keran Howe held a teleconference and drafted a submission for project funding to develop a model for advocacy for women with disabilities in Victoria. WHV applied for the funds and a partnership agreement was drawn up. The project received \$40,000. Women with Disabilities Victoria was to provide leadership and strategic guidance while WHV supplied the financial governance framework.

Around the same time that the new money became available, some new blood was injected into the organisation. Tricia Malowney assumed the position of Convenor after Margaret Stevens vacated the role, believing that Tricia had the appropriate skills and attributes to revitalise the organisation. Her leading role proved to be absolutely vital to the successful partnership outcome. With the funding approved, Marilyn Beaumont, Executive Director of Women's Health Victoria attended some meetings and negotiations began to establish a formal link between the two organisations.

Needless to say there was some anxiety about the establishment of the partnership and 'what it would look like'. Natalie Tomas, who was a member of the Partnership Governance Group recalled tensions around

some issues, mainly because of the different histories and cultures of the two organisations that were joining forces. WHV was a strongly administered, formally governed organisation, described metaphorically as a 'locomotive train', as distinct from the 'babbling brook' that was the ideologically driven, loose, grassroots network of passionate members, Women with Disabilities Victoria.



A copy of the Draft Partnership Agreement between Women with Disabilities Victoria and WHV.





2007 Tax exemption status; income tax concession; Fringe Benefit Tax Exemption; GST concession and refunds of franking credits on any Australian or New Zealand investments.

As Keran Howe explained the process:

With a long history of women with disabilities being 'done to' rather than 'doing with' the network was keen to minimise power imbalances in any partnership undertaken. As the network was a largely voluntary organisation without a paid workforce, it was of critical importance that our advocacy information service would not be subsumed within such a well established organisation and that we retained our role as lead agency. Considerable time has been taken to workshop how the partnership strengthens the network and enables both organisations to gain wisdom and knowledge from our collaboration.

An outside consultant, Cathy Wilson, was employed to guide the process of partnership formation to a successful conclusion. Women with Disabilities Victoria looked for models of partnerships in other sectors where power imbalances had to be managed. The international development sector where wealthy countries engage with poor countries to assist them with aid programs provided such a model. Linda Kelly, a consultant in the international aid sector, was invited to discuss the issues involved. According to Marilyn Beaumont, adopting this model was an inspired choice, because it offered her a 'light bulb moment'; a way of seeing how to move forward in the negotiations. As a result of these discussions Women with Disabilities Victoria and WHV recognised the need to maintain the integrity of both organisations and that difference could be beneficial to mutual growth. Importantly, however, differences must be made explicit.

Marilyn Beaumont also saw the involvement of Tricia Malowney in the steering committee as crucial to the successful outcome. She had incredible energy and the capacity to respect the past while moving forward with the present. But, as Tricia Malowney noted, it was easy to



Jess Kapucinski Evans (left) entertains the audience at the 2005 AGM. With her is Vanessa Simpson (right), an early employee of Women with Disabilities Victoria.

adopt this approach because the women involved had the drive, energy and commitment to negotiate the partnership. The women of Women with Disabilities Victoria 'weren't misery girls', she said. They wanted to help women 'who don't have it as good as us.' The feminist movement wasn't going to do so, the disability rights movement hadn't; it was up to them. This partnership was the way. It had to be negotiated.

From 2005 there was a consolidation of the groups with respect to meeting structures, and the WHV and Women with Disabilities Victoria Partnership Document was signed on 10 August 2005. Subsequently, an organisational readiness taskforce was established to assist Women with Disabilities Victoria build capacity to become fund holders in their own right. All parties agreed that, over time, Women with Disabilities Victoria would take over the running of the service. This aim was achieved, to great celebration, in 2009.

The 'partnership period' represents the most dramatic turning point in the organisation's identity. As Lesley Hall remarked, the transformation of the social support organisation, that began in the early 1990s, into an effective advocacy organisation was necessary if they were going to survive. They had to change their management structures, in order to be funded and taken seriously. As the Board of Governance took on the responsibility of management, inevitably, the nature of the relationship with the members changed. Members are, of course, still vital in setting the agenda. But they can't be as active on a day to day basis. Women with Disabilities Victoria has managed this change with effective use of their paid staff. Communication and consultation with members are always at the forefront of their operations.

2007-2008 – Adoption of new constitution and Board Structure: Women with disabilities appointed as Directors and women with key expertise who share vision of Women with Disabilities Victoria appointed as advisors; new Vision and Mission statement.

2007 Appointment of Keran Howe as Executive Officer.

Women With Disabilities Get A New Board and Constitution

2007-2008 saw Women with Disabilities Victoria reinvigorated with the adoption of a new constitution and Board structure. Women with disabilities were appointed as Directors and women with special expertise, who shared the Women with Disabilities Victoria vision, were appointed as advisors. New Board members included Wendy Brooks, the current Co-Chair of Women with Disabilities Victoria with Tricia Malowney. Board members held positions on committees such as: Family Violence State-Wide Advisory Committee; Victorian Advisory Council on the Prevention of Sexual Assault; Victorian Disability Advisory Council; Disability Services Board; Victorian Disability Advocacy Network Committee of Management and the Equal Opportunity Commission Disability Reference Group. Keran Howe was appointed as the first Executive Officer and she created opportunities for Women with Disabilities Victoria to increase funding and to expand its network in government and non-government agencies concerned with implementing programs which impacted on the lives of women with disabilities.

New Vision and Mission statements were adopted. Women with Disabilities Victoria's Vision was to achieve 'A world where all women are respected and can fully experience life'. Its mission was expressed as 'leading the way for Victorian women with disabilities and improving women's choices by building partnerships and providing support, information and community education'.

The Women with Disabilities Victoria Board 2009-10 is represented by:

Wendy Brooks, Co-Chair (Governance)	Brenda Gabe
Tricia Malowney, Co-Chair (Representation)	Sharon Granek
Simone Rutherford, Treasurer	Effie Meehan
Margaret Bayly	Delia Portlock
Catherine Brooks	Margaret Stevens



From Left: Margaret Stevens, Keran Howe, Simone Rutherford, Effie Meehan, Catherine Brooks (previous Board member), Wendy Brooks, Tricia Malowney, Brenda Gabe, Margaret Bayly with Charlotte Mclain Nhalapo. Missing from this photo are Sharon Granek and Delia Portlock.



Catherine Brooks, Sharon Granek and Simone Rutherford at a 2010 planning meeting.

2009-10 Board Member Delia Portlock (right) with Gina Lyons, advisor to the Board on Governance matters in the first year of the Board's existence.

2008 Independent website was launched.

2009 Responsibility for funding and staff of AIS after 6 year partnership with WHV.
2009 Simone Rutherford (CPA) joins the Board, bringing over twenty years accounting experience and thus strengthening the Board significantly.

Current Staff At Women with Disabilities Victoria

Sarah Boyd

Sarah Boyd began work at Women with Disabilities Victoria in March 2009 as the Information and Administration Officer. She considers her role to be very broad and diverse and allocates roughly 50% of her time to each component, depending on priorities. Her responsibilities include regular information communications with members (e-Bulletin and Newsletter), book-keeping, managing membership processes, assisting with events, supporting the Board, managing the Clearinghouse, developing the website and assisting the Executive Director and other staff, as required.

The website is something that she confesses to being particularly passionate about – as it is available globally and accessible all the time. 'The website is Women with Disabilities Victoria's public face. Many individuals and organisations look up our submissions to government or other publications to inform and educate their positions. As a centralised location for information and engagement, the website is a fantastic resource - with exciting growth possibilities'. Furthermore, it is in cyberspace where many young women may connect with the organisation. In Sarah's opinion it is important that Women with Disabilities Victoria embrace avenues of social media and find ways to deliver their message across a variety of mediums that may be more accessible to different communication styles or preferences.



Sarah Boyd (right) - Information and Administration Officer.

Prior to working for Women with Disabilities Victoria, Sarah had no previous knowledge of the organisation or of the intersection between women and disability. Her university activism encompassed welfare, education and indigenous issues, women's collectives and the queer movement, but nothing on disability. She was, however, familiar with conceptualising marginalisation or disadvantage as social or structural and was committed to redressing this disadvantage - coming to the problem from a human rights perspective.

Working with Women with Disabilities Victoria represented an opportunity to act on her belief system and be 'part of the solution'. For Sarah, the opportunity to work for something you believe in, and believe is making a difference, is what makes her job special. That, and the supportive work environment. She believes that, 'the staff and work environment are very supportive – we are all different, but our personalities go together well and we all do our best to provide support and encouragement to each other as colleagues'. Another key benefit of her job, Sarah notes, is that it regularly affords her interaction with inspiring women. 'I am continually inspired by our Board Members – some have little money to get by on, but still choose to work full-time as volunteers for the benefit of the community'.

