The effect of language

While this image is taking a humorous look at terminology, the use of such terms limits the scope of what people think about people with disabilities. When we are described as ‘wheelchair bound’ or ‘confined to a wheelchair’ it evokes an image of one being trapped and unable to ever escape. I have always compared my wheelchair to someone else’s legs. I describe myself as a wheelchair user. I use the wheelchair to get from A to B and I get out of my wheelchair to use the toilet, shower, bed, car and so on.

Language is interesting as I believe it depends on your own experiences as to how you view things and the language you then use. To an outsider, using a wheelchair may seem binding or confining, but it is in fact our liberation. Sure, I’d absolutely love to not have to use the thing and to be able to walk, but the alternative to no wheelchair is to sit in a sedentary chair at home all day, having someone bring things to me. When thought of in this regard you could say ‘wheelchair liberated’ or ‘wheelchair active’ instead.

These limiting terms are often used in the media where articles are written to elicit sympathy, empathy or what I refer to as the ‘inspirational factor’. There seems to be a need for many people to view people with disabilities as ‘poor’, ‘confined’, bounded people, rather than every day, normal, empowered people. And I feel this is what often leads people to think we’re so ‘inspiring’, because they have an image of us being so downtrodden and confined that when we do go out to buy the milk it’s inspiring in their eyes. Many able bodied people (notice I didn’t say ‘normal’, which I’ll get to in a minute) won’t understand what I mean by this. I have an able bodied friend who can’t comprehend why I feel uncomfortable with being an inspiration. Maybe it’s something you just can’t understand unless you’ve been there.
I had an interesting experience many years ago when I submitted a story idea to Cleo magazine. I have always had a strong interest in sexuality and people with disabilities. I wanted to submit a story on my dating experiences and to awaken people to the fact that people with disabilities were sexual beings. I received a response that they liked the idea, but would want a deeply emotive, inspirational slant to it. I knew exactly the type of piece they wanted as I have read these articles many times before – poor wheelchair bound girl didn’t date during high school, instead looking on as her friends did, but eventually she met a man who could see the beautiful person she was inside despite the wheelchair. By all means I encourage empathy and understanding when writing about people with disabilities, because as we have read lately there have been many reports of demonising those with disability as lazy and social security cheats, however I believe media also have a responsibility to edit the language they use so as not to portray us as less than others.

This brings me to the word ‘normal’. This is a term that I’m sure all people with a disability can relate to and have experienced in other people’s language. Ashamedly I have sometimes used the word myself. I have on occasion without thinking said, oh a normal person just walked out of that disabled toilet (another misnomer as the toilet isn’t actually disabled, it’s wheelchair accessible or an access toilet – see aren’t you learning a lot today). Of course the issue with the word normal is that how does one measure normality? Sure I am not like you if you are walking and I’m wheeling, but maybe you have a habit of wearing red socks on your hands as you eat breakfast each morning. Is that normal? Are you any more normal than I? By referring to able bodied people as normal it implies disabled people are abnormal, and well that would hurt anyone.

I, like many people, can appreciate that political correctness has gone too far in some areas, and on a personal level I don’t care too much about the disabled toilet – it’s an inanimate object after all – but I believe when referring to human beings, who have a right to dignity, people need to be more aware of the language they are using. People with disabilities sacrifice much of their dignity in various areas of life, such as medical and care needs, let’s give them the dignity of being referred to with terminology that is inclusive and positive rather than confining.

Correct terminology:

- Wheelchair user or uses a wheelchair
- Access toilet
- Disabled and able bodied

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Would you be happy to receive PDA’s Newsletter via email?

If you would be happy to receive this newsletter via email instead of by mail please email PDA’s Communications Officer, Joanne at communications@pda.org.au

If you would like to subscribe to receive our monthly e-bulletin or newsletter send Joanne your email address.

Also if you have a new email address or have closed an email account would you please notify Joanne.

And....

If you move address, please let our office know

pda@pda.org.au
What is Physical Disability?
In each newsletter we will be featuring people with varying disabilities, in order to develop a picture of what physical disability is and how varied they can be. This month’s featured disability is Tarlov Cyst Disease.

