Hello to all members and readers of the dArpa newsletter. They don’t come fast but we hope that you find the content useful and enjoyable.

There have been many changes in the disability sector this year in both names and methods of funding.

1. IDSC, Independent Living Centre, and Julia Farr Centre have become Disability SA, and
2. ACROD has finally changed its name to National Disability Services Ltd (NDS),

Just to identify a couple of changes.

dArpa attempts to keep its members up to date with events, conferences, employment opportunities and other matters of importance through the website at http://darpa.asn.au/

Nevertheless, the dArpa committee feels that a newsletter is an important part of what is provided to the membership and we will continue to make efforts to provide these as regularly as time allows.

In this issue we will discuss

- The dArpa AGM in September 2006—thanks to TUTTI Ensemble for their fabulous performance after the formalities.
- The dArpa 3rd State Conference—Health and Disability—Strategies for Change (July 2007)
- People with Multiple Chemical Sensitivities (MCS)
- Coming Events in 2007, and

USEFUL INFORMATION ON THE dArpa WEBSITE

The dArpa website is frequently updated, so check some of the useful information there. Just go to http://darpa.asn.au/ and follow the Coming Events link or the Job Information link on the left of the home page.

Some of the useful information is about

- Ability Edge Education - Childsafe Environments - Reporting child abuse and neglect.
- Leveda will be facilitating a three day workshop in late January related to Making Action Plans (MAP) and Planning Alternatives Tomorrows Hopes (PATH)
- CHECK BOTH LINKS OUT!
THE DARPA AGM IN SEPTEMBER 2006
EXCERPTS FROM CHAIRPERSON’S REPORT

The dArpa committee has been relatively inactive since the last AGM due largely to a bit of burnout and personal pressures on Committee Members.

The Coming Conference
Planning is continuing for our 3rd State Conference Health and Disabilities – Issues and Strategies for Change which will be held at Flinders University July 16th and 17th, 2007 [Included in this newsletter is a call for papers]

Activity during the year
One activity occurred during the last year was a joint activity with ASSID – SA entitled – Flinders University Research Showcase. This was a well attended event held on October 25th 2005 at which academic staff in Disability Studies at Flinders University talked of their research interests and recent postgraduate students highlighted their efforts. Thanks to all who contributed or attended.

Also, prominent in our activities for the year was the maintenance and regular updating of the dArpa website at http://darpa.asn.au/. Members and other interested people are notified of updates to the website by email and most of the feedback I have had about this has been positive. This continues to be our main source of communication with members and others. Our thanks to Flinders University for allowing us the web space to offer this service to our members and the disability field.

Multiple Chemical Sensitivity Task Force
Peter Evans from the MCS (Multiple Chemical Sensitivity) Task Force has provided an article for this newsletter (see pages 3 & 4) and, during the year, dArpa has continued to advertise and organise events that are as chemical-free as possible. Peter reports that there have been considerable improvements in this area recently and he is a mine of information on this topic.

I was pleased that, at an event at Flinders University on July 18th this year, Mark King from the department of building and property was most cooperative in organising a toilet area that was chemical free. Thank you Mark!

Managing System Change and Maintaining Quality Work with Clients
Aldred Neufeldt, Director of the Community Rehabilitation and Disability Studies program at the University of Calgary spoke at a joint event sponsored by the Department of Disability Studies, Rehabilitation Counselling Association of Australia (RCAA), and dArpa at DIRC on Thursday October 12th [Subsequent to the AGM]
Aldred addressed a range of important disability and rehabilitation issues from an international perspective and the discussion about a range of disability related issues was informative for the group of about 30 who attended.