2009-2010 Further Employment of paid staff to focus on priority areas.

2010 Name change from Victorian Women with Disabilities Network (VWDN) to Women with Disabilities Victoria.

Jen Hargrave

Jen Hargrave is the Policy Officer with responsibility for the Violence Against Women with Disabilities priority area. It's a position funded by the Office of Housing, that she has held since 2009. Despite the confronting nature of the work, she loves her job. 'Three things make this workplace special,' she says; 'the nature of the work is proactive; the focus is on systemic issues, which gives a greater sense of optimism, and the organisation stands for what it says it stands for.'

Jen is legally blind, but this did not stop her studying visual arts at the University of Ballarat. After graduating, she practiced as an artist and art teacher for several years and completed a Graduate Diploma in Education at the University of Melbourne. She then moved into advocacy roles in the Disability Liaison Units at Ballarat, La Trobe and Melbourne Universities. These jobs taught her the fundamentals of advocacy and the importance of defending people's independence.

Jen was introduced to the family violence sector in 2007 as a phone volunteer at WIRE (Women's Information Referral Exchange). She met Chris Jennings, who suggested that she apply for the job at Women with Disabilities Victoria. Kate Hood, the previous Project Officer, was moving on and Chris thought she would be an excellent replacement.

Jen has been encouraged to see that, even in her short tenure, the sector's level for improving access to services has improved dramatically. 'Women with Disabilities Victoria have achieved so much,' she says, 'securing ongoing representation at law reform consultations and receiving invitations for members to speak about disability and violence in forums all over Victoria'. Of course, there is much work to do, but she thinks that they are making a difference by 'chipping away and teaching people the song we are singing'.

Lauren Hayes

Lauren Hayes, who has a background in music therapy, commenced work in her position as Project Officer for Peer Mentoring and Support in March 2010. Her job entails supporting members in their representation work - for example those who sit on committees and boards or write submissions - by providing them with accurate information. She aims to increase membership capacity, create new partnerships and collaborate with other women's services. She also aims to set up a peer mentoring program to enable members to feel empowered and gain the skills and confidence to take on representation roles.

Lauren had not really thought much about the intersection between women and disability before starting with Women with Disabilities Victoria and was surprised at the notion of feminism and disability going together. She initially thought of feminism as 'bra burning and hating men' but has since come to identify more with feminist concepts. She never thought that she might be doubly disadvantaged. Although she had to fight for her rights as

a person with a disability and she experienced social isolation at school, she had never thought that being a woman might contribute to her disadvantage. Working at Women with Disabilities Victoria has assisted her to understand the systems of power that underscore gender and disability as discriminatory systems.



Lauren Hayes – Project Officer for Peer Mentoring and Support.

Keran Howe

Keran Howe has been a strong advocate for women with disabilities since her car accident at nineteen years of age gave her first-hand experience of life as a woman with a disability.

In March 1972 Keran had not yet completed her first twelve months of nursing training when a car accident and spinal cord injury changed the course of her life. Having deferred the offer of a Commonwealth scholarship in order to test out nursing, she accepted the scholarship offer almost immediately after having the accident. About twelve months later, after completing rehabilitation, she began a BA at the University of Melbourne, graduating at the end of 1975. After a year in the work force, postgraduate studies in Social Work at La Trobe University followed. Since then, Keran has made it her business to work for social justice and, in particular, for women and for people with disabilities, in a voluntary and professional capacity.

Embarking on a university degree was extraordinary for Keran on several levels; she was a country girl who was the first in her family to do so and she was a woman with a disability. 'Thirty years ago,' she says, 'the concept of what it meant to have a disability was completely different, it was very narrow. Even the notion of going to university was out there for me... it was a big leap'.

'I had no idea what might be a practical profession for me, but one based on an Arts degree seemed a likely possibility,' she said. She was interested in what a general arts degree had to offer, in any case, because of a lifelong interest in social justice issues. Brought up in the progressive Catholic tradition, it seemed to Keran that the practical implications of Christianity were politically aligned to social justice.

Keran acknowledges that feminism did not inform her early political theory but when she studied social work, in 1977, that theory and experience began to intersect in her thinking. She came to understand the impact of power relations for women, especially women in the home, not only in theory but in practice, as she recalled her mother's experiences.



Keran Howe (right) with Tricia Malowney in 2007.

The way social and cultural systems, including normative understandings of 'woman's place' created oppression and disadvantage became clearer to her.

Her thinking about disability as a socially created phenomenon also began to evolve. She recognised that the general perception of disability was as a medical condition that created personal challenges. People with a disability were construed in popular media as being defeated by, or 'courageously' confronting and 'overcoming', adversity. Says Keran:

I felt the message I was receiving was that disability is a personal challenge that must be borne. I observed that if people with disabilities complained about things, such as the inaccessibility of public buildings, they were described as 'bitter' or 'having an axe to grind' or individuals who were clearly 'not coping'. But what I was experiencing were architectural barriers that were needlessly restricting my life and attitudes that suggested I was a second class citizen.

She was often confronted by people who saw her spinal injury as a tragedy - 'it's amazing that you can still smile' – or strangers who stopped her in the street to ask 'what happened to you, dear'? People didn't seem to want to talk about their own personal lives, Keran says, 'they just wanted to satisfy their curiosity.'

In time Keran turned her thinking around to realise the problems experienced by people with disabilities were problems of socially constructed systems. She realised that everyone was responsible for creating and, therefore, dismantling social barriers. People with disabilities should not be forced into 'a parallel universe of adjustment', in order to accommodate faulty systems. Once she reached this understanding, it was easy for her to respond to those who asked what had happened to her with, 'Nothing. I'm fine!' It also influenced the direction her professional life took.

So, it was with this developing theoretical and personal understanding of social disadvantage that Keran entered the workforce. She began at Yooralla, in 1979, as a regional community development worker, working with other people with disabilities in creating community supports and services. This was a period when discussion about disability as a social movement was opening up at a grassroots level. Discussions were further propelled in the lead up and during IYDP in 1981. It mainstreamed issues, with the slogan being 'Breakdown the Barriers'. And it offered scope, through funding, for practical initiatives to bring about change. For instance, Keran was involved in developing the 'Interchange' program for families with children with disabilities. She sat on the Victorian Council of Social Services Taskforce on Transport, advocating for better access to public transport. She attended meetings to support the establishment of the Disability Resource Centre.

After three years working at Yooralla, Keran moved back to her home town of Deniliquin and found employment as a Social Worker at the Deniliquin Hospital and Community Health Centre. As a counsellor, she was introduced to women's experiences of domestic trauma at a deeply personal level. As a professional with an enduring interest in social policy, she worked with newly formed government units with a mandate to prioritise gender issues in policy formation, such as the Office for Women's Policy in New South Wales. She was involved in establishing community action groups, such as the Deniliquin Access and Mobility Group, an organisation of people with disabilities who successfully applied for funding to ramp the town. She also joined with other women to form the Deniliquin Women's Awareness Group. Personal and professional experience consolidated Keran's belief that communal effort to influence social policy, as well as individual support, was critical to bringing about the changes needed in people's lives.

Keran moved to regional Victoria in 1989, to work at Ballarat Community Health Service where, again, she was involved in a range of advisory committees and boards concerned with women's health and disability. These various interests began to coalesce when she was involved in a project through the Women's Health Service that was undertaking research into the role of women as carers. Through the course of

interviewing carers, she saw that they needed better services and support. At the same time, she was concerned that policy was starting to focus on families as the provider of services that needed support rather than focusing on the services that people with disabilities needed. She believed that if people with severe disability received the services and care they needed, then families would automatically be relieved of the 'burden of care'.

Increasingly, she was concerned that people with disabilities, particularly women, were getting less direct access to government services to assert power over their own lives. These ideas took on a much more sharply focused feminist perspective as she became associated with WWDA. She became a member in 1993 and was excited to discover that a group of Victorian women with disabilities (Women with Disabilities Victoria) were beginning to meet.

Keran returned to Melbourne in 1994 to work as Service Development and Research Officer at the Royal Women's Hospital. She continued in this role until 2001 when she took up the position of Manager of the Royal Women's Hospital Social Work department, Women's Social Support Services. Back in Melbourne her involvement with Women with Disabilities Victoria became more regular. Still involved in WWDA (Keran chaired that organisation for a period) she was also a member of the state based network, which was linked, formally for a while, to its national counterpart. However, by early 2000 it became quite clear that if the organisation was to develop its voice as an advocate, it needed to find a more sustainable funding model, one that enabled the employment of permanent staff to do the work that volunteers hitherto working fulltime had taken on.

