



# community partners in disability

Autumn 2004

Issue 3

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## A message from the Executive Director

### Welcome to the Autumn edition of *Community Partners in Disability*

In this edition of the newsletter, we feature a number of articles specifically for young people with disability—one of the focus areas for us in Disability ACT. We are working with young people, families, carers and service providers, to develop and implement policies and programs that will positively impact on the lives of young people with disabilities in the ACT.

However, at an individual level, each of us has a responsibility to:

- inspire a shared vision of the place of people with disabilities in the ACT with all people with whom we have contact.
- champion the rights of people with disabilities.
- speak up and question incidents of exclusion when we see it in any area of life.
- inform, educate and steer people in positions of influence to enable them to better meet the needs of people with disabilities.

- join and cooperate with others in efforts to enhance and improve opportunities for people with disabilities
- select where possible, people for influential roles who share our vision.

One of the ways we will be moving forward will be through consultation on the proposed future direction for the disability sector in the ACT in April and May 2004. I encourage young people to have a voice in shaping their lives through involvement in this consultation, and at all levels across community and government. The following articles explore some of the ways in which you can also make change happen.

I welcome your ideas on how to best support you in achieving your goals.

**Lois Ford**  
Executive Director  
lois.ford@act.gov.au

Image: seventyeight.com.au



Young people can experience the fun of horseriding at Pegasus Riding School.

department of disability, housing & community services



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# Vision and Values statement: the potential impact

*Matt Drummey is a member of the Disability Advisory Council. He has a strong interest in youth issues and his goal is to study social work in 2005. Community Partners asked Matt his thoughts on how the 'Vision and Values Statement' impacts on young people.*

## The Vision and Values Statement was originally developed by the Disability Reform Group and expanded on by the ACT Disability Advisory Council.

It is a big step forward in terms of achieving a fully inclusive society. When fully implemented, the potential of the Statement to improve the lives of disabled persons is immeasurable.

Young people would benefit in a number of ways especially since the quality of services would improve to a degree where they could live their lives in a manner that is equal to their able-bodied friends and family.

The Vision and Values statement offers all disabled young people the chance to live full, productive lives and they can improve the quality of life for the disabled young person and their family.

Growing up is hard enough to do when you don't have a disability, but being disabled only adds to that already overwhelming burden. One problem I encountered as a disabled young person, was that the services and the workers in those services, despite their best efforts often had no clues as to how to help me with my disability and the changes that I was forced to make in my life as a result of the disability.

In today's materialistic world, people are often marginalised for the slightest thing and having any form of disability is unfortunately one of those things. The aim to reduce the amount of marginalisation and inequality suffered by many disabled young people by promoting a more caring and accepting community. Increased levels of caring and respect within the general community towards disabled young people.

The Vision and Values statement can only help to improve that situation which is unfortunately encountered by many disabled young people on an all too regular basis.

The Vision and Values statement covers many topics which are of concern to any disabled young person ranging from the obvious equality, to things like safety and family involvement.

The Vision and Values statement can only help any disabled young person to realise that just because they have a disability they don't have to lead a life that is any less active and fulfilling than the lives that their able bodied counterparts lead.

To understand the potential impact that the Vision and Values statement could have on the life of a young person you must be able to understand how things are now and how they could be if the Vision and Values were to be fully implemented, To do that you need to look at certain

facets of the community in regards to people with a disability.

**Inclusion** — perhaps the one thing that all people strive for in their life and as a disabled young person this need is often enhanced to levels that cause great stress. The Vision and Values statement aims to increase the amount of inclusiveness within the ACT community to a point where a disabled young person can live their life with the same amount of enjoyment and pleasure that able bodied people have.

**Equality** — along with Inclusion, equality is one of the biggest concerns in the life of any disabled young person, the Vision and Values statement hopes to instil the belief in everyone that just because a young person has a disability it doesn't make them any less worthy of a chance to be a productive useful member of society.

Too many times as a young person with a disability I was told things such as 'You can't do that', or 'Because of your disability I can't allow you to do that'. At times these statements had merit, especially in regard to Occupational Health and Safety concerns.

All too often the statement was made simply because there was no idea about how the activity could be modified so that I could do it. It isn't always possible for something to be modified so that it can be done by a

## on a young person

disabled person, but advances in technology over recent years means it is now possible for people with a wide range of disabilities to do most things such as driving and sport.

And upon successful implementation of the Vision and Values statement the amount of activities available to disabled young people will increase as will the knowledge of the operators of such programs who will then be able to promote equality within the community by openly encouraging disabled young people to participate in activities such as learning to drive and play sports.