Brian Matthews
Chairperson

Thank you, Welcome, & Farewell
Thanks to Sue Goodall for her efforts as Treasurer over the last few years and to Simon Pavelic for taking on both this role and that of Treasurer once personal and work pressures made it difficult for Sue to continue. Also, my thanks to all the other Committee Members (Muriel Bic – incoming Secretary, Verity Bottroff, Jan Cockrum – Correspondence Facilitator, Vikki Schultz - retiring, Lorene Thiel – Membership Secretary, and Kellie Thomas). Welcome to new Committee Members - Melissa Flanagan, Charmaine Mahar, Katie van der Walt, Barbara Yates, and Graham Webber. Finally, a farewell and a big thank you to Vikki Schultz on her retirement from the Committee. Vikki has been an active member of the Committee for the last 5 - 6 years and has positively contributed to both of the State Conferences and has played a role as both Committee Member and Membership Secretary.

In the last year that have been some interesting activities including

- Flinders University Research Showcase
- Managing System Change and Maintaining Quality Work with Clients
- National Disability Services (formerly ACROD) Ageing & Disability Conference in April
- dArpa 3rd State Conference on Health Issues in July
- Sex, Drugs, and Rock & Roll—National Conference of the Australian Association of Developmental Disability

And in 2007 there are a number of interesting conferences in Adelaide

- National Disability Services (formerly ACROD) Ageing & Disability Conference in April
- dArpa 3rd State Conference on Health Issues in July
- Sex, Drugs, and Rock & Roll—National Conference of the Australian Association of Developmental Disability

“Remember, Billy — when you don’t get what you want, at least you get experience.”

Thanks to past and present committee members for the work they have put into making dArpa an active and useful organisation for people with an interest in disability and community rehabilitation issues.
Wearing a Different Hat
(Richard Bruggemann,
former CEO of Intellectual Disability Services Council)

Hello from the Department of Disability Studies at Flinders University. After 24 years with the Intellectual Disability Services Council, I have joined the Department as Professorial Fellow. At Flinders I will be involved in some interesting projects, including:

- Developing an educational program for managers of disability services;
- Examining the issue of isolation and loneliness, and looking at ways we might address it;
- Promoting the capacity of people with intellectual disabilities to speak for themselves;
- Developing workshops on key disability topics;
- Promoting the participation and contribution of people with disabilities in the South Australian community; and
- Supporting the development of disability professionals.

I am in Room N202 in the Sturt Building of Flinders University, phone 8201 3430, email richard.bruggemann@flinders.edu.au.

If you have got ideas you would like to share, issues you want to debate, or would just like a chat, please feel free to contact me.

RICHARD BRUGGEMANN

DISABILITY LEADER FORCED OFF FLIGHT - LAUNCHES DISCRIMINATION CASE AGAINST VIRGIN BLUE

29 September 2006
The ACT Disability Advisory Council’s Chair, Craig Wallace, has lodged a personal discrimination complaint with the Human Rights and Equal Opportunity Commission (HREOC) after he was forced to abandon a booked flight to return from a national meeting of Government appointed Disability Advisory Councils around Australia.

Mr Wallace, who uses a wheelchair and is also a national board member of People with Disability Australia, was told he would not be able to board a (Qantas booked) Virgin Blue direct flight (DJ578) from Adelaide – Canberra scheduled for 4.05 pm on Sunday 8 October 2006 as he allegedly did not meet Virgin Blue’s ‘independent travel criteria’. follow the links from http://www.virginblue.com.au/bookings/ssrs/

This criteria includes a requirement that he be able to assist himself evacuate out of the plane in an emergency or travel with a carer.

“Virgin was told of my disability when it accepted my booking and we paid the fare. Only afterwards did it reverse its decision,” Mr. Wallace said.

To add insult to injury, Virgin Blue has also refused to refund $418 in fares from the flight for Mr Wallace or Council staff. Ironically, they have listed these fares as a ‘credit’ – a credit Mr Wallace or other people in his situation are prohibited from accessing by Virgin’s own policy.

“This looks like it is solely designed to block a whole class of people from using a transport carrier that is meant to be available to the public,” he said.