Keran had an opportunity to be involved in developing this model. She was Chair of the Disability Advisory Council of Victoria whose role was to provide advice to the Minister for Disability Services, Christine Campbell. She became aware of some funding available from within this portfolio for supporting advocacy programs. It was feasible therefore, for a women's service to be funded and the policy officer from WHV approached Keran to discuss how they might collaborate with Women with Disabilities Victoria to provide a service for women with disabilities, a development she endorsed. (The details of partnership formation are dealt with in a previous section.)

Once the partnership was finalised, Keran continued on the Management Collective but in 2005 took time out to travel on a Churchill Scholarship to the United States and Canada to study hospital responses to women experiencing violence. Her findings contributed to the Royal Women's Hospital's policy on screening for domestic violence.

On her return from long service leave, she acted on Marilyn Beaumont's (WHV) suggestion that she take on a job in Women with Disabilities Victoria so that it could establish some strong leadership and public presence. Still working for the Royal Women's Hospital she came across on a twelve month secondment and helped to develop a new constitution, establish the networks, help obtain the Donor Gift Recipient status and apply for funding for a number of important projects, including the application that would go on to support the 'Building the Evidence' project. At the end of 2007, her employment with Women with Disabilities Victoria became permanent after she successfully applied for the newly created Executive Officer's position. Keran still holds that position, although its title has changed to Executive Director. In 2010 she was publicly recognised for the important work she does promoting the human rights of all women, but especially those with a disability, with induction to the Victorian Honour Roll of Women.

I feel enormously privileged to have had the opportunity to work for Women with Disabilities Victoria, with women who are so passionate and clear about what needs to change, who recognise that raising community awareness about the plight of women with disabilities in Victoria is critical to changing this intolerable situation.

Keran believes that Women with Disabilities Victoria has had an impact by its constant advocacy. Engagement with government and service providers has been vital to changes in policy and responses. For nearly twenty years Women with Disabilities Victoria has been a group of women with disabilities advocating for the rights of women with disabilities. This, says Keran, is the source of its strength and effectiveness. 'It's more empowering...and if we don't have that, we might as well go home.'

Tricia Malowney



Tricia Malowney at the 2005 AGM.

Tricia Malowney contracted polio in 1954 at the age of four months, but as the result of her parents' advocacy, attended mainstream school and later joined the work force. She grew up in a large (she is the second of ten children), outgoing and inclusive family where having a disability "was no excuse for special treatment." After her schooling and work at the State Bank of Victoria, she travelled to the Northern Territory where she saw the plight of Aboriginal Australians. This further strengthened her resolve to fight for issues of social justice in the community. In 1977 she spent five months in the USA. After marriage in 1980, she returned to complete her year 12 at the Council of Adult Education and later enrolled at La Trobe University where she completed a degree in Anthropology.

Tricia's involvement with Women with Disabilities Victoria did not begin until 2004. She left full time paid work in 2000 after being diagnosed with post polio syndrome in 1996. She rested for two years and by then was ready to take on a new cause. She had previously worked with Victoria Police as Research Officer, later moving to its Equal Opportunity Unit, where she developed policy and wrote submissions. This experience made her an ideal person to take Women with Disabilities Victoria to another stage in its evolution. She became Convenor in 2004 and was responsible for overseeing the partnership agreement with Women's Health Victoria to develop the Advocacy Information Service and the redevelopment of the organisation.

She has had extensive experience influencing government and community service organisations, and sees her systemic advocacy as a way of ensuring inclusion. She also believes that it is crucial to speak to women with disabilities about their lives, and she brings their stories to her work in representing Women with Disabilities Victoria. She uses her roles as the President of the Disability Services Board, member of the Victorian Equal Opportunity and Human Rights Commission Disabilities Reference Group, Deputy Chair of the Victorian Disability Advisory Council, and Council Member of Women's Health Victoria to ensure that the needs of all Victorians are considered in policy planning and development, service delivery and research.

For Tricia, the issues aren't about disability; they are about human rights, social justice and influencing change. She works to 'affect the mainstream so that they always consider the needs of women with disabilities.'

As she argued in a recent letter to *The Age* on 11 August 2010, people with disabilities 'are no different to the rest of the community and require access to health, justice, education, housing and meaningful work.'

Karleen Plunkett



Karleen Plunkett (left) with Pamela Menere, Margherita Coppolino and Keran Howe.

Karleen Plunkett first learned about Women with Disabilities Victoria through another member, at a time when experience had taught her that women with disabilities suffered discrimination in almost all areas of life. She believed that nothing more than complete systemic change was required to redress this. This belief led her to join Women with Disabilities Victoria in the mid 1990s. She remained active until the early 2000s when she moved to country Victoria.

In the early years of Women with Disabilities Victoria, when the Collective met at Women's Health West, Karleen was the contact person, and organised meetings. She served as Convenor for a year in 2004, remained on the Collective until 2006, and currently participates on relevant committees.

Karleen was a member of the steering committee when the advocacy service was being established and represented Women with Disabilities Victoria on the Statewide Committee to Reduce Sexual Assault in 2006. In her view the success of Women with Disabilities Victoria to this point is due largely to two people. 'I give total credit to Keran Howe and Tricia Malowney for the hard work and commitment they have made over the years to increase the awareness of the major issues that women with disabilities face every day'. Karleen continues to be a member of the Disability Advisory Council Victoria and is currently employed as the Disability Service Officer at La Trobe City Council, in regional Victoria.

Jan Testro

Jan Testro will be remembered as a remarkable woman of vision. She was a long standing member of Women with Disabilities Victoria and a member of the Management Collective until the time she moved to Barwon Heads in the 1990s.



Jan Testro at the *Building the Evidence* launch.

In the early days of her involvement, she was particularly interested in accessibility issues. In 1998, she co-ordinated a series of meetings with the Queen Victoria Women's Centre to improve access for women with disabilities. These meetings resulted in significant changes to the building, although the heritage nature of the building and the cost of renovation meant that not all issues could be addressed. In the same year, she organised a forum on 'Public Transport, Women and Safety'.

After moving to Barwon Heads Jan continued to attend Women with Disabilities Victoria forums and events, and to provide support to women with disabilities in the Barwon region. She represented Women with Disabilities Victoria on the Barwon Sub-Regional Family Violence Integration Committee until it was restructured in 2009.

Jan was a passionate advocate for women, for the environment and for social justice. She participated in initiating and organising the Lesbian Art Works exhibitions and publications for Matrix Guild. After moving to Barwon Heads she undertook a Diploma of Land Management and Conservation and became an active member of the Barwon Heads Association advocating for better bus services and, with others, put together a submission to Heritage Victoria to get the Barwon river/estuary listed as a heritage waterway, seeking statutory recognition as a site of significance under Environmental Protection Act. She also helped initiate and run the Barwon Heads Film Society.

Jan Testro died on International Women's Day (8th March) in 2010. She will be remembered for her wonderful contribution and for the way she lived life joyfully whatever the obstacles in her way.

Building Networks

Information Officer, Sarah Boyd, described attending a conference with Keran Howe. Within five minutes of entering the room, she had shaken hands or spoken with at least twenty people. Keran's ability to make friends and influence people, in formal and informal settings, has been crucial to the establishment of the quality partnerships and networks that Women with Disabilities Victoria has been able to develop.

Keran is one of a long line of women in the organisation who understand the intrinsic importance of connecting with people to create change. From the outset, before the partnership with Women's Health Victoria, Women with Disabilities Victoria recognised that creating links and partnerships would be crucial to their success as an advocacy organisation. The organisation had to implement strategies that would enable it to gain the ear of those in government who made funding decisions. As a volunteer network with no ability to apply for funding in its own right it needed to build partnerships with like-minded organisations that could. It needed to establish networks of influence.



Kirsten Deane (Disability Advisory Council of Victoria), Miriam McDonough (Disability Advisory Council of Victoria) and Deb Humphris (Women with Disabilities Victoria) at a Women's Health Meeting hosted by Women with Disabilities Victoria.

Important partnerships in the History of Women with Disabilities Victoria

The women of Women with Disabilities Victoria have placed great store on the power of partnership to influence government and community. Creating partnerships with other women's organisations such as Women's Health Victoria, Domestic Violence Resource Centre, Domestic Violence Victoria, the Royal Women's Hospital and with universities, particularly the University of Melbourne has been a key strategy for the organisation.

WESTCOD and Reichstein

The earliest successful partnership, in terms of funding outcomes was formed in 1994. Women with Disabilities Victoria received a grant from the Reichstein Foundation in 1994, under the auspices of WESTCOD (Western Region Committee of Disabled Persons) for \$12,000 to run consultations in rural and city areas on health and advocacy issues for women with disabilities.