**Self-determination**—is vital for a young person with a disability if they are to overcome the obstacles that their disability presents them with and lead a full and productive life.

The Vision and Values statement aims to increase that self determination by providing a more accepting and knowledgeable community for the young person to live in, such a community would allow for a disabled young person to be less self conscious—which can be a barrier to living an enjoyable life and it would increase their self esteem and self determination to levels that would see them become more

active in the community and put them on a road to a happier life.

**Family involvement**—perhaps one of the most essential things for any disabled young person to have in their lives. The Vision and Values statement holds great potential in being able to establish and strengthen the involvement of families in the lives of their disabled relatives and once fully implemented disabled people of all ages will be able to look forward to living as part of a family unit where they receive full support from all the other members of that unit.

Those are just a few of the topics covered in the Vision and Values statement and one article does not provide enough room to go into detail about each one. I'll close by saying that once the Vision and Values statement is fully implemented into the ACT community, disabled young people and disabled older people will have the chance to grow and live in a more accepting, understanding and respectful community.

Until that day arrives I, along with the rest of the Vision and Values sub-committee will continue to work on finding ways to get the Vision and Values statement into the community.

Aiming to **reduce** the amount of **marginalisation and inequality** suffered by many disabled young people by **promoting a more caring and accepting community.**

## Post-schools options

### A few facts and figures about young people who have a disability.

According to the estimates in the ABS Survey of Disability, Ageing and Carers, in 1998 around 7.2 per cent of youth and young adults with a disability in the ACT were aged 15–24 years of age. This figure includes all kinds of disability—mental, physical, intellectual and sensory.

Approximately 35–40 young people a year with a disability will need to find an alternative to employment or tertiary education. There is virtually no opportunity for a young person with an intellectual disability to further their formal education once they leave high school.

Currently, many parents who care for young people with a disability find that they have to give up work (or go part-time) when their son or daughter leaves school. Added to this, is the fact that there is not a lot of opportunity for young people with a profound physical, sensory and /or intellectual disability to get part- or full-time work

This is not just the experience in the ACT, it's a similar story pretty much everywhere. ►

## Post-schools options—continued

### How is Disability ACT helping to address these issues?

Many young people who have a disability will go from school to a job, attend tech or uni, or do other things. Some people may move away from the family home and go and live with friends, or other places such as hostels or boarding houses. A few people won't be able to make these choices and need to be able to explore different options after leaving school. In many cases, family members are relied on to plan, and make decisions on the young person's behalf.

In 2001, families approached the ACT Government asking for their support to help young people with disabilities who had finished school and who wanted to explore different options other than those already available. These young people wanted to have the opportunity to plan their life in the same way as their peers.

The ACT Government has provided funding of \$1 million to support young people and their families to choose—and use—a range of options that could help them to continue with education. This includes ways in which young people can, as much as possible, link to existing opportunities in the community available to all young people. The program is called 'Post School Options'.

The funding was to be available for the first three years after leaving school, by which time it's assumed that individual needs for learning may have changed.

### What do you think?

Disability ACT asked a number of young people and their families about their views on post school education options. We found out that the situation is mostly okay—but not fantastic—and some things need to change. Issues raised included:

- young people are getting 'stuck' in the system rather than being able to move on to other opportunities
- evidence that shows that much of the support that is available, is provided as centre based
- quite a lot of support is delivered on a group basis, rather than individual—not a bad thing, but options to tailor programs to better suit individual needs are always welcome
- concerns that young people are losing the skills learnt at school
- concerns that young people are going to activities where they have no interest, or do not want to be involved in, and
- recognition that there is very little choice for young people who cannot move much, or talk, hear or see or understand what's going on around them.

### What is happening next?

It's really clear that we need to take another look at this whole issue of how young people can get more, and better opportunities to get on with their lives. We know that we cannot possibly cover every option, or provide everything that is needed. However, we do think we can improve the current situation.

To make change happen, we need more information from everyone who has an interest in the future of youth and young adults in the ACT. As part of this, we will be looking at what is happening for young people with a disability in the ACT, across Australia (and other in other parts of the world), and then see what can be developed here.

Evaluating the current Post-Schools Options program and centre based day activities will give us a better picture of what type of programs and activities that young people want. This will put us in a better position to report back and work with you to find ways to support you and your families in what can be, a challenging experience.

