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Newsletter
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disability justice advocacy

The Broadcaster

Disability Activist a profile by Sue Whiting

I have been a disability activist and advocate since the mid 70's. I have been involved with many Boards and committees, both State and nationally discussing issues including transport, attendant care and communication.

As a Project Officer I have supported a number of people with disabilities and have assisted in the development of an independent advocacy organization for people with high support needs. Currently I'm Chairperson of that organization, Disability Justice Advocacy Inc (DJA).

DJA is facing one of its biggest challenges since it's beginning. DJA must be allowed to continue to provide advocacy to people with high and complex needs but we need to make some changes, and I will be putting in my 110 per cent to assist the staff to achieve this.

In my other life, I enjoy spend time with friends and family, my pets, gardening, movies, meditating, shopping, cooking, current affairs and all sports, writing and swimming.

Advocates Report by Rachelle Porter

My activities as advocate over the last few months have been varied. They have included things such as advocating for someone seeking employment, advocating for new equipment, advocating for care packages, and continuing to support a service user with ongoing financial management.

I have advocated for a number of people to staff members involved in their lives in order to raise concerns and try to negotiate better outcomes. I have also been monitoring the activities of other staff, such as case managers and DHS representatives to ensure that they are pursuing services and actions that the service user requested.

**Advocates Report
By
Rachelle Porter cont**

These have been going well. I have been pleased with the work of some individuals in other positions as they have been actively pursuing services and my role as advocate has been simply to keep everyone informed as to what is happening. It is times such as these when the role of advocacy is straightforward and pleasant.

I have also been participating in the Aides and Equipment Action Alliance which is still in the early stages of development but is beginning to organize so that actions can be taken.

We are in the process of seeking funding for a project worker and have established a ministerial and media working sub-group as well as an evidence sub-group to gather data for future lobbying. It is exciting the number of organizations and individuals who have joined the alliance, proving the importance of the issue and hopefully indicating the potential for success.

**DJA would like to thank
Our Supporters**

Lease Plan

For their continued generosity in providing two vehicles for DJA to use in their advocacy role.

Goodcompany

For their assistance in providing solutions to a wide range of issues here at DJA.

Elaine Gan

For her continued assistance with the design of new logos, business cards and letter heads.

Harvey Norman P/L

For their continued and their recent donation of a bar fridge for our office.

The Goodguys Preston

For their contribution of a sandwich maker for our office.

Isaac Nakhla

For his continued assistance with the design of our new web page.

The doctorate of mind over Matter

Peter Gibilisco's PhD draws on his own experience with disability.

A thesis on the disability of our market economy has broken new ground, writes Adam Morton.

PETER GIBILISCO'S PhD thesis is steeped in his own experience; experience that tells him he shouldn't have lived this long. A couple of months shy of his 44th birthday, he has spent nearly half his life in a wheelchair, immobilised by Friedreich's Ataxia, a degenerative condition that attacks the nervous system.

Ataxia has reduced his hands to tight knots, leaving him reliant on visiting carers to lift him in and out of bed and cook his meals.

He can type only three words a minute. And yet he recently finished a 100,000 word PhD in five years - faster than many able-bodied students. "I'd say I was on the computer eight hours a day, seven days a week. On a good day's work, I'd say I'd write 300 words," Dr Gibilisco says.

His thesis, on how current economic thinking leads to the social exclusion of people with disabilities, was praised by one examiner as a

unique work beyond the scope of books in the area.

It compares three political ideologies - social democracy, neo-liberalism and the "third way" fashioned by British Prime Minister Tony Blair and adopted by the Bracks Government among others. Dr Gibilisco believes the third way's market-based economics excludes the disabled from education, employment and services.

His work reflects his experience fighting for improved home care at the Dandenong apartment where he has lived alone for 17 years. He says researching the PhD was very disillusioning. "I could see there was so much error in the third way. They've got this weird idea that less entitlement for people with disabilities is somehow more empowerment."

Dr Gibilisco broke ground merging his own story with the wider thesis. One examiner noted that biography was becoming an acceptable part of sociological research, but "this is the first time I have seen autobiographical research in such a work".