Health and Well-being Projects

The *More and Less* and *Doing it for Ourselves* projects were important exercises in empowerment, but they were also key exercises in building complex partnerships that were effective when it came to improving the health of women with disabilities. As Marilyn Beaumont, Executive Director of Women's Health Victoria said, when asked what motivated her to establish a partnership with Women with Disabilities Victoria: 'We wanted to work with them; they had a reputation for producing results.'



Carol Thomas (guest speaker), Tricia Malowney and Kirsten Deane (DACV) at a women's health forum hosted by Women with Disabilities Victoria.



Fiona Strahan at an event associated with the model women's refuge project, c. 1997.

Woorarra Model Refuge Project

In 1997 Women With Disabilities Australia, in partnership with Woorarra Women's Refuge and with strong support from Women with Disabilities Victoria, undertook an audit of a women's refuge in Victoria. They wrote guidelines for the development of a Disability Action Plan to respond to issues relating to services for women with disabilities experiencing domestic violence, in the context of the legislative framework established by the (relatively) new Disability Discrimination Act (1992). The process involved extensive consultations with women with disabilities about their experiences and needs. Fiona Strahan wrote the final report. *Woorarra Women's Refuge Disability Action Plan* involved detailed analysis of the Act, including what needed to be done in the women's refuge sector in order to achieve compliance with it.

The Action Plan contained detailed information about how the refuge would eliminate discrimination against women with disabilities. Physical access to the building posed a particular and perhaps atypical challenge, since the refuge was on the side of a cliff! Nevertheless, the architect came up with some very innovative ideas, **proving that any refuge can improve access**. Indeed, the whole project indicated that compliance was not difficult, if people chose to look at the issues through a diversity lens.

The project was important for two major reasons. Firstly, not only were women with disabilities involved from start to finish, they were in charge. The Steering Committee, the Working Party, the consultant, the focus group members and the focus group facilitator; all were women with disabilities.

The second important point was that the project confirmed the need for Women with Disabilities Victoria to prioritise the problems of violence against women with disabilities, as they developed their advocacy role. Consultation in the community and networking with people in the service sector, such as Chris Jennings from the Domestic Violence Resource Centre, established the overwhelming need for further research and the need to develop networks to support this research.



Kirsten Deane, Margaret Bayly, Deb Humphris and Maree Ireland at a women's health forum in 2005.



Violence and Women with Disabilities Project
Auspiced by the Domestic Violence and Incest Resource Centre

**Break Down the Barriers -
Work in Partnership to Effect Change**

'Research indicates that regardless of age, race, ethnicity, sexual orientation or class, women with disabilities are assaulted, raped and abused at a rate of at least two times greater than non-disabled women, yet are much less likely to receive assistance or services if they experience violence. (WWDA 1998)'

If a woman with a disability wanted to disclose her experience of violence:

- Who could she tell?
- Where could she go for support?
- Which supports would be able to offer her ACCESS to the services she needs?

**Inclusive support for women with disabilities experiencing violence –
How would you 'Rate' the service or organisation you work for?**

Currently there is a significant lack of co-ordination between the domestic violence, disability and community support sectors at both a programmatic and community level. This results in women with disabilities, who experience violence, receiving inadequate service from all sectors.

**Support the 'Violence and Women with Disabilities Project'
Improve service access.**

Women With Disabilities Affected By Family Violence Project

The Woorarra Women's Refuge project documented the need for further research into the issue of domestic violence and the women of Women with Disabilities Victoria kept advocating to get the funding to do it. After four years of false starts and incredible persistence, success came in a grant of \$95,000 from the State Government. Christine Campbell, the Minister for Community Services, who was well aware of the work of Women with Disabilities Victoria by this time, approved the project funding, under the auspices of the Domestic Violence Resource Centre (DVRC). Money flowed through in 2002 and Chris Jennings was appointed to a position to support collaboration between family violence and disability services in the Western region. So began a relationship between DVRC and Women with Disabilities Victoria with the aim of creating partnerships between disability services and domestic violence service providers. 'Break down the barriers' was a landmark project and the foundation for other important partnerships.



The *Building the Evidence Project* team, Felicity Julian, Cathy Humphreys, Keran Howe, Chris Jennings and Lucy Healey.

Building the Evidence: the status of policy and practice in responding to violence against women with disabilities in Victoria

This was a complex project that involved developing a partnership with the University of Melbourne and the DVRC to pave the way to researching this issue in greater depth. Old friends, such as the Reichstein Foundation, provided funding to support the report, as did the Bokhara Foundation and the Melbourne Community Support Fund.

Professor Cathy Humphreys, the Alfred Felton Chair of Child and Family Welfare at the University of Melbourne, was the major partner and employed Dr Lucy Healey as the Research Co-ordinator. DVRC was an important partner with Chris Jennings contributing an analysis of workforce development and models of best practice in Victoria. The Disability Services Division and the Office of Housing, Department of Human Services enabled the work to progress through additional project grants.



Networks in Action: Melanie Heenan, (Victorian Health Promotion Foundation, Anna Moo (then Aged Care and Disability Division, City of Port Phillip), Kate Gilmore (Executive Deputy Secretary General, Amnesty International), Rhonda Cumberland, (then Director, Office of Women's Policy) and Keran Howe (Women with Disabilities Victoria) at the 2008 launch of *Building the Evidence*.

Centre for Women's Health, Gender and Society

When Wendy Brooks, who worked at the University of Melbourne, became a Women with Disabilities Victoria member, she created access to new networks of influence at the university. In 2008 Keran Howe attended a meeting with the University of Melbourne Faculty of Medicine, Dentistry and Health Sciences to discuss ways to involve women with disabilities in health research.

At the same time Keran and Tricia met with the new Director of the Centre for Women's Health, Gender and Society, Anne Kavanagh, to discuss ways that the Centre might incorporate women with disabilities into their research. Says Anne Kavanagh, 'Women with Disabilities Victoria is inspirational. I have found it a great privilege to work with such a committed group of women who are really making a difference to the lives of women with disabilities.'

Persistence in this partnership has paid off, and has resulted in Women with Disabilities Victoria's involvement in a significant new partnership. Women with Disabilities Victoria will work with the Centre for Women's Health, Gender and Society, in collaboration with VicHealth, Melbourne City Mission and Flinders University of South Australia to undertake research with funding from the Australian Research Council. The project will access existing data sets to, among other things, develop an evidence-base to inform cross-sectoral policy development and service delivery in relation to housing, employment, education and mental health for people with disabilities.

Ordinary Women, Extraordinary Lives

Inspired by the success of the dinner held in June 2000, the management committee decided to hold another event in December the following year. While the 'Ordinary Women, Extraordinary Lives' gala dinner was envisaged as an opportunity to showcase the talents and achievements of women with disabilities, more was expected this time. The committee saw this as an opportunity to create links with people of influence. Samantha Jenkinson, who had performed at the previous dinner, had a key role in organising the function.

At this time there was interest amongst some figures in government to assist capacity building exercises for women with disabilities. The Office for the Status of Women and the Department of Human Services were approached for financial assistance and things took off from there. 'Ordinary Women, Extraordinary Lives' was an event run by women with disabilities, featuring the talents of women with disabilities, to be attended by women from all walks of life, so that they would network with women in government, service provision and so forth. The aim was to connect and showcase; to demonstrate that women with disabilities were ordinary women dealing with extraordinary issues.

Over 200 people attended the event, including the Minister for Community Services, The Honourable Christine Campbell, and the Minister for Women's Affairs, The Honourable Sherryl Garbutt. Tables of ten were sold, but the organisers requested that people donate two tickets from each table to a woman with a disability who would otherwise not have been able to afford to go. In this way, members were able to attend at reduced costs, and networking opportunities were created.



Stella Young, Caroline Bowditch, Margherita Coppolino and Samantha Jenkinson at the Ordinary Women, Extraordinary Lives Gala Dinner.

As is usually the case with these events, what was eaten was secondary to what else happened on the night. There was an exhibition set up in the main foyer, and entertainment aplenty. Janice Florence danced, Margherita Coppolino did stand up comedy, Samantha Jenkinson sang and Stella Young was the M.C. for the night. It was a roaring success and significantly raised the profile of women with disabilities. It created networking opportunities and, very importantly, provided a reference point for future attempts at getting funding. When government and other funding providers received applications from Women with Disabilities Victoria, they now knew who they were dealing with.



Guests at the 2001 Ordinary Women, Extraordinary Lives Gala Dinner.



Stella Young, George Taleporos and Caroline Bowditch at the end of a good night.