For more information, email Ian Ross at [ian.ross@act.gov.au](mailto:ian.ross@act.gov.au)

**\$1 million to support young people**  
and their families to **choose**—  
and **use**—a range of **options** that  
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to **continue with education.**

# Feature: Opportunities for Youth in the ACT Community

## There is a range of facilities and services for youth in ACT that provide terrific opportunities for young people.

These are provided in the areas of entertainment; recreation and sporting activities; increasing social networks; drop in facilities; education; counselling and support; housing; emergency relief; advocacy and reform.

*Community Partners* approached **Craig Wallace**, President of People With Disabilities and Chair of the Disability Advisory Council to provide some thoughts and ideas for young people.

## Find your dream and run with it

The focus of this edition of *Community Partners* is on young people with disabilities, and this is very timely, with National Youth Week running from 27 March to 4 April.

One of the priorities that the ACT Disability Advisory Council has now identified is a need to make sure the lives and experiences of people with disabilities are reflected in mainstream community life, such as participation in events like National Youth Week.

People with disabilities are not all the same, with the one set of issues,

but we do face many of the same issues at various life stages.

Possibly the biggest issue facing young people generally is of managing life transitions through school and beyond school to training and employment.

For many people with disabilities these issues can be doubly important. Sometimes the life transitions are experienced differently, and there are added challenges in many of them for young people themselves and for families.

One of the challenges that young people with all kinds of disabilities and their families often talk about, is that they worry that they are missing out on opportunities to make friends, gain new skills and 'be part of the action'.

Youth development activities can have an important role to play in addressing this challenge. So, just what is out there in Canberra for a young person with a disability?

Find your passion and get involved. Consider opportunities for active involvement in the community — either through the issues of disability, environment women's issues or social justice — or whatever you are passionate about.

This involvement can be a great way to find support networks and practical assistance to manage life's challenges, but also to gain skills and experiences that will be relevant in whatever you do.

The *Consumer Strengthening Innovations* project being run by

People with Disabilities ACT has been outlined in this newsletter. This project focuses on providing people with disabilities with the opportunity to build skills in areas like public speaking, assertiveness, attending meetings and negotiating.

To discover what's happening in the community, the *Contact* book produced by CIRSACT (6248 7988), or the *Fridge Door* in *The Canberra Times* provide information on groups and organisations.

## Become a volunteer

Volunteering can be a great way to make new friends, gain skills and broaden your social networks while doing positive things in the community. It's important to find the right opportunity for you, and that's where Volunteering ACT can help.

Volunteering ACT's Referral Service operates Monday to Friday, and is wheelchair accessible. To find out more, contact 6251 4060 during office hours, or visit

**[www.govolunteer.com.au](http://www.govolunteer.com.au)**, or you might like to explore *Bridge to Volunteering*. This is an informal short workshop facilitated by an experienced volunteer trainer, that is designed to explore the benefits and pitfalls associated with volunteer work. The next workshops will be April 21 at 10 am, May 27 at 5.30 pm, June 28 at 12.30 pm.

## Become a writer or a poet

The disability community has a number of writers, poets and artists whose work was showcased in

PWD's *Leap Out Anthology Project*, and there are some great opportunities to share creative talents.

Primary and high school students can get involved in writing through the *Young Writers' Competition*, run by the ACT Writers Centre, with support by the Department of Urban Services' Community Partnership Program.

Entry forms are available from ACT Libraries, the Writers Centre or [www.library.act.gov.au](http://www.library.act.gov.au). Further information can be also at [www.actwriters.org.au](http://www.actwriters.org.au) or **6262 9192**.

The ACT Writers Centre will be conducting some special workshops on Writing Stories for Competitions on 3–4 April. Cost is \$5.00 per person and bookings are essential. Contact **6262 9192** for more details.

### Find a youth development opportunity that suits you

Organisations are getting better at integrating young people with disabilities into their activities and events — and National Youth Week provides a perfect opportunity to get them thinking!

*Living Choices*, produced by the Australian Government contains useful information on a range of youth development opportunities as well as other programs and services for young people. It is available at [www.thesource.gov.au/livingchoices/default.htm](http://www.thesource.gov.au/livingchoices/default.htm).

Find out about events, activities and things to do by subscribing to

a Yahoo! Group called *YouthGAS*. The group currently has over 2000 subscriptions and features heaps of news, information and opportunities all focused on young people. [www.youthgas.com](http://www.youthgas.com)

This year's slogan for National Youth Week is '*Run With It*'. I would encourage young people with disabilities to run (or walk or roll) into the various activities on offer.