Tarlov Cyst Disease
Tarlov Cyst Disease is rare, affecting less than 200,000 people in the USA. It is not uncommon to have Tarlov Cysts; however it is rarer for the cysts to become symptomatic.

‘Tarlov Cysts are fluid-filled sacs that most often affect nerve roots in the sacrum, the group of bones at the base of the spine’ While not all sufferers will end up with symptomatic cysts, for the ones who do it is a painful condition as the cysts compress the nerve roots. There is shooting pain through the lower back, and due to sciatica (the sciatic nerve is the longest nerve in the body, starting at the S2 and ending in the foot) can go through the buttocks and down one leg. One sufferer described the sciatica shocks as so bad that she would sometimes yell out in pain. She says:

‘I felt like I was paralysed even though I could move. My hips and legs hurt too. I began having trouble walking. This disease is life changing. One minute you have to lay down, the next get up, the next sit crooked in a chair, the next walk, then lie down again. Usually lying down felt the best. You get weird nerve sensations. At least I didn’t have many of the other problems that some people get from this disease.’ – Christa

Some of those other problems include urinary incontinence, headaches, blurred vision, dizziness, sexual dysfunction, constipation and pain in areas from the chest, neck, arms and hands, to weakness and cramping in the arms and legs depending on the location of the cysts on the spine. A major symptom for many sufferers is difficulty in sitting. Sufferers describe it as feeling like they’re sitting on a rock. Pressure on the nerves next to the cysts can also cause pain and deterioration of the surrounding bone. Tarlov cysts can be present since birth or for many years without the person knowing, so there is often evidence or erosion of the sacral bone or the other vertebrae that have been affected. The cysts become known as Symptomatic Tarlov Cysts once symptoms develop.

Symptoms can be brought on following trauma such as falls, car accidents, heavy lifting and childbirth, which causes the build up of cerebrospinal fluid. Women are at much higher risk of developing these cysts than men. Tarlov cysts are diagnosed through MRI or CT scans.

Treatment can be difficult for several reasons. The cysts cannot simply be cut out because they are a part of the nerves. Treatments include pain medications such as anti-seizure drugs and antidepressants. Transcutaneous Electrical Nerve Stimulation or TENS is successful in managing pain for many people. TENS works by sending electrical impulses to the nerves, through the skin.

In circumstances where pain cannot be relieved or other symptoms become intolerable then surgery is an option. For larger cysts, surgery involves a small cut into the cyst, where it is drained and then the dead spaces are packed with fat or muscle. Some nerve root cysts are only wrapped, which stops enlargement. One suture is used at the neck of the nerve root to hold a piece of fat in place inside the cyst. Then a separate piece of bovine tissue is used that wraps around the whole nerve root like a sleeve. This is to block the entrance of the cyst so as to avoid it refilling with fluid.

There are of course risks to such delicate surgery, such as further nerve damage or spinal fluid leaks.
Recovery time can vary; some patients experience immediate relief, while others can take months or years to experience the full benefit.

For more information check:
http://login.npwebsiteservices.com/Tarlov_Cyst_Disease_FoundaAYSCXT/Home.asp

Colin James’ Book Launched
Popular Bendigo identity Colin James, has self-published his autobiography.
Most people who have met Colin know him as “the little guy in the wheelchair” who is often seen ‘buzzing around town’ or, until last year when another illness forced his retirement from entertainment, he was well-known as a performing and recording artist. Colin would often be seen sitting in his chair on stages or at the market entertaining his audience with songs and jokes, but his new book reveals that he has achieved much more than that.
He has received no formal education due to being diagnosed with Stills disease (juvenile rheumatoid arthritis) at the age of three, which confined him to bed or a wheelchair for the rest of his life. These limitations, however, have not prevented him from teaching himself to read and write or achieving the following:
● Being awarded the Medal of the Order of Australia by the Queen for service to the community (mainly as a fundraiser through performing as an entertainer for charities).
● More than forty years experience as a professional entertainer, songwriter, theatrical booking agent, promoter, radio presenter, freelance journalist, motivational public speaker… and now, a published author.
● Was recognised in 1995 as a campaigner for the rights of disabled people and in fund-raising, by the National Telecom Phonecard, ‘Local Legends’ promotion.
● In 2000, was chosen to carry the flame as one of the torch bearers for the Olympic Games torch relay. That same year saw the completion of another major project… the research, review and marketing of ‘The Wheelie’s Handbook of Australia’… a guide to accessible accommodation and tourist attractions for people in wheelchairs. It is Colin’s honest belief that, had he not been so physically restricted, his life would have been nowhere as interesting or rewarding. He has been able to assist others in many ways BECAUSE of his limitations and would like to spend the remainder of his life continuing in this manner.