Samantha Jenkinson

Samantha Jenkinson is currently the 'Count Me In' Ambassador Project Officer for the Western Australian Disability

Services Commission. A native of WA, her involvement with Women with Disabilities Victoria happened in the early 2000s after she moved to Melbourne in 1999. She began as an ordinary member, and took on the role of Co-Convenor before returning to live in WA. She remembers fondly her role in organising the 'Ordinary Women, Extraordinary Lives' gala dinner in 2001.

Sam's life was standard for a girl growing up in the Pilbara in WA. 'I grew up as a typical teenager in a small town,' she says, 'exploring drinking and boys because there was nothing else to do, while madly planning how one day I would leave.'

She achieved this aim, and went to university in Perth, where she did typical student things like partying and engaging in student politics. At the beginning of second year, she volunteered to help out on the orientation camp for new students. Then things changed. On the third day of the camp she was involved in a car accident where she broke her neck and became a quadriplegic. 'OK,' she says, 'so my life wasn't so ordinary anymore!'

Despite her injury, Samantha has attempted to live an 'ordinary' life ever since. It's just that, as a woman with a disability, there are barriers in place that make it hard to do so. Her life since the accident is a living demonstration of what it is that women with disabilities want – an ordinary life where they are free to be educated, to work, to travel, to have hobbies, to do community work, to enjoy consensual sex, to form meaningful relationships, to have children. It also demonstrates the barriers they must overcome to enjoy these basic human rights.

Due to the circumstances of her accident and injury, Samantha describes herself as 'a lucky quadriplegic'. There were no on-going complications, no extended stays in hospital and because she was in a car accident, she received a big pay out over which she had total control. This was crucial

to her ability to live an 'ordinary' life, despite the difficulties. It also explains her enthusiasm about 'In Control', a group of individuals and organisations who aim to bring about systemic policy change in Australia to enable individuals with disabilities and their families to self manage their support.

When Sam moved to Melbourne in 1999 to see whether her relationship with her then boyfriend, now husband, stood a chance, she became a member of Women with Disabilities Victoria, attending their meetings at a Carlton restaurant. These gatherings were very important to helping her develop a feminist theoretical perspective and linking that perspective to an understanding of the systems of power that enabled discrimination against women with disabilities. 'People might have a feminist perspective,' she said, 'but they don't necessarily put two and two together.' Women with Disabilities Victoria dinners did that for her.

Working as a case manager where she saw the lived experience of abuse against women with disabilities, who felt that they had no option but to stay in abusive relationships, provided the practical focus for the gender theory she was learning. In particular, she began to see how easy it was for domestic violence against women with disabilities to be hidden. In the mainstream community, women without disabilities can form friendship groups who will notice things:

You'll go to the pub for a drink with friends and people might ask one of the group 'what's that bruise? How did you get it?'
If she keeps turning up bruised, you'll ask other questions.
Women with disabilities don't have the same opportunities for unofficial checks and balances.

Since moving back to WA, Samantha maintains her connection with Women with Disabilities Victoria through her involvement with WWDA. In employment and in advocacy, she has broadened her concern to developing programs whereby all people with disabilities have greater control over their own lives, especially when it comes to determining how they should be able to spend their own money. She nevertheless acknowledges the gendered perspective to this issue. 'Women are still the most likely to feel the impact of lack of control worst'.

Wendy Brooks

Wendy Brooks is Chair (Governance) of the Women with Disabilities Victoria Board. She has had a fascinating and extensive career spanning music, marketing, fundraising and management across the welfare, arts and health sectors. In early 2010 Wendy moved from her role as Director of Advancement and Marketing for the Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne to be Head of Business Development, Personal Services at The Trust Company. Wendy was previously Director of the Royal Women's Hospital Foundation which supported research, clinical services and health care programs for women of all ages and new born babies. This gave Wendy a wonderful insight into the social issues affecting women's health.

From 2000 to 2005 Wendy was the Strategy and Development Manager for Orchestra Victoria and established an extensive performance and education program throughout regional Victoria. As a music graduate and keen violist she had a long performing and teaching career. She performed in, managed and toured with a number of chamber and symphony orchestras. In 1991 Wendy established and directed Bay City Strings, a youth orchestral program. Wendy's life partner, Rod, also works in Marketing and they have four children. Since acquiring a neuro-muscular condition Wendy has used an electric wheelchair, which has given her and the family an insight into living with a disability.

'When my neuromuscular condition took hold in 2000 and I had to use a wheel chair, I was personally confronted with the barriers and inequities faced on a daily basis by people with disabilities,' says Wendy. She came to recognise that women with disabilities are more likely to experience barriers and violence than any other sector in society. 'We no longer live in well connected communities. It is easier today for us to be ignorant of the injustice suffered around us and this lack of connectedness means that we run the risk of becoming cold and heartless. Those of us with a voice and the personal experience to truly understand the barriers and prejudices are well placed to raise awareness and effect change. We are all better off if we strive for a more caring and compassionate community.'



Wendy Brooks, Lucy Healey and Delia Portlock at the launch of the new name in August 2010.

As well as her support for Women with Disabilities Victoria Wendy has advocated strongly on access to public transport and has featured regularly in newspapers and through her personal blog.

One of the highlights of the Women with Disabilities Victoria 2009 Leadership Forum was an interview conducted by Catherine Brooks with Wendy, her mother, and with Effie Meehan, on their experiences as mothers raising children while juggling the challenges of their disabilities. Wendy regaled the audience with hilarious stories of these experiences. 'I quickly learnt that it is not what happens to you in life that is important, but what you do with it.'

Wendy's contribution to the development of Women with Disabilities Victoria has been significant since she joined the Board in 2007. Wendy's experience and networks in the marketing and communications field resulted in Women with Disabilities Victoria receiving pro bono support from AJF Advertising and her expertise in the nuances of communication have complemented the community education work of the members of Women with Disabilities Victoria.

She believes it is a joy and privilege to belong to Women with Disabilities Victoria:

I am surrounded by women who throw themselves into life and make a wonderful contribution to our society. Although I have only been involved in the organisation for three years, I have seen it make an enormous transition. This is largely due to the vigour of the Board directors and the outstanding leadership of Keran Howe, Executive Director and her enthusiastic team.

Others know that it also due to the significant effort made by Wendy herself.

Jody Saxton-Barney

Jody Saxton-Barney is an Urangin/Birri-Gubba Deaf woman from South East Queensland. She now lives in regional Victoria and is the sole operator of a business she began in 2007, the Deaf Indigenous Community Consultancy. She works nationally and offers consultancy and training services for organisations, departments, community co-operatives and service providers who need assistance assessing the impact of deafness in Indigenous communities on community capacity building.

Deaf and Hard of Hearing Indigenous people have issues that are unique to their community. In particular, their relationship to AUSLAN is different from the mainstream community. In the first instance, significantly fewer Indigenous people have access to learning it. Furthermore, there are complex cultural requirements that make it difficult for Indigenous signs to become universal. As Jody explains, 'Indigenous Deaf people's use of local cultural signs, hand talk and gestures is linked to knowledge of country, history, family, storytelling and lore, ceremonies, customs and performances.' To use some of these signs off country, she says 'is offensive and dis-respectful and punishable by cultural law (lore). Doing this can and has led to the individual Deaf person being banned or rejected by their communities.'

Jody first became involved with Women with Disabilities Victoria in 2005 when she attended a National Women's Health Conference. She started as a general member and then became a member of the Board, claiming that during her time on the Board 'I had a say in about nearly everything!'

Some significant milestones with which she has been involved were the redevelopment of the



Jody Saxton-Barney (second from right) with Tricia Malowney, Natalie Tomas and Keran Howe at the Australian Sign Language Interpreters Association (ASLIA) Awards in 2008.

constitution and working towards getting the organisation Donor Gift Recipient accredited. *Building the Evidence* was a project she 'found very moving to participate in'. That important report 'leads the way in showing the needs of women with disabilities in our communities.'

Jody has since resigned from the Board to devote time to the development of her business, but remains an interested member, doing what she can to 'promote the network in my extended circles to improve the access and rights of women with disabilities in Victoria.' She is particularly keen to build opportunities for women in remote and regional Victoria to participate.

When asked what attracted her to the organisation she replied, 'The women of course!!! I was just in awe of the process, support and leadership. I fitted into the network like a duck to water. I found that I had the same vision, views and moral compass as many of the other women in the network.'

Furthermore, she says, Women with Disabilities Victoria respects diversity, and is 'encompassing of all cultures, backgrounds and disabilities.' As a result, they have developed 'good strong partnerships with important organisations and services to improve their processes on accessibility rights for women with disabilities in Victoria.' She is working to develop links with Indigenous communities, to encourage Indigenous women with disabilities to get more involved. In this regard, she says, 'I have a plan!'