“Despite claims to the contrary by Virgin Blue Public Relations officials, the problems with Virgin Blue are far from over. If I can’t fly back to Canberra from the peak national disability councils’ conference, then what hope do other travellers have?

“I have lodged a personal complaint with HREOC and have briefed the ACT Minister for Disability and Community Services Katy Gallagher MLA, who views the treatment by Virgin as inexcusable “

Mr Wallace says he would like to talk directly to international Virgin Blue boss, Richard Branson to try to convince him to change his mind.

“I appeal to Virgin Blue to end this unfair practice of discrimination against Australians with a disability — a discrimination which prohibits them from enjoying the same modes of travel as other Australians.”

Mr Wallace said.

MEDIA CONTACTS: CRAIG WALLACE – 0413 135 731 – CRAIGWALLACE@GOLDWEB.COM.AU
Imagine the following scenario. Your employer renovates the office during work hours with new carpets, fresh paints, vinyl tiles and adhesives, plastic fittings, and new equipment. During the renovations you are troubled by the smells and experience headaches, runny nose, sore eyes, difficulty breathing, muscle aches, memory loss, stomach problems, and persistent fatigue. Your doctor says you might have a virus and suggests a few days off, but on returning to the office you find that the symptoms worsen.

You persevere but in the next few months your health deteriorates with multiple symptoms triggered by common products such as perfumes, cleaners, and air-fresheners. But your employer is unsympathetic and refuses to consider changing any cleaning products, modifying your work practices, or asking work colleagues to limit their use of personal fragrances. You complain regularly to your doctor, who simply shrugs the shoulders, notes that your conventional blood tests are normal, and suggests you see a psychiatrist for stress.

The psychiatrist seems sympathetic but is baffled by your problems and nothing changes. In fact, the chemical sensitivity broadens to include seemingly unrelated products such as pesticides, tobacco smoke and vehicle exhaust. Your symptoms worsen and become chronic. Work is no longer possible due to persistent pain and fatigue – a diagnosis of chronic fatigue syndrome soon follows. Your compensation claim for chemical injury due to the workplace renovations is dismissed by Workcover and you are forced to apply for disability support from Centrelink, where it is made very clear that you are considered to be a fraud and a malingerer.

Time passes. After years of searching for an answer to your complex health problems you visit an inter-state medical specialist who diagnoses multiple chemical sensitivity, tells you there is no cure, and advises that the most effective treatment is to avoid chemicals, foods and medications that trigger symptoms. In the meantime, your health continues to deteriorate and you can no longer manage to live independently at home but your partner does not understand the problems and a painful separation ensues.

You apply for priority public housing but are told there is no housing stock for people with MCS. Going to the supermarket is almost impossible because the smells from the laundry aisle leave you disoriented and confused. Food reactions mean you must avoid common foods like wheat, dairy, soy and beef. Organic produce is essential, and restaurant meals and take-away convenience are no longer an option as chemical food additives and pesticide residues make you sick. You cannot sit in your doctor’s waiting room because other patients are wearing fragrances. The nearby hospital is not accessible because it has no MCS protocols and staff members cannot accommodate your individual needs. The local park is out of bounds because herbicides sprayed by the council severely exacerbate your chemical sensitivity, leaving you barely able to walk.

At home, gas sensitivity means the gas stove and water heater must be replaced with electric utilities, the tap water needs filtering because the chlorine gives you a severe rash, and an air filter is essential because of traffic exhaust and paint fumes from the nearby crash repair shop. You have no money but social services claim that MCS is not a disability and deny you any assistance for essential equipment or housing modifications.

So you turn off the gas, cook everything in a single electric frypan, wash yourself in a bucket of kettle-boiled water, and close all windows and doors to keep out the urban pollution. Alone and unsupported you continue to exist with grim determination but major depression, which cannot be treated with medications because of severe side-effects. Finally, you begin to develop sensitivity to sunlight and electromagnetic fields and wonder when the nightmare might ever end.