So, my message is, '*don't be held back, don't always believe the people who say 'no you can't do it'*'—and yes—do follow those dreams. Have a great National Youth Week.

### Craig Wallace

Thanks Craig for your inspiration, and useful information. *Community Partners* continues the theme, with a brief overview of other services and activities for young people in ACT. These include:

### Youth Coalition of the ACT

The Youth Coalition is the peak youth affairs body in the ACT and actively promotes the wellbeing and aspirations of young people. The Coalition advocates on behalf of young people and those who work with them on a number of government advisory bodies. It organises National Youth Week activities in Canberra, advises on youth policy and youth sector issues, and administers the website *Making Contact*.

The website and information officer can provide extensive information

regarding all organisations within the ACT that provide services to youth locally.

For more information contact Matthias Schmidt on 6247 3540; answering machine after hours 62473540 or fax 62491675 visit [www.youthcoalition.net](http://www.youthcoalition.net) or email [matt@youthcoalition.net](mailto:matt@youthcoalition.net)

### RecLINK

RecLINK is for young people who are experiencing (or are at the risk of experiencing): disability; geographical or family isolation; accommodation difficulties; vocational and educational difficulties; drug and alcohol difficulties.

Young people who are clients of Youth Justice, or the Youth Supported Accommodation Assistance Program, or who are part of low income families, can also access the service.

It provides young people with the opportunity to participate in sporting and recreational activities through a range of avenues, including:

- **Centre based activities.** These operate weekly during the school term at Turner and Erindale PCYCs, Belconnen Community Centre and Tuggeranong Youth Centre. Qualified tutors and coaches manage the activities, which include boxing, basketball, kickboxing, drama, art, weights training and soccer.
- **Outreach activities.** Sport and recreational activities are provided in a wide range of locations around the ACT. Outreach activities are targeted in areas that are isolated. Activities include barbeques, volleyball, skateboarding competitions and touch football.
- **Specialised programs.** Structured activities can be organised for community groups

**run with it...don't be held back...**  
**don't always believe the people**  
**who say 'no you can't do it'**

at venues and times that best suit their needs. Examples of community groups that are accessing the RecLINK program include schools, health services and multicultural services.

If you would like to receive a RecLINK timetable and/or become a member of RecLINK contact Elaine or Sean on 6247 0206.

### Youth Resources — Australian Federal Police

ACT Policing provides a wide range of resources for young people in Canberra. A number of programs focus on building community partnerships between police, youth and kids at risk.

For people who are looking to get fit, try new activities or have some fun, the Canberra Police and Citizens Youth Club (PCYC) centres may be a good option. The centres are friendly and positive places to go to try new experiences, develop skills, meet people, get advice or just hang out.

Youth between 11 and 18 can join the Police Scouts, and become involved in camping and other activities.

**Project Saul** consists of a number of programs providing outdoors based fun and adventurous activities at the Eagles Rest Outdoor Education Centre near rural Yass, just outside the ACT.

The **Safety House Program** is a community-based network of safe places in a local area. Safety Houses can be a house, shop or a business and they can provide assistance if young people feel threatened or unsure, especially when travelling to and from school.

**Gungahlin Youth Services (GYS)** aims to 'Provide a community service for all Gungahlin youth, encourage a philosophy of self and community responsibility.'

GYS is a community service offering a wide range of programs to the youth of Gungahlin between 11 and 25, with a focus on 12 to 18 year olds. GYS has trained and experienced youth workers who are employed to develop and facilitate a youth program that meets the needs of Gungahlin youth. These programs include the Young Parents Group, School/Literacy Programs along with providing a regular drop-in.

Friday nights provide the opportunity for youth to participate in a pool comp, enjoy a free meal or, relax in a quiet area to watch TV, read, talk or create art and craft.

For those people interested in dance, drama, music and creative expression, there is a trained performing arts/singing teacher who facilitates a weekly workshop every Saturday. For more information contact 6228 9211 (Office) or 6228 9277 (Youth Centre) or email [gungyth@webone.com.au](mailto:gungyth@webone.com.au)

**Communities Online.** This is a website that has details of hundreds of community groups and organisations. Advertising on the site is free and all groups and organisations are encouraged to apply. The website has information regarding major events, culture and interests, education and childcare, holidays and tourism, health and wellbeing, getting or providing help, markets or fetes, ethnic or indigenous support and activities, fund-raising events. Visit [www.actco.org.au](http://www.actco.org.au) to see what's out there.