From the outset, Jody was 'blown away by the support of such a small operation.' She was inspired and encouraged by their capacity to achieve. 'To see the network evolve to do so much and be fully inclusive of all women with disabilities,' she says, mindful of her own challenges as a small businesswoman, 'I am in awe, and hope my small business can make a dent with the same integrity and honesty.'

Jody's guiding principle is based on '*Giving the Community a Voice*', which means you 'have to have the conversation, learn the language and take the time to LISTEN'. When she tells people that, she says that they often laugh. 'Ha-ha,' they say. 'You have to listen. That's funny - you can't hear'; a response which only makes her more determined to prove that listening is different from hearing and involves more than just 'using your ears.'

Influencing Change: The Core Business of Women with Disabilities Victoria



Bill Shorten, then Parliamentary Secretary for Disability Services, meets with Keran Howe and Tricia Malowney.

In order to be effective agents of change, advocates need a credible knowledge base to call upon. Women with Disabilities Victoria members knew from the outset that the absence of comprehensive research, statistical analysis or information that addressed how gender intersected with disability to produce a double disadvantage was a problem they needed to redress. How could they advocate effectively without an evidence base?

Early efforts to develop this knowledge base have been discussed in previous sections. Continued research has been a vital area of activity for the organisation. Women with Disabilities Victoria has commissioned several reports and conducted research, establishing the facts about the reality of everyday living for women with disabilities in Victoria.

They have also been committed to making sure that the reports don't lay at the bottom of decisions makers' drawers, gathering dust. The women of Women with Disabilities Victoria have been 'getting the message out' through their members' attendance and presentations at conferences and by sitting on committees advising the State Government.

The following section sets out initiatives taken to influence change, especially in the priority areas of violence against women with disabilities, parenting rights of women with disabilities and health issues for women with disabilities. **During the course of 2009-2010** Keran Howe, Lauren Hayes, Tricia Malowney and Kate Hood presented a total of **17 conference papers and submissions** and Keran Howe, Brenda Gabe, Tricia Malowney, Margaret Stevens, Liz Ellis, Jody Saxton-Barney, Kate Hood and Jen Hargrave have made a total of **14 representations**. It makes for exhausting reading!

Women with Disabilities Victoria Clearinghouse

Before focusing on the research and representation, it is important to acknowledge the systematic way that Women with Disabilities Victoria has built its knowledge base. A very important, early initiative to build evidence was the development of the Clearinghouse of material and publications; a database that can be drawn on for submissions and for use by others in advocating for change. In 2007, Melanie Thomson, as Information Officer, contacted 120 organisations which worked in the area of women with disabilities in different countries and sought permission to include links to their web resources in the Women with Disabilities Victoria Clearinghouse. By June 2007 the Online Resource Collection held 358 resources, 210 of which were to be available online and by 2009 this number had increased from 388 to 497. In 2009 Women with Disabilities Victoria was able to claim that 'there is no other searchable Clearinghouse of information resources addressing these issues in Victoria, or Australia.'

Influencing change: Priority Areas

1. Violence against women with disabilities

A key issue for Women with Disabilities Victoria has been addressing sexual assault, domestic violence and abuse that women with disabilities are more likely to experience than other women. Raising awareness of this intolerable state of affairs has been a constant priority throughout the organisation's history. In addressing these issues Women with Disabilities Victoria has worked closely with Domestic Violence Victoria and Domestic Violence Resource Centre as well as with government through the Family Violence Statewide Advisory Committee.



Attendees at the Framework for Influencing Change Launch.



Chief Commissioner Christine Nixon, Keran Howe and Tricia Malowney at the launch of the Framework for Influencing Change. Chief Commissioner Nixon said she felt 'humbled by the issues'.

'A Framework for Influencing Change – Responding to Violence against Women with Disabilities'

In 2007, Christine Nixon, the then Victoria Police Chief Commissioner, launched '*A Framework for Influencing Change – Responding to Violence Against Women with Disabilities*'. Keran Howe, as Project Manager, was responsible for developing this framework. An important tool for raising awareness of the issue, the Framework report generated discussion and provided opportunities to be a catalyst for change in both the family violence and disability sectors.

More than 130 people attended the launch, an occasion that provided a great opportunity to sheet home to this wider audience the need to confront these issues. Those present included politicians, the Disability Services Commissioner, The Executive Director Disability Services Division, ministerial advisors and staff from the Departments of Human Services, Justice, Planning and Community Development. In addition, staff from Victoria Police, the courts, family violence, sexual assault, and disability service providers, advocacy groups and women with disabilities attended. Keran Howe emphasised the importance of mainstream policy makers collaborating with Women with Disabilities Victoria to recognise that as a community this issue can no longer be ignored:

For people with disabilities, respectful and affirming relationships whether within families, shared houses, workplaces or communities, are by no means guaranteed... We have all heard the facts and figures on isolation, discrimination and marginalisation... It is therefore shocking that as a community we have largely ignored violence against women with disabilities.

The Building the Evidence Research: a case study



Dr Helen Szoke, Commissioner, Victorian Equal Opportunity & Human Rights Commission, at the *Building the Evidence* Launch in 2008.

Women with Disabilities Victoria's commitment to evidence based research is demonstrated in the realisation of the 2008 *Building the Evidence Project*. Women with Disabilities Victoria recognised the need to map what was currently happening in Victoria's family violence sector with regard to women with disabilities in order to have a credible base on which to advocate for change. The project explored the status of family violence policy and practice in Victoria in responding to violence against women with disabilities and was an important response to the lack of relevant statistics. It demonstrated that the majority of women with disabilities lacked access to the resources they required to protect themselves. The research partnership included new colleagues (Professor Cathy Humphreys and Dr Lucy Healey who coordinated the research team) and familiar collaborators Domestic Violence and Incest Resource Centre (Chris Jennings).

The report found that:

- family violence sector standards and codes and guidelines had little to say about how to support women with disabilities;
- most services did not routinely collect data on disability and family violence; little was known about the experience of women with disabilities who sought assistance after experiencing violence;
- a need for sustained collaboration between disability and family violence services was identified in order to rectify these major service gaps.

Helen Szoke, the Victorian Equal Opportunity and Human Rights Commissioner, launched the report, which carried 53 recommendations, in 2008 at Melbourne at the 5th International Conference on Mental Health and Mental Behaviour Disorders. The findings of the report have been presented

to Government Ministers and senior bureaucrats at both state and national level. It has also been presented to workers and academics in the disability, women's health and family violence sectors. The research report is featured on the Women with Disabilities Victoria website and has been a valuable resource in arguing the gaps and deficiencies in Victoria's domestic violence response system.

To educate workers in the field Women with Disabilities Victoria convened a statewide forum in 2009 in conjunction with Women's Health in the North, and the University of Melbourne Family Violence Actioning Interdisciplinary Research team. The '**Working with Women with Disabilities Experiencing Violence Forum**' brought Dr Gill Hague of the Social Policy Unit at Bristol University to be the keynote speaker. Dr Hague presented research into domestic violence service provision to women with disabilities in the UK from the perspective of both providers and users of the services. As part of the research, service providers gave examples of best practice responses to women with disabilities, while women with disabilities replied to questions about their experience of the services. Lesley Hall, a member of Women with Disabilities Victoria and Chief Executive Officer of the Australian Federation of Disability Organisations (AFDO), chaired what was described as 'a dynamic interactive panel of women with disabilities speaking about 'what is a disability?'' The Forum gathered over 130 workers across the sector and started a conversation about how organisations can better approach their work with women with disabilities.

As a result of the research and dissemination effort, the findings of *Building the Evidence* have been considered by the Interdepartmental Committee on Family Violence and the Statewide Advisory Committee on Family Violence. In 2010 the key recommendations are now reflected in the priorities of the Victorian Government's Ten Year Strategic Framework on Family Violence.



Staff and Partners and Helen Szoke at the *Building the Evidence* Launch. From Back Left: Chris Jennings, Felicity Julian, Melanie Thomson, Lucy Healey, Helen Szoke, Vig Geddes, Cathy Humphreys, Keran Howe.

2. Women's health

Women with Disabilities Victoria's commitment to women with disabilities enjoying equal access to health services in Victoria has meant that it has had to educate the mainstream health service providers to consider the specific needs of women with disabilities. For instance, women with disabilities are physically unable to access breast, cervical and bowel cancer screening programs if health clinics fail to provide accessible parking, toilets and examination tables.

Early reports, like *More and Less*, provided evidence of the nature and range of health and community services that women with disabilities required in order for them to lead satisfying lives. Although most participants in the project indicated that they experienced a sense of well-being for most of the time, the issues of loneliness and isolation, limited income or employment issues and affordability of social activities and/or the cost of aids and equipment, influenced this sense of well-being. It made recommendations under the headings of income and access to services; health and well-being; community facilities and supports.

