

## **Submission to Productivity Commission on DDA**

### **Out of the Cleaner's Cupboard - The DDA's Impact on My Life**

**Becky Llewellyn**

I am writing to share my experience of life before and after the DDA. Others will make critiques and suggestions for change of the Act. I want to stress its positive and developmental effects from my experience as a carer.

For thirty years since 1972, I have been the wife of a person with severe physical disabilities. As you can imagine, many things have changed over that time. The invention of the electric wheelchair, other technological and medical advances have all enriched our lives. The International Year of Disabled Persons (IYDP) 1981 was a huge catalyst to awaken community attitudes and begin the process of hearing the voices of people with disabilities.

But from my perspective, the Australian Government's passage of the Disability Discrimination Act 1992 has changed our lives and that of people with disabilities more than any other single factor. As powerful national legislation, it brings the principle of access to facilities and services into every level of community life. Systematically over time this Act has the potential to dismantle discrimination on the grounds of disability. My hope is that the review will be able to sharpen its ability to do so.

It is absolutely crucial for the continued dignity and equity of people with disabilities and their associates that this legislation continues to be supported and promoted. Why? Because the waste in human potential of people being shut out, locked in, feeling alienated and dependent is the opposite of the productivity that can be gained as the DDA opens up society. Continuous health studies show poor outcomes for people who are depressed and lonely, further sapping society's resources and creating multiple disadvantage for those who acquire disability.

The Bureau of Statistics estimates that almost 1 in 5 people have some form of disability. The DDA also includes family, work and social friends as associates who can claim the benefits and rights of the Act and the inclusion of associates, widens further the numbers of people who may benefit. So if the 1 in 4 Australian citizens who have disability in their lives feel supported in their rights to participate with equity the DDA can make a significant impact on productivity.

This movement to participate is good for the people with disabilities and as the chicken and egg of accessible services and facilities grows in all areas of business, it will spread economic benefits throughout the community. Organisations in arts and sports who have worked to make these changes are already commenting on enhanced bottom lines.

Here is how different living with disability feels to me before and after the DDA.

Before:

Even in the 1980s, people weren't used to seeing people with visible severe disabilities enjoying and participating in a full range of life's experiences. The thought of 'catching wheelchair' seemed frightening and access was something that few planners thought of. For people with disabilities, you had to have guts aplenty to take to the city streets and risk the stares, the pats on the head, the over-sympathetic voices.

Disability had not emerged from the leftover attitudes from the shame and taboo of various religious programming, from associating people with the charity body where they may have received services, from keeping people who were different out of sight and out of mind. Many Australians had no first-hand contact with disability.

Our first overseas trip in 1973 found us in the Sydney Airport using a cleaner's cupboard as there were no unisex toilets. Airports were not used to handling people in wheelchairs and lacked systems and experience. If people travelled, it was often in a group to a 'specialist' wheelchair event. There were not accessible taxis or buses to get people to and from airports. There were not accessible hotels to stay in when travelling interstate.

My husband at this stage worked in the State Government, but he was not allowed to have a superannuation policy through this work because of his disability. While at 66 he has now outlasted many of his then-peers, this prohibition based on disability placed extra pressure on us to plan for an independent future. Neither of us accepted the conventional expectation that we should be dependent on the state forever.

The assumption was at the time that all people with severe disabilities should be IN-valid pensioners and dependent on either the government and/or charities for their specialist needs. There was no community housing and supported accommodation was in its very infancy. Attendant care as a concept was over a decade away.

In the mid 1970s, I taught at our shiny new centre for 'crippled children', where they could have therapy, schooling and even live in to make things easier. The fact that they didn't get to know and make friends with kids in regular schools was not the main thing. They were being 'well taken care of' in a medical kind of understanding. One of these students now sees himself as a 'hidden' generation – taken away from family life because there weren't services or facilities nearby. No institutional care situation can nourish children the way a family can. Disability precluded normality. Families were not included in case conferences about their own child's well-being. There were 'experts' and the rest.

In our lives before the DDA, there were many steps. I pushed my husband in a manual wheelchair everywhere. We went up steps to get into movies, in theatres, in sporting venues. An electric wheelchair would have been laughable, because ramps, kerb ramps, etc were not part of the infrastructure and would have added to the frustration of trying to get into places. In our city of Adelaide, there were rarely any toilets, except at the State Library. We never heard other people talking about their disability, in fact we didn't really want to associate with those disability organisations. We fixed

our own problems the best we could and fortunately my husband had a strong reputation as a successful business operator.