## Youth work placements

**Do you have an opportunity in your business to offer a work experience placement or a traineeship to a young person with a disability?**

Capital Careers currently have ten recent school leavers attending training at Capital Careers in Belconnen. The students are working hard towards gaining a nationally recognised Certificate I in Business.

The skills-based program provides training in Word, Excel, experience in using a range of office equipment, keyboarding and telephone techniques. In addition, the students are learning to be independent travellers, to be organised, and to become great communicators.

The current students are all looking forward to contributing to the Canberra workforce and just need employers who are willing to give them a go!

For details on how easy the process can be to employ a young person with a disability please contact Jacky Ryles at Capital Careers, 6253 0682 (email [jacky.ryles@capitalcareers.com.au](mailto:jacky.ryles@capitalcareers.com.au)).

*Capital Careers offer a range of specialist equipment to support people with disabilities in the learning environment. They were recognised in the 2003 Inclusion Awards, receiving the prestigious Chief Minister's Award for Excellence in Inclusion.*

Certificate I students at Capital Careers.

Image: Capital Careers



# Disability Advisory Council

## Notes from the Chair

### It's National Youth Week and the focus on youth for this edition of *Community Partners* is welcome.

Being young is all about getting out there, finding your passion and trying new things and elsewhere in this edition you will find some information about local youth development opportunities. I would encourage you to get out and explore these. One result may be that youth services and providers get better at catering to the needs of people with disabilities and that in itself is an important achievement.

I would also encourage you to read the article from Council member Matt Drummey, also in this edition. He focuses on the Vision and Values for disability services and their relevance to young people with disabilities.

More than anything else, the Vision and Values challenge us about the legacy we will all leave to future generations of people with disabilities, including people growing up right now.

An important part of getting the legacy right will be the availability of talented and skilled people who enter the disability field as a career of choice.

A few days ago I was delighted to be invited to speak at a graduation ceremony for students who had completed a Certificate III in Community Services (Disability Work) from the national Community Services Training Package.

During the ceremony, I was pleased to learn that the ACT was the first in Australia to establish a traineeship in disability work using nationally accredited standards. That is an achievement well worth celebrating.

Council continues to be very busy. Our recent focus has shifted towards pushing for specific funding measures for people with disabilities as part of the ACT 2004/05 Budget Process.

Council has identified a number of broad budget priorities that respond to developing the Vision and Values framework, the reform process and broad community priorities for improvement in disability service provision in the ACT.

Some of the key broad priorities are:

- supporting funding in 2004/05 to meet a significant backlog and unmet need
- skills development and capacity building in disability services
- identifying better housing models
- addressing unmet need for equipment to make lives of

people with disabilities easier, safer and more comfortable, and

- supporting a more welcoming environment for ACT families of people with disabilities.

Council has offered six specific initiatives for consideration in the 2004/05 Budget context as part of a disability services renewal package in response to some of these priorities.

Highlights of these include our recommendations for a boost to general support funding, a series of small grants for equipment, a community capacity development initiative, a skills and training initiative, a better practice housing and disability project and an ACT Companion Card. Council has also flagged the need for additional support for individual advocacy.

We recognise that the additional resources we are seeking will only scratch the surface of unmet demand, and only time will tell how the priorities we have identified will fare among the others faced by Government.

Of course, not all the problems that people with disabilities and families confront in our day to day lives can be solved by Government writing a cheque.

As last year's ACT Inclusion Awards and International Day of People with a Disability demonstrated, there is

the **ACT** was the **first in Australia** to establish a **traineeship in disability work** using **nationally accredited** standards

# Innovation Grants: Update

## PWD Consumer strengthening project

tremendous potential for people with disabilities and families to gain from measures that encourage business, and other community agencies to discover the needs (and the purchasing power), of our disability community.

An example here is the need for discounts, 2 for 1 offers and other measures that recognise the additional costs faced by people with disabilities, especially when accompanied by companions and family members.

This is one reason that I am especially keen on an ACT Companion Card. It is an idea that I hope the Stanhope Government will examine carefully, along with our other Budget suggestions.

Further information on the Budget priorities as well as the other developing focus areas of Council is now available on Council's new page on the Disability, Housing & Community Services website at [www.dhcs.act.gov.au](http://www.dhcs.act.gov.au) — go to the Disability link.

A web presence is an important step for Council. It provides information on council members and our key focus areas, as well as a mechanism to provide ongoing feedback to us. I encourage you to use it.