Women with Disabilities Victoria recognised that in order to undertake effective community and professional education more systematic understanding of the research was needed. In 2010 they commissioned a literature review of the status of research on access to health services for women with disabilities. Sylvia Patrony and Philomena Horsley undertook this review which was launched by Women with Disabilities Victoria in October 2010.

This postcard was an initiative of PapScreen Victoria and Hobsons Bay City Council's Metro Access Program, a partnership between local government and the Department of Human Services Victoria. It was part of an on-going campaign to raise awareness that women with disabilities need access to basic women's health services.



3. Contributing to awareness raising on Parenting

Parenting is the third priority for Women with Disabilities Victoria. In relation to issues such as sterilisation, abortion, pregnancy or parenting, the evidence shows that women with disabilities are treated differently to women without disabilities. They encounter discrimination, are subject to invasive medical procedures and are denied their basic human rights and bodily integrity because of their disability. From the Women with Disabilities Victoria perspective, although extensive research has been conducted into the needs of parents of children with disabilities, less information exists on the needs of parents with disabilities. This perhaps reflects prevailing community attitudes towards women with disabilities who are commonly thought of as asexual, dependent and essentially 'unfit' mothers; attitudes that Women with Disabilities Victoria are determined to change.

During 2005 the working party for the Parenting Rights for Women with Disabilities was established. Members included Tricia Malowney, Debbie Humphris, Natalie Tomas and Sarah Waters.

In her role as Manager of Women's Social Support Services at Royal Women's Hospital (RWH) Keran Howe advocated strongly for the need for Maternity Services to be better tailored to the needs of women with disabilities, particularly women with intellectual disabilities. The RWH took up the challenge and gained funding for a pilot project of an antenatal-postnatal service for women with learning disabilities. At the end of the pilot an evaluation was conducted which saw the continuance of the Women's Individual Needs (WIN) Clinic at the RWH.

In 2008 Women with Disabilities Victoria gave a presentation at a Yooralla Society of Victoria forum on support for women with disabilities as parents. A key issue that emerged was the importance for parents to be able to use their income support not just for their individual needs, but also to assist in the care of their children. Keran Howe raised this issue with the Minister for Community Services and the Executive Director, Disability Services Division and received their assurance that the policy would allow for that situation. Future work of Women with Disabilities Victoria will focus upon drafting a framework for Women with Disabilities Victoria to support advocacy that addresses the parenting and reproductive rights of women with disabilities.

Community and Professional Education

From the start Women with Disabilities Victoria members have viewed presentations at public forums as an important way of getting the message out there. Even when the organisation was run by volunteers, women such as Karleen Plunkett, Maree Ireland, Sam Jenkinson, Tricia Malowney, Natalie Tomas and Keran Howe, were out in the community getting the word out, appearing at public forums and delivering academic papers at domestic violence, disability and health conferences locally and abroad. The papers were sometimes delivered under the name of Women with Disabilities Victoria and at other times auspiced by various organisations including WWDA, the Disability Advisory Council of Victoria and the Royal Women's Hospital.

The message was consistent: women with disabilities were marginalised and systematically denied their human rights and the right to be healthy, free of violence and able to participate fully in life. They have taken their message to a global audience. In 1999 Keran Howe and Di Temby presented papers on women with disabilities at the Interdisciplinary Conference in Edinburgh, Scotland and again experienced an opportunity to meet with women from Europe, the USA and South Africa who were concerned with violence against women with disabilities.

In 2008 Tricia Malowney attended the Fulbright Symposium on 'Healthy People, Prosperous Country', which focused on health policy. It was hosted jointly by Flinders University, Adelaide and the Cooperative Research Centre for Aboriginal Health. Tricia raised the subject of health issues for women with disabilities and spoke directly to Sir Michael Marmot, Chair of the World Health Organisation's Commission on the Social Determinants of Health. She stressed the importance of recognising people with disabilities as a disadvantaged population in the World Health Organisation's '*Closing the Gap in a Generation: health equity through action on the social determinants of health.*'



Margaret Stevens, Keran Howe and Kate Hood role - playing at the Working with Women with Disabilities Experiencing Violence Forum.



Cathy Humphreys working the room at the Working with Women with Disabilities Experiencing Violence Forum.



Members of the disability and domestic violence services at the Working with Women with Disabilities Experiencing Violence Forum.

Influencing government policy

As a result of their advocacy work, Women with Disabilities Victoria members have contributed to legislative change in Victoria. Examples of legislative reform that better reflect the needs of women with disabilities can be found in the Sexual Offences Act 2005, Abortion Bill 2008, the Family Violence Protection Act of 2008 and the Personal Safety Bill 2010. Legislative reform campaigns have involved collaboration with Domestic Violence Victoria, Domestic Violence Resource Centre Victoria, Women's Health Association of Victoria, the Federation of Community Legal Centres and Victorian Council of Social Services.

In the area of family violence Women with Disabilities Victoria are currently represented on no less than fourteen government and community advisory committees. Fiona McCormack CEO, of Domestic Violence Victoria, reflected on the impact that Women with Disabilities Victoria has had through its representation:

There was no presence and no visibility of women with disabilities until Women with Disabilities Victoria brought the issues to the government and community tables. Their impact has been remarkable and now more and more women with disabilities are a part of the considerations when government policy and service delivery are being developed.

Recent activities in the areas of women's health policy include:

- Contributing to Women's Health Ten Point Plan. As a member of the Women's Health Association of Victoria (WHAV) Women with Disabilities Victoria contributed to the development of the Ten Point Plan for Women's Health in Victoria. This plan calls on government to commit to women's health and improve women's health status as well as improving environmental, social and economic outcomes for women. It adopts the social determinants of health and calls for an inclusive and whole of government approach that recognises the diversity of women, including women with disabilities.

- Contributing to the Victorian Women's Health and Wellbeing Strategy 2010-2014. Women with Disabilities Victoria has been keen to ensure that women with disabilities are included in the Third Victorian Women's Health and Wellbeing Strategy 2010-2014. Members of Women with Disabilities Victoria attended a consultation forum and Keran Howe has represented Women with Disabilities Victoria on the Victorian Women's Health and Wellbeing Strategy Advisory Committee.
- Contributing to National Women's Health Policy. Women with Disabilities Victoria asserted the critical importance of inclusion of women with disabilities in all women's health policy and service delivery in a submission to the National Women's Health Policy Consultation.
- Four Women with Disabilities Victoria members attended the Australian Women's Health Conference held in Hobart, where over 600 women from around Australia and New Zealand gathered to discuss women's health issues. They joined with other women with disabilities from around Australia in presenting papers on their issues of concern and in asking questions from the floor.

The Women with Disabilities Victoria Board is committed to building and presenting the evidence of the impact on women with disabilities of domestic violence, lack of access to health services and of the denial of parenting rights in its goal to influence change. It has continued to strengthen the online resource centre, which provides all members with access to the information which can assist them in their own advocacy efforts. The paid staff and the Board members present this evidence at a range of meetings and conferences. In this way key decision makers and members of the broader community are confronted with the realities of the inequitable treatment of women with disabilities, thus strengthening the capacity of Women with Disabilities Victoria to assert the right of women with disabilities to be treated as full citizens in their communities. If their communities continue to ignore these realities, they must take full responsibility for their actions. They've been told.

Building the Plan – Thinking Strategically

Women with Disabilities Victoria is testament to the hard work and advocacy of many women over many years. At its heart, is the belief that what women want is equality - to participate in public life, to have fun, to work, to access health services, to be part of the overall community. But what women want is to do this in a way that they define, not a way that is defined for them. This is the basis of their mission and indeed is fundamental to acknowledging that women with disabilities have the same human rights as anyone else! 'Nothing about us without us' is even more critical when we see the additional challenges that women with a disability face, when we think about violence against women, which may be perpetuated by carers or partners, and also the unique role they play as parents.

– Dr Helen Szoke, Commissioner,
Victorian Equal Opportunity & Human Rights Commission.

Since 1992, when the first meeting was held, Women with Disabilities Victoria has been defending the rights of women with disabilities in Victoria to speak for themselves and advocate on their own behalf. From the very first days, they were about 'Empowering Women'. Their effectiveness has been acknowledged by government and central departmental agencies and, according to Helen Szoke, 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'.

Their commitment to independence and individual empowerment underlines their approach to advocacy. They are an organisation based on feminist principles that has transformed significantly over time, from a volunteer, grassroots organisation to an effective advocacy and information service. Despite changes to the membership, leadership, structures of governance and mission statement, one thing has not changed.