His book, titled “If I Can Do It…”, should go a long way towards achieving that goal. He says, “I hope it will be of some inspiration to many others who feel as though their life is full of negatives and that they have little to live for”.
Today, Colin, 73, also suffers from chronic kidney failure, which necessitates dialysis treatment three times a week. This effectively put an end to his singing career and days of travel to spread his message outside his local area. He is
still available, however, for speaking engagements at schools, nursing homes and service clubs. Colin’s autobiography is available, together with photographs and other information, direct from (03) 5443 5560 or mobile 0439 989 454 or by email at coljames@bigpond.com.au
It is $20, plus $5 postage and handling (if applicable). As there are no card facilities, all payments should be made by personal cheque, postal note or direct into Colin’s bank account (013-030 587-371-766). Roberta Exell. Support Worker and Publicist.

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Resources – Books, Reports, Websites, Lists

Community attitudes to people with disability: scoping project
February 2012
This report investigates current research on community attitudes towards people with disability. It was an initial step towards building an evidence base on Australian community attitudes to people with disability, on the impact of these attitudes on outcomes for people with disability and on effective policies for improving community attitudes towards them.


Make your environment more accessible

Does your workplace/workforce understand accessibility? Increased theoretical and practical understanding of accessibility in the built environment enhances environmental, social and economic sustainability. Visionary Design Development’s Short Courses, tailored to the needs of your organisation, include Models of Disability, Principles of Universal Design, Wayfinding for the Vision Impaired and Fieldwork assessing accessibility in your environment. Access to Premises Standard - know the implications for your business. Enquiries contact MaryAnn, Ralph, or any of the VDD Team.

Tel +61 3 9329 7887
Fax +61 3 9376 6020
admin@vdd.com
facebook.com/VisionaryDesignDevelopment

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CERTIFICATE III OR IV IN DISABILITY SERVICES

Do you or someone you know wish to gain a nationally accredited Certificate in Disability Services?

QSSS offers courses in Brisbane (in class) and External Courses for people anywhere in Australia. We have qualified experienced Trainers who are people with the lived experience of disability and a high percentage of our students are gaining permanent work in the disability sector once they have completed their course.

Courses can be self-paced, or one Unit per month; excellent training resources and Trainer support. Payment plans may be negotiated and some discounts for people on pensions.

CONTACT: Trinette Westwood (Training Consultant) on (07 3388 0074 Mob: 0409 956 108
Email: trinette@qsss.com.au
Website: www.qsss.com.au

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Conferences

Roundtable on Print Disability Conference 2012
When: 28 April to 1 May, 2012
Where: Perth, Western Australia
What: Hosted by the Western Australian Association for the Blind, the conference covers a wide range of topics around blindness, vision impairment and other print disabilities, including education, digital delivery of print materials, web accessibility, assistive technology and audio description.