In person, Dr Gibilisco tells his life story as a mix of frustration, perseverance and survival. He was diagnosed with the onset of the ataxia - a genetic condition that affects one in 50,000 - at 14, and was in a wheelchair at 23. "Judging by medical books, I shouldn't be around now," he says.

"It's very rare to see people living 10 years after being in a wheelchair."

The deterioration was slow. He travelled overseas with a cousin for a final fully-mobile fling before losing the ability to walk. "My only apparent initial physical abnormalities were the appearance and unco-ordinated gait of a drunk," he wrote in a recent online opinion piece.

On his return he was admitted to St Vincent's Hospital, where he met and embarked on a whirlwind romance with a nurse. They moved in together and got engaged but broke up six months later. Dr Gibilisco says the relationship failed partly because he was living a "fantasy based on false expectations".

The break-up prompted him to take up study. Not having finished his HSC, he enrolled in accounting at TAFE at Dandenong. He followed this with degrees in Arts and Accounting at Monash University, graduating with a Major in Sociology in 1997.

Then came a master of arts and, from 2000, a PhD at the University of Melbourne, supported by a research scholarship and the annual June Opie Fellowship, awarded to high achievers with severe disabilities.

His PhD supervisor, Tim Marjoribanks, says Dr Gibilisco's work - *The political economy of disablement: a sociological analysis* - was an important contribution in an emerging field.

"Peter shows that current policies supposedly promoting the rights of people with disabilities promise a lot but don't deliver very much at all, and often make the situation worse for a lot of people," Dr Marjoribanks says. "It is research which provides much evidence to inform policy development in this area."

Matthew Brett, manager of Melbourne University's disability liaison unit, says the thesis was a personal triumph: "He has shown amazing perseverance to complete his PhD in five years when he can only type at three words a minute."

After more than a decade, Dr Gibilisco is now adjusting to life without study. Each day starts with a visit from a carer and a short black from his coffee machine. The carer returns at night to help him clean up and get back into bed. He gets 24 hours of help a week.

He sees his father, who lives in Patterson Lakes, weekly, and makes occasional hospital trips for speech and physical therapy. Leaving the house is a big exercise. He visited Melbourne University once a fortnight during his PhD study, but taxis are expensive.

So he writes. He is re-writing his thesis into a book and hopes to get it published. He has contributed to social and academic journals and presented his work at conferences.

His condition frustrates him to tears and can make his life monotonous, but he says he is going to be around for "at least the next 10 years" and is making plans for the future. Top of the list is applying for a post-doctorate fellowship in disability studies at the University of California at Berkeley. He will learn whether he has been successful shortly. "That is my ultimate goal," he says.

**My future My Choice
Better living options for
younger people in
residential aged care
DJA have been active**

Background :The Council of Australian Governments (COAG) announced an agreement on 10 February 2006 to reduce the number of younger people with a disability living in Residential Aged Care (RAC) facilities. The COAG commitment acknowledges the increasing demand from younger people with a disability for specialist age appropriate services to meet their ongoing needs and aspirations. The aim is to reduce the number of younger people with a disability living in RAC.

Objectives: *my future my choice aims to provide better living options for younger people in, or at risk of entry to, RAC. This will be achieved through the development of innovative support models that respond to complex clinical and health care needs, whilst also providing lifestyle and social opportunities that younger people can identify with.*

The initiative has three strategic objectives:

To provide alternative supports

Provide better living options for younger people with a disability in residential aged care settings, where it can be made available and where this is what the younger person chooses

To enhance disability supports within RAC

Promote a more age appropriate response to those younger people with a disability who choose to remain in residential aged care, or for whom residential aged care remains the most suitable supported accommodation option available

To minimise future admissions to RAC

Provide alternative responses, where possible, for younger people with a disability who are at risk of admission to residential aged care.

The initial priority is to achieve this for people aged less than 50 years (although those aged from 50 to 65 may also receive assistance).

Guiding principles

The implementation of *my future my choice* will be underpinned by a number of important principles. These are:

Participation in the initiative is based on choice – a person can choose to “opt in” or “opt out” if they meet the criteria for eligibility and priority. This means that a person who doesn’t want to be involved initially who can request to participate later. Participation will not commit someone to changing their current arrangements unless that is what they choose.