Dr Helen Szoke, Commissioner, Victorian Equal Opportunity & Human Rights Commission.

Women with Disabilities Victoria has never lost sight of the vision of 'a world where all women are respected and can fully experience life'. Aspiration and passion have driven them from day one.

Nor have they deviated from a value base that upholds:

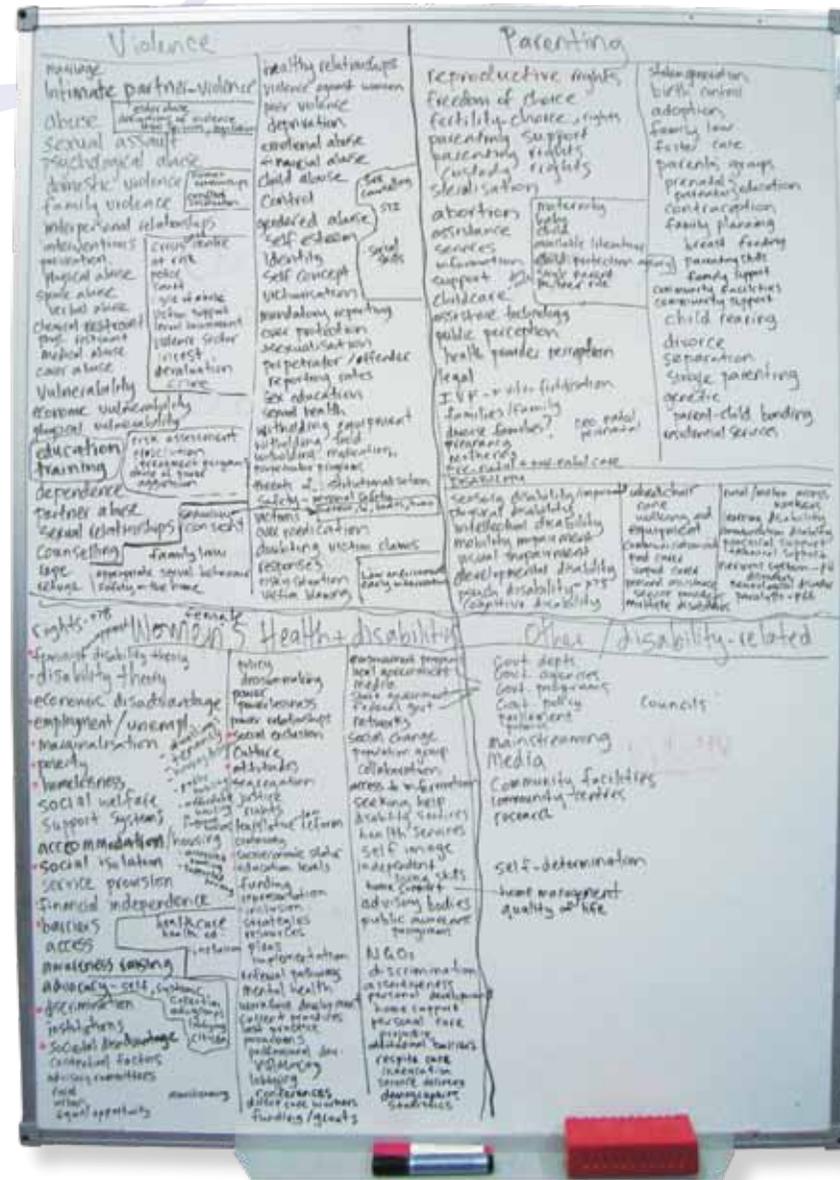
- Equality of opportunity
- Accessibility for all
- Respect for all
- Working together collaboratively
- Effectiveness
- Creativity
- Different opinions and perspectives
- Human rights
- Social justice
- Diverse abilities



Board Members and Staff at the 2010 planning meeting.

Women with Disabilities Victoria is still, at its core, the same organisation that, in 1995, was made up of members that sought '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'.

What has changed over time is the structure of the organisation and its ability to imagine this world and live these values on a sustained footing. The focus on challenging imbalances of power and the disadvantage that results remains as crucial now in Women with Disabilities Victoria's work as it was in raising awareness and providing social support in 1992. In a world where women with disabilities are more likely to be disadvantaged in housing, more likely to be institutionalised, more likely to be unemployed and less likely to have access to education and rehabilitation services than men with disabilities, let alone other members of the community at large, then the socio-economic disadvantage that accompanies disability is a feminist issue. Combine this with the high rates of discrimination and appallingly high rates of violence and sexual abuse that women with disabilities are vulnerable to and the urgency of this feminist perspective is obvious.



White board recording a brainstorming session at a planning meeting.

The women of Women with Disabilities Victoria, throughout the course of the organisation's short but eventful history, have made a real difference to the lives of women with disabilities in Victoria. Disability services and family violence services both have a greater awareness and understanding of what is at stake when they encounter women with disabilities. Many health providers have learned that they must change the way they do business, if they are going to be accessible to women with disabilities. Sexuality and reproductive rights as human rights issues have been brought to the forefront. The work of Women with Disabilities Victoria in these areas is gaining international repute. There can be no question of this small but mighty organisation's effectiveness at a policy level. And even at a practical level, Women with Disabilities Victoria are helping to implement change, although this is a harder, much more complex task.

There is, of course, still so much to do. But despite the overwhelming task that confronts them, or perhaps because of this, Keran Howe says, 'we just need to keep working to keep the message out there'.

In claiming its future, Women with Disabilities Victoria will continue to prioritise special areas of interest, which are:

- To continue to build the evidence base for advocacy regarding violence against women with disabilities, access to health services and parenting rights;
- To advocate to reduce and prevent violence against women with disabilities;
- To improve access to health care for women with disabilities;
- To uphold the parenting rights of women with disabilities.

Women with Disabilities Victoria will continue to search for funding to explore new projects that support the implementation of these goals as fundamental tenets of their Strategic Plan.

Specific projects aimed at implementing their strategic vision are as follows:

- Planning will commence on the feasibility of establishing a community education program on gender and disability. This will consider the potential for women with disabilities providing professional education to health and community service providers to improve their understanding and competence in responding to women with disabilities.
- Women with Disabilities Victoria will seek to expand its Information Program including opportunities for greater utilisation of social networking and multi-media approaches to accessible information and community education.
- Leadership programs, particularly for isolated women with disabilities, will continue in partnership with other disability organisations and a mentoring program for women with disabilities is planned that will target young women with disabilities in particular.
- Funding will be sought for the development and implementation of a parenting strategy and to advocate for improved individualised support packages for women with disabilities who are parents.
- Strengthening the partnership with the Centre for Women's Health, Gender and Society at the University of Melbourne to support the conduct of research to explore disability as a health determinant and inclusion of disability as a key item in routine health data collection.

And much, much, more! Of course, they'll be doing this for themselves. 'Nothing About Us Without Us.'



Board Members and Staff at the 2010 planning meeting.



Board Members and Staff at the 2010 planning meeting.

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The archives of Women with Disabilities Victoria were a very useful source of information in the period after 2004. There are limited, but useful records for the period 1995-2001. Copies of all the major reports referred to are in these archives. They can also be obtained online at

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Melbourne Community Support Fund
Portland House Foundation
The Reichstein Foundation
Victorian Health Promotion Foundation
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If you would like to support Women with Disabilities Victoria's work or to fund a specific project please contact Keran Howe, Executive Director at keran.howe@wdv.org.au

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All donations over \$2 to Women with Disabilities Victoria are tax deductible. You can donate to Women with Disabilities Victoria in the following ways:

1. online at: <http://www.givenow.com.au/wdv>

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Women with Disabilities Victoria
GPO Box 1160
Melbourne Vic 3001

3. by direct credit payment

Account name: Women with Disabilities Victoria Inc
Bank: Commonwealth Bank of Australia
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Account number: 10207357

BECOME A MEMBER

Full membership of Women with Disabilities Victoria is available to all women with a disability who live in Victoria. Full members are encouraged to participate in advocacy and representation and to nominate for the Women with Disabilities Victoria Board. There is no fee for full members.

Associate membership of Women with Disabilities Victoria is open to individuals and organisations supportive of the aims of Women with Disabilities Victoria and its members. Associate members do not have voting rights and are ineligible to join the Board.

For more information or to access a membership form, email wdv@wdv.org.au or visit the website at <http://www.wdv.org.au/membership.htm>.

You can write to Women with Disabilities Victoria at the following postal address:

GPO Box 1160
Melbourne Vic 3001

The office is located at:

Level 8/255 Bourke Street, Melbourne 3000

Please call:

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Or visit the website:

<http://www.wdv.org.au>