We didn't like the word 'handicapped' (cap-in-hand) because of its connotation of begging for help and were looking for a non-medical, neutral and dignified term. The term 'carer' was not around. I didn't like it when it came; for me it seemed like a one-way role – I 'care for' my husband. Don't people with disabilities get the same chance to live and love and care for others in our language usage?

### US Model for Change

We were both challenged to new possibilities on a trip to the US in 1973, where my husband studied at a US university. The entire attitude was one of helpfulness and open access. In contrast, he had been denied enrolment in two courses in Adelaide because they couldn't get him into their classrooms and that was seen as enough of an excuse. In America, there were accessible pathways, signage, facilities and the offer of note-takers, etc to facilitate involvement. The emphasis was on participation in education and employment, not on a lifetime of welfare dependency.

We wondered what was different about Australia that we couldn't provide these opportunities? We returned and became involved in forming early self-help groups of people who wanted to see change. Since IYDP in 1981 and more particularly, since the DDA, the pace of change has continued to accelerate.

Before the DDA, when we encountered barriers such as steps or lack of toilet facilities, we talked to facility managers and owners and could only ask them to consider providing access on the basis of;

1. You probably have a barrier because you've never thought about this issue.
2. It would be a nice thing, a charitable thing to do.
3. It might help you encourage new customers, students, workers, etc

After:

With the DDA, I feel enabled as a person who cares for and lives with a person with disability to point out that when they upgrade their facility, it is the law to make it non-discriminatory.

The difference in attitude I feel from one of virtually begging is that now I feel supported by benefits of citizenship in a democracy that cares about involving all its members. I no longer feel ashamed of needing to ask for something 'special' and 'different'. Our requirements for access are just that – part of making the environment better for everyone.

### Access to Premises

As our children and myself live with my husband's severe physical disability, access to premises was one of the major barriers to participation. With the adoption of the DDA and further refinement of Australian Standards codes, the building industry and architects have become much more aware of planning and building to eliminate barriers. The local government sector have been key players in lodging Disability

Action Plans and raising awareness of their planning and certification processes. We are spoiled for choice when we go to town today for which toilet to use. That change is tremendous. And as our whole society ages, it is an incredibly good investment in the future.

There is more work to do in harmonising the DDA and the BCA so that people are more clear as to their options. In our experience as access consultants, the attitudinal change is filtering through society so people building in the public and commercial sector are much less likely to build in barriers unthinkingly. The threat of a DDA complaint has turned out to be a powerful mechanism towards creating a more accessible built environment.

Where there still remains a huge gap in facilities is in the residential sector with homes and flats designed for renting and buying that are adaptable. Access in private housing remains a hit or miss prospect.

With the ageing wave coming in Australia, we are not providing anywhere near the housing options that will be needed for people to age well with the disabilities that are associated with normal ageing. The DDA needs to lead in this area to make significant change occur.

#### Access to Transport

The DDA was responsible, through a well-publicised complaint in our State brought by three people with disabilities, for the fact that almost every bus going past my home now has an electric ramp and signage to tell us we can use this service. This change seemed a dream beyond our scope without the DDA. We thought that making a separate accessible taxi network with subsidised vouchers would be as good as it gets.

We were wrong. Almost every day, I see people in wheelchairs and scooters using the normal public train and bus systems. I've heard many parents say that the new low floor buses are much easier for their prams, etc. The integration of bus/train interchanges has meant that so many more choices are opening about where you can go. In terms of productivity, this has broken down many barriers.

It does not however solve all problems for all people with disabilities. We are lucky to live near a bus route and in an accessible city. What of rural Australians where there is no public service?

We have encountered barriers in one type of transport that haven't been addressed. The the large tourist boats on the Great Barrier Reef and Gordon River claim to have access. We drove all the way to western Tasmania to find that the promised access doesn't work if you use an electric wheelchair. Steps built to keep water out of compartments are barriers and the toilets are tiny. My husband spent his Great Barrier Reef tour outside on the deck because the inner spaces were not accessible to him. Reform in these sectors will provide the experiences in two of Australia's natural wonder areas that is currently missing.