The theme is “Universal access - are we there yet?” focusing on the impact of digital technology on a space which was formerly occupied by books and print media. The term “print disabilities” includes people who have difficulty accessing printed materials, such as those with dyslexia, vision impairment or restricted mobility. Speakers, panel discussions and workshops.
Info: Contact Chris Whitelock, Conference Convenor, on (08) 9311 8209 or Chris.Whitelock@guidedogswa.com.au
See http://printdisability.wordpress.com/


Daily Living Expo
When: 16-17 May, 2012
Where: Caulfield Racecourse, Concourse Level
What: Exhibition featuring rehabilitation and aged care equipment. There will be more than 50 exhibiting companies.
For more information phone 1300 789 845 or visit www.dailylivingexpo.com.au

Queensland Polio Health & Wellness Retreat 2012: Body/Mind/Spirit
When: Thursday 26th – Sunday 29th April, 2012
Where: Ramada Hotel and Conference Centre, Marcoola Beach (formerly SurfAir at Queensland)

What: Polio Australia will once again be facilitating its 3 day Polio Health and Wellness Retreat for polio survivors and their partners, this time on the beautiful Sunshine Coast in Queensland. This third Retreat promises to build on previous sessions and participant feedback to present a range of self-management techniques which will enable participants to achieve general wellbeing, as well as providing options for people to remain as mobile and independent as possible.
For more information: http://www.polioaustralia.org.au/?page_id=39

4th National Disability Advocacy Conference
Advocating for Inclusion

When: April 30 – May 1, 2012
Where: Canberra Rex Hotel, 150 Northbourne Ave, Braddon, ACT, 2612
What: Advocacy strategies for achieving community living, full inclusion and participation of people with disabilities

We will focus on 6 key life domains and ask some critical questions:
What is the current policy and political context?
What are people with disabilities experiencing?
What would people with disabilities experience in a fully inclusive society?
What can we do as advocates and organisations; as individuals and collectively to get from where we are now to where we want to be?

Six Key Life Domains

Community Living Family and Relationships
Employment Decision-making
Life-long Learning Society, Culture and Recreation
Conference Registration:


The Conference Dinner will be held on Monday 30 April 2012 in the Grand Ballroom at the Conference venue.

Some budget accommodation is available at the Conference venue. (Please note the hotel does not have wheelchair accessible rooms)

Please make your own accommodation arrangements.

This Conference is supported by the Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs.

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Leaders for Tomorrow update

February 2012 saw a new intake of participants commence the Leaders for Tomorrow program. There has been a significant increase in applications for the program this year.

Leaders for Tomorrow is a national program which provides up to 12 months of leadership development support to 200 people with disability from across the country. It supports participants to develop the skills and confidence to become leaders in business, the community and government. They have access to training, coaching, mentoring and other leadership development opportunities through the program.

Some of the most significant achievements so far include:

• Participants taking on significant voluntary roles, for example: Several are advocates for specific organisations, eg, Vision Australia; Several have been elected to boards
• Enthusiasm and commitment from mentors, employers and supporters (AICD gave a 50% scholarship, an employer has contributed to the costs of an AICD course)
• Peer mentoring
• Participants reporting increased confidence in different areas in their daily life
• Of the first group of 36 who began in September 2011, between them they have completed, or are currently undertaking, 46 training programs as part of their leadership goal.
• One participant was the recipient of the Doug Pentland Award (Tasmania)
• Several participants have gained promotions or have been appointed to new positions since joining the LFT Program
• One of the February 2012 group was appointed as Associate Director of Accessible Arts Victoria – for The Other Film Festival

Some positive feedback from participants:

o “I cannot thank you enough for the help you have provided. I wish there were more people like you in the disability sector.”

o “The provision of information in the form of handouts at the Retreat was excellent. This enabled the participants to be across the information ‘in their hands’, and to take them home for their use.”

o “I would recommend this program for anyone who wants to make a difference to the lives of people with disabilities and special needs.”
“Surprised at how much I have achieved through the program. More than I expected.”

Participants’ interests are diverse and broadly include:

- Advocacy
- Developing small business
- Access auditing
- Motivational speaking
- Disability awareness training
- Career advancement
- Paid employment
- Board/governance skills
- Educating through writing - books/articles on disability
- Consumer representation
- Political aspirations
- Formal leadership training
- Teaching and mentoring other people with disability
- Regional or cultural interests
- Voluntary board roles

Below are the number of participants state by state:

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I’d like to thank Catherine Starling, Manager, NSW Consumer Support and Training Project at Hunter Tafe for providing us with the above information - Joanne

It’s time: Tell every MP to Make NDIS Real

It doesn’t matter which political party is in Government. It’s time to make the NDIS real. Time to make it clear to every MP across the political spectrum that we expect them to support the NDIS.