At all stages, **the person with a disability will be central to decision making** about their future support and care arrangements. It is expected that in many instances, people will want to involve family members, friends or carers in the decision making. It is the person’s choice as to who is involved.

A holistic and comprehensive approach will be taken to assessing a person’s needs and aspirations, and will consider support, healthcare and accommodation needs alongside other important lifestyle factors.

Support/advocacy will be available to facilitate and support a person to participate in the planning and assessment process.

Information provided will be clear and in an accessible format.

Privacy and confidentiality will be respected. An **independent complaints process** will be established for people participating in the initiative. Implementation and new service development will take place in accordance with **relevant legislation and Disability standards**.

The initiative will build on and **strengthen existing support networks and service options** and work towards achieving a more responsive and sustainable service system for young people with disabilities who require alternatives to Residential Aged Care.

Advisory Committee

[An Advisory Committee](#) has been established with broad representation from the department, community members, Young People in Nursing Home (YPINH) Alliance and representatives from key stakeholder organisations.

Eligibility and assistance

People who meet the following criteria may be able to receive assistance under *my future my choice*:

- are aged less than 50 years at 1 July 2006
- live permanently in residential

aged care, or
 - are at risk of admission to an aged care Facility or
 - are eligible to receive Disability Services.

Those aged between 50-65 years may still be eligible to receive assistance, although the immediate priority is for people aged less than 50.

The types of assistance that may be provided include accommodation, personal support, health care and community access. Transitional support, case management and advocacy may also be provided. The time taken to plan and receive assistance will vary from person to person, depending on the nature and complexity of the situation, and the availability of required supports and accommodation options.

Contact details

The DHS Disability Intake and Response is the key point of contact for people with disabilities and their families. This service will connect you to your regional office and is available during business hours, Monday to Friday from 9am – 5pm on 1800 783 783 or TTY 1800 008.

To request materials in other languages or formats, or for general enquiries telephone (03) 9096 8724 or email: myfuturemy-choice@dhs.vic.gov.au

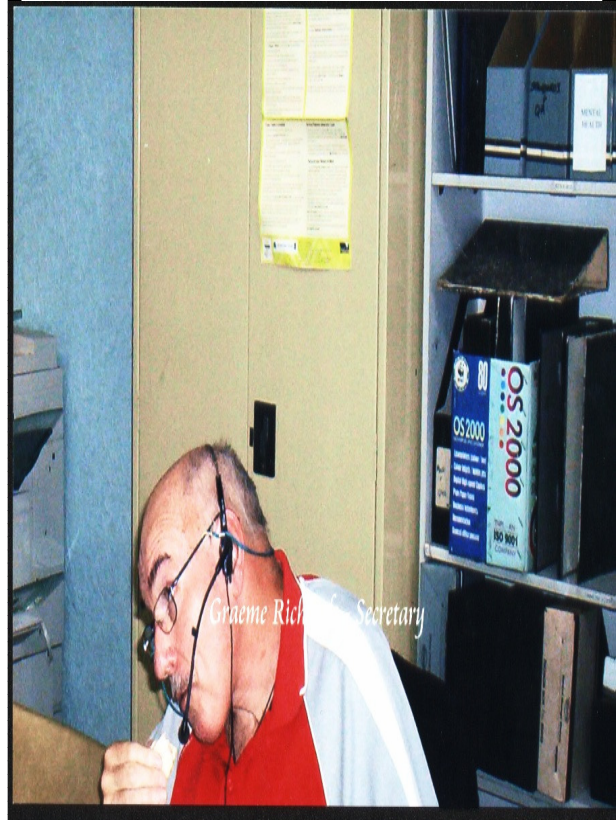
DJA have been active members of the YPINH consortium for a number of years.

In Memory of Graeme Richards

It is with sad regret that we advise our members of the death of Mr. Graeme Richards.

Disability Justice Advocacy Inc were shocked and saddened to hear that Graeme Richards had passed away in March 2007.

Graeme was a much loved and valued Board member here at DJA. He will missed by all the staff and board members.



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