If you think this story sounds fanciful, think again. Although the above scenario represents a severe case, MCS is no longer a rare condition experienced by a few isolated individuals. A recent Parliamentary Inquiry into MCS in South Australia found that “MCS is very real” and that “up to 6 percent of the population may have MCS, with between 10-25 percent experiencing sensitivity to chemicals.” The inquiry also found evidence that “herbicides such as Glyphosate, pesticides, solvents, and sterilisers, have been associated with the condition” and warned that this evidence should not be ignored.

To date, Germany has been the only country in the world to formally recognise MCS as a defined medical condition. However, population studies by health departments in New South Wales and South Australia show around 3% and 1% of respondents, respectively, have been medically diagnosed with MCS (1). Even more disturbingly, the Inquiry into MCS was presented with informed medical opinion that the incidence of MCS is increasing in our communities. These national figures compare with the USA and Canada, where between 2% and 6% of their population have been medically diagnosed with MCS (2), with 2% no longer able to work as a result, and possibly more than 12% actually suffering from MCS (3).

Although it is often assumed that MCS is a psychological disorder requiring no organised public health or disability access strategy, there is actually very little evidence to support this position. In their 2003 study of MCS Caress and Steinemann found that “A significant percentage (27.5%) of people with MCS reported that their hypersensitivity was initiated by exposure to pesticides, whereas an equal percentage (27.5%) attributed it to solvents. Only 1.4% had a history of prior emotional problems, but 37.7% developed these problems after the physical symptoms emerged. This suggests that MCS has a physiologic and not a psychologic etiology.” (3)

The USA and Canada have been engaged in the development of MCS disability access policy for at least fifteen years. In a major new Australian development the Inquiry into MCS recommended the exploration of “practical measures that could assist in addressing disability access issues experienced by MCS sufferers, in relation to public facilities and services in the community.” Unfortunately, the government’s response to this recommendation, through the Department of Families and Communities, has been to deny people with MCS access to disability services by...
claiming that “MCS is a chronic medical condition, as opposed to a disability.” In addition, the Department of Health has also refused to support any recommendations for practical assistance to people with MCS because: “as MCS is not recognised as a defined medical condition in Australia, DH is unable to extend its stretched resources to assist MCS patients at the loss of assistance to sufferers of recognised diseases.”

The government’s hard-line policy of denial of MCS is at odds with Australia’s human rights institutions. For the last several years the Human Rights and Equal Opportunity Commission has considered medically diagnosed MCS to be a legitimate disability under the Disability Discrimination Act. This is also true of similar state-based agencies. However, this situation is not widely understood by people with MCS, who are often too sick and isolated to even contemplate such a course of action in any case.

Despite the seemingly insurmountable obstacles facing them, people with MCS in their growing numbers are making slow progress with their cause. Most Australian states maintain community-based groups whose MCS affected members volunteer their time and limited energies in order to offer information, referral and support to others with MCS. Together with a growing public awareness that many common chemicals are causing serious harm, persistent lobbying by these groups has resulted in an improved community willingness to embrace new solutions to MCS. This is particularly true of people who have some form of personal association with the complex problems that MCS presents.

As understanding of the issues grows, community organisations and increasingly disability advocacy services are now beginning to embrace MCS. In 2004 the AIDS Council of South Australia became one of the first organisations in Australia to formally adopt an MCS disability access strategy, in association with its occupational health and safety policy. A similar policy was subsequently adopted by Adelaide’s Disability Information Resource Centre, and the Disability Advocacy and Complaints Service of SA is currently ratifying its own MCS disability access policy. Importantly, the Disability and Rehabilitation Professionals Association has also agreed to place MCS on its agenda for discussion.

There are a range of reasonable disability access measures that can be implemented relatively easily to assist people with MCS to return to their rightful place in the community and the workplace. These measures also help to reduce public exposure to chemicals that have been identified by research as initiating MCS related symptoms, notably pesticides, solvents, petrochemicals, new building materials, and harsh cleaning agents.