Our MPs need to know we won’t give up the NDIS. So let’s tell them!

There are several actions you can take by visiting the Every Australian Counts website. ([www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)) You can join and spread the campaign and there is information on talking to your MP.

To keep people up to date with the Government’s progress towards a NDIS, a website has been created. It provides easy-to-read information, up-to-date news, disability and carer resources, and fact sheets on reform of disability care and support services.

To keep up to date: [www.ndis.gov.au](http://www.ndis.gov.au)

[MAKE IT REAL NDIS 2012]

"I'M COUNTING ON THE NDIS" It's time to act. Tell Australia to Make it Real in 2012.

[MAKE IT REAL NDIS 2012]

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Reforming the Disability Support Pension

From 1 January this year, people who apply for the DSP will be assessed under revised Impairment Tables.

The Impairment Tables are used in DSP assessments to measure how a person's impairment affects their ability to work.

They were last reviewed in 1993 and contain anomalies and inconsistencies which have distorted the assessment process.

The revised Impairment Tables are consistent with modern medical and rehabilitation practice and can be viewed at:

The revised Impairment Tables will apply to all new applicants for DSP and any existing DSP recipients selected for medical review from 1 January 2012.

Recognising A Stroke

Most effects of strokes can be reversed if the stroke is recognized, diagnosed, and the patient is medically cared for within 3 hours. The stroke victim may suffer severe brain damage when people nearby fail to recognize the symptoms of a stroke. Ask 3 simple questions:

S - Ask the individual to SMILE.

T - Ask the person to TALK and SPEAK A SIMPLE SENTENCE (Coherently, like “It is sunny out today.”)

R - Ask him or her to RAISE BOTH ARMS.

If the person has trouble with ANY ONE of these tasks, call emergency number immediately and describe the symptoms to the dispatcher.

A new Sign of a Stroke - Stick out Your Tongue OTE: Ask the person to 'stick' out his tongue. If the tongue is 'crooked', if it goes to one side or the other that is also an indication of a stroke.

Source: Arts Access Australia – December e-newsletter
Advertisement:

AT LAST - A PERSONAL SUPPORTS SERVICE THAT DELIVERS!

DO YOU: LIVE IN BRISBANE, SUNSHINE COAST, GOLD COAST OR TOOWOOMBA?
- WANT A PROVIDER THAT IS TRANSPARENT, NON-INVASIVE, HONEST & RESPECTFUL?
- WANT MORE CONTROL OF YOUR SUPPORTS & INSIGHT INTO THE MANAGEMENT OF YOUR FUNDS?
- GET FRUSTRATED WITH YOUR CURRENT SUPPORT SERVICES? WANT STAFF TO TURN UP (& ON TIME)?

QUEENSLAND SUPPORT SERVICES & SOLUTIONS (QSSS):
- ONLY SUPPORTS PEOPLE WITH PHYSICAL DISABILITIES & CHOOSES TO BE A SMALL PERSONAL SERVICE
- WORKS ON PRINCIPLES OF SELF-DETERMINATION, EMPOWERMENT, VALUE & RESPECT
- IS OWNED AND MANAGED BY QUALIFIED PEOPLE WITH DISABILITIES & EXPERIENCED STAFF
- PROVIDES YOU WITH REGULAR STATEMENTS SHOWING YOU THE STATUS OF YOUR FUNDING/HOURS
- HAS REASONABLE FEES (THE MORE YOU ARE INVOLVED, THE LESS WE CHARGE) E.G.
  ➢ CHOOSE YOUR OWN STAFF;
  ➢ MANAGE YOUR OWN ROSTERS;
  ➢ OVERSEE TIMESHEETS;
  ➢ PROVIDE FEEDBACK ON YOUR STAFF PERFORMANCE.