## Access to Employment

Technology both helps and hinders in employment for people with disabilities. We work from home with computers and email. My husband had to forego his government job when the building became loaded with security controls that he couldn't reach or use. Controls are the new barriers in the environment that steps once were. Much more thought of their design and placement is needed.

Employment has been difficult challenge for me, as the sole physical support for our family. I could not see how I could raise two children, drive my husband to and from his work and work myself. What would happen if any of those three people I loved were sick? I doubted that employers would have sympathised with family leave or carer's leave pre-DDA. Many carers have postponed or been unable to continue employment because of the constancy of care they provide at home. There is a cost to society in this and personal frustration, loss of individual achievement, not to mention income.

There is much more work to do in providing productivity gains for people who live with disability, either their own or their family member. Self-employment is one area which may provide flexibility, but more support and training is needed to grow this sector.

Another area is taxation. There continue to be no provisions in the tax system to encourage people with disabilities to work through acknowledgement of the extra costs of disability. The cost of equipment continues to spiral and people say they want to have workers with disability, but where are the incentives in the tax system?

## Access to Services

The DDA is national legislation yet the situation of a person, say a person who needs help getting up, is different in every state and territory. The Commonwealth-State Disability Agreements need to be overhauled so that no matter where you live, there are more consistent programs and provisions in regard to care services and equipment. Similar problems exist in other State disability provisions, such as parking permit legislation and taxi voucher schemes.

However, as a South Australian family, we have benefited from access to services that support many of our equipment and care hour needs. The waiting lists for necessary equipment are too long and the services are not particularly transparent to consumers, but it is an improvement on pre-DDA services. These services attempt to involve consumers in forums and reference groups to improve their processes.

Access to other service areas than direct disability services, seems too to have improved. Many organisations are aware of the DDA, have made DDA Action Plans or have programs in place to make adjustments for any barriers to participation. The kindness that once was directed solely to charities for 'handicapped people' is present in the community now in a more dignified and positive manner.

This is important, for as more people with visible and hidden disabilities participate in recreational activities, education, employment, sport and the arts, it lessens the fear of

others of how they might be if they had a disability. They have models to learn from. The Sydney Paralympics was a great display of diversity and participation in the community and revealed how Australians want to “be in it”!

In my experience with progress of one organisation alone, the gains of making a DDA Action Plan have been amazing. The Adelaide Festival Theatre has taken its plan seriously, made very big structural alterations, improved all of its information, marketing and programming areas, and working with the Patron Reference Group that we belong to, is now working on ideas and initiatives, such as audio description of theatre performances to further involve people with various disabilities. The Action Plan process and staff training have created a culture of valuing which is moving beyond the conventional access solutions to partnerships in the adventure of sharing the arts.

That to me is the power of the DDA. It is not a minimum standard, a lowest common denominator for ‘compliance’. It is an invitation to open, and we are just at the beginning of discovering what that may mean for individuals, families and Australian society. It is a significant piece of legislation and should not be diluted.

#### Attitudinal Discrimination

A deeper modelling that disability provides is one of diversity and difference with limitation. In our society which tries to defy ageing with every cream and surgical procedure possible, the presence of men, women and children who live and accept their disability as part of who they are, is an important sign: We are mortals. Challenge can help you grow. It’s OK to not be perfect. These are a few of the lessons that can be seen through being involved with people with disabilities.

Because of this key learning from being exposed to or knowing someone with a disability, I would make one final observation. The role of the Disability Discrimination Commissioner is a pivotal leadership role in supporting and encouraging people to make changes. It would be out of the question for a key adviser for women or aboriginal people to be from out of their milieu.

The first Disability Discrimination Commissioner, Elizabeth Hastings worked from a wheelchair after a life of encountering barriers. The Act meant a lot to her – she had the self-interest herself, for her friends with disabilities and for her society. This passion meant that the progress during her period as Commissioner was outstanding. Through her travelling, speaking, writing, meetings, she made the possibilities of the DDA come alive.

I hope that further appointments to this position return to this original base, where the person who lives it can bring that energy, commitment and empathy to the position. People with disabilities want a high profile advocate from their community in the Human Rights arena. The DDA’s concern with equity should make this appointment a necessary pre-condition for future government appointments to this position. If not, what message is being sent?