The following are some examples of MCS disability access provisions based on US and Canadian models.

- Create a fragrance-free, smoke free environment. Modern perfumes and colognes contain industrial solvents and petrochemicals known to trigger symptoms of MCS. While some people might claim that it is their right to use personal fragrances, most people would not seek to intentionally harm others with the use of products that are, at best, a fashion accessory. For those who might wish to go the extra mile in scent reduction, fragrance-free and low-scent antiperspirants are commonly available in supermarkets. Controls on smoking in public areas already exist but may need to be extended.
- Use non-toxic, fragrance free cleaning and sanitary products and avoid air-fresheners. Most health food stores and some supermarkets carry a range of safer cleaning products.
- Use non-toxic building and maintenance products and avoid paints, stains, and clear finishes containing solvents. Many water based paints can contain significant amounts of solvent. Most major paint companies and some smaller ones offer least toxic paint options at comparable cost.
- Avoid pesticides and herbicides. Use environmentally friendly, non-toxic pest controls.
- Maintain good indoor air quality at all times by ensuring that toxic products do not enter buildings, that air conditioning systems are monitored regularly, and that windows and vents are opened to allow fresh air to circulate. Where no alternative to toxic products exists, ensure that prior notification and warning signage are provided.

The disability sector has known for many years that disability access means more than just wheelchairs and white canes. As the parameters of disability access broaden, it is no longer reasonable that people with MCS be expected to carry the burden of this serious public health problem alone. The wider community must come to terms with the new paradigm of MCS disability access as an equitable and necessary step forward in addressing the ongoing negligence in chemical regulation.

References

CALL FOR PAPERS

DisAbility & Rehabilitation Professionals’ Association
3rd State Conference
Health and Disabilities – Issues and Strategies for Change
Flinders University July 16th and 17th, 2007

Two very successful State Conferences have been run by dArpa in recent years (December, 2002, Journeys Through Life; and January 2005, Embracing Diverse Abilities).

This time we plan to change directions a little and focus on the range of health issues that affect people with disabilities in our community. Thus the title for our next conference Health and Disabilities – Issues and Strategies for Change.

A major purpose of these conferences is to connect disability professionals from a diverse range of allied disciplines. The purpose of creating a forum for all disability professionals is to reduce the fragmentation, which often exists in the disability field.

Our aim is to build a stronger disability sector through collaboration and networking. Therefore this conference will provide a forum for a range of service providers, families and people with a disability to meet, and share knowledge and experiences with disability and rehabilitation professionals from various disciplines.

Ask someone who went to the last dArpa Conference what they thought about it! And check the dArpa website http://darpa.asn.au/ for video snippets of the 2005 Conference.

POSSIBLE CONFERENCE THEMES

- Complementary therapies and people with disabilities
- The health education needs of workers supporting people with disabilities
- Generic health professionals/allied health professionals and their understanding of the needs of people with disabilities.
- Multiple Chemical Sensitivities
- Diet and implications for people with disabilities
- Leisure, recreation, and lifestyle issues for people with disabilities
- Sexual health
- Ethics and health care for people with disabilities

dArpa will accept conference presentations on any of the above themes and will accept papers on other themes related to health and people with disabilities.

CONFERENCE HIGHLIGHTS

- Keynote speakers who will entertain and challenge you. Whatever happens, you can rest assured that the Keynote speakers will leave you thinking.
- Welcome drinks and nibbles at the Conference Venue on Monday 16th July at 5:30 pm.
- Opportunity for discussions and networking.
- Presentation of extremely innovative case studies and workshops.
- Optional post-conference dinner on Tuesday 17th July (evening).
- Entertainment by people with disabilities during the conference.

dArpa is calling for the submission of abstracts from people wishing to present papers at the Conference that address the Conference themes

See dArpa website for format of abstracts and other details related to submission of conference presentations http://darpa.asn.au/