CONTACT: Louise Lowe (07) 33989965 Email: louise@qsss.com.au Website: www.qsss.com.au

Media Release

Supporting people with disability into work

Date: 15/02/2012
Joint Media Release with:

Senator the Hon Jan McLucas, Parliamentary Secretary for Disabilities and Carers

Australians with disability will receive greater support to help them into work where possible under legislation introduced into Parliament today.

The Social Security and Other Legislation Amendment (Disability Support Pension Participation Reforms) Bill 2012 introduces new participation requirements for Disability Support Pension (DSP) recipients who have some capacity to work.

The Bill also introduces more generous rules to allow DSP recipients to work up to 30 hours a week and continue to receive a part-pension, subject to income and assets testing.

From 1 July this year:

- For the first time DSP recipients aged under 35 years with some capacity to work will be required to attend regular participation interviews with Centrelink to develop participation plans, to help build their capacity and overcome barriers to work; and
- All DSP recipients will be able to work up to 30 hours a week without their payment being suspended or cancelled, subject to the income test. Currently DSP recipients granted after 11 May 2005 can only work up to 15 hours a week before their payment is
suspended or cancelled. These people find it difficult to find work that is limited to only 15 hours a week and many want to work more hours. This important change will give people with disability the security they need to test their ability to work more hours, without worrying about losing qualification for the disability pension. This will encourage about an estimated 4,000 DSP recipients to take up work, and an estimated 3,900 DSP recipients who are already employed to work extra hours.

The Government believes we can do better than a lifetime spent on income support for Australians who have some capacity to work.

A job provides more than just a pay packet—it gives people dignity and purpose, provides security for the future and connects people to their community.

That’s why this Labor Government is taking steps to make it easier for people on the disability support pension to get and keep a job.

In addition to these changes to the DSP, the Government is delivering extra support for people with disability, including more employment services and new financial incentives for employers to take on more people with disability.

The Government will also ensure the DSP continues to be an essential safety net for Australians who are unable to work.

The Bill also introduces new, more generous rules from 1 July this year that allow DSP recipients who have a severe and permanent disability and no future work capacity to travel overseas for more than 13 weeks while retaining access to their pension.

Today the Government also introduced the Family Assistance and Other Legislation Amendment Bill 2012 to deliver on changes announced in the Mid Year Economic and Fiscal Outlook to strengthen incentives for immunisation, by linking the Family Tax Benefit part A supplement to immunisations from 1 July 2012.

The Bill also helps make sure the family payment system is sustainable into the future, by resetting the baby bonus to $5000 from 1 September this year. The baby bonus has increased by 67 per cent since it was introduced in 2004, and this measure will provide a saving to the Budget of $358 million over four years.

This Bill will also deliver on commitments under the Australian Government’s National Carers Strategy, announced in August last year.

Carers play a critical role in the community, often combining paid work with their caring responsibilities.

The Bills are expected to be debated in the coming weeks.

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**When did you last review your eligibility for concessions?**

Concessions change from time to time. It is worth reviewing your eligibility to ensure that you are claiming any concessions to which you are entitled. Some of the things you may receive a concession on include transport, gas and electricity, council rates, and health care.

To read more: [http://www.disabilitydirectory.net.au/blog/2012/02/07/when-did-you-last-review-your-eligibility-for-concessions/](http://www.disabilitydirectory.net.au/blog/2012/02/07/when-did-you-last-review-your-eligibility-for-concessions/)
# Membership Application Form.

Free for people with disability. $27.50 for organisations + GST

**Name:**

**Address:**

**State:** NSW QLD VIC SA TAS NT WA ACT (please circle)  
**Postcode:**

**Email Address:**

**Phone Number:**

**Mobile Number:**

**Date Of Birth:**

**Gender:** Male/Female (please circle)

Please use the space below to describe your physical disability

Please describe the service you offer if you are an organisation

Please indicate if you would like to receive information via email or post or discussion list?

- Hard Copy via mail
- Email
- Online E-Discussion list

**Signed:** __________________________  
**Date:** __________________________

**Office use only: membership accepted date:**

**Date entered into membership register:**