### Craig Wallace

Chair

ACT Disability Advisory Council

People with Disabilities ACT (PWD), (formerly Disabled Peoples Initiative), has received Innovations Grant funding from the ACT Department of Disability, Housing and Community Services, for an exciting new idea called the *Consumer Strengthening Project*.

The idea of the Project is to provide ways to develop people with disabilities to speak out and be active consumer representatives or new leaders. Another stream of the Project will work with vulnerable people with disabilities in accommodation services to build their capacity to speak out and be heard.

The project is in development phase and this is being overseen by a joint steering committee including PWD, DHCS, Toastmasters, Volunteering ACT and Belconnen Community Service. Work is underway to identify community partners to work with PWD to deliver the various program elements.

Learning for new leaders and a register of consumer skills

People with disabilities who join the new leaders stream of the project will be provided with training, mentoring and

development in areas such as public speaking, building confidence and assertiveness.

On completion, people can join a Consumer Skills Register, which will link them to supports, skills development and training. People on the register will also be referred and matched to consumer representation opportunities that suit their skills and interests through the PWD network and the ACT Government.

### A great opportunity for young people with disabilities

This is a great opportunity, especially for young people with disabilities, to build skills, meet new people and gain experience in areas such as volunteering, representation, leadership and public speaking. Prior experience in leadership roles is not necessary to join the program—just enthusiasm and a willingness to grow.

To find out more, contact Briony Young, project coordinator on 0407 939 413 or to register for the Program contact the SHOUT office on 6290 1984 (email [brionyyoung@bigpond.com](mailto:brionyyoung@bigpond.com)).

### Craig Wallace

President, People With Disabilities (ACT)

**Build skills,  
have fun and  
speak out!**

## Support for siblings

Young people with a brother or sister who has a disability often face difficulties not normally encountered by their peers. Even though there are a lot of young people in Canberra who share this family experience, it can still feel like no one else understands what it's like.

One place that young people can go to meet other people who also have a sibling with a disability is the *Siblings and Friends Craft Afternoons*. These are held on the third Sunday of the month from 2 pm to 4 pm, and costs \$5.00.

The afternoons are suitable for young people aged 7 to 13 and friends are welcome. For more information, contact SHOUT on 62901984. Parents who can provide assistance are always welcome.

The internet can be a great source of information on issues and problems and how other people have handled them. Useful websites are:

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### [www.yourshout.org.au](http://www.yourshout.org.au)

Created by adolescents for young people to express their views and connect with other young people.

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### [www.acd.org.au](http://www.acd.org.au)

This is the *Association for Children with a Disability* website. They have a great publication called 'Supporting Siblings'— a useful read for teenagers and parents.

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### [www.wch.sa.gov.au/sibling/index/html](http://www.wch.sa.gov.au/sibling/index/html)

Information for young, teen and adult siblings as well as parents.

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## Presented in style

**Recent graduates of the Certificate III in Community Services (Disability Work) course, received their certificates in beautiful presentation scrolls created by students from Hands on Studio.**

The Narrabundah based studio offers classes for people with physical and intellectual disabilities in pottery, painting, sculpture, craft and printing.

Under the expert tutelage of Margaret Notaras, students from the craft class handmade the scrolls by shredding and pulping paper, pressing it into sheets and shaping it into cylinders. Paint, varnish and ribbon trim were the final touches in creating functional works of art.

The glamorously packaged certificates were presented by Bill Wood, Minister for Disability, Housing & Community Services at a graduation ceremony held on 18 March at the Canberra Museum and Gallery.

Guests included family and friends of the graduates, people with disabilities and training staff, disability advisory council members and staff from Disability, Housing and Community Services.

More creativity is on the way with *Hands on Studio* holding an exhibition of students' work— 'A Special Kind of Magic' on 3–4 April as part of the Canberra and Regional Heritage Festival.

Contact Carolyn Jander on 6232 7187 for more information on classes and exhibition opening times.

Image: Hands on Studio



Artists at work (L–R): Eve Newman-Martin, James Walker (volunteer), Michelle Gribble, Shane Tunks (student and volunteer, standing), Remedios Humphries (volunteer), Margaret Notaras (teacher), Beverly Bergein, Teena Barry.

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# Epilepsy and the teenage years

**Epilepsy is a complex condition. It is vital that you discuss your particular situation with your doctor and epilepsy counsellor. This article is a general guide only. Reprinted with the permission of Epilepsy Australia Ltd.**

Epilepsy is the most common neurological disorder of adolescence with an estimated prevalence of around 1 per 100 children aged 14–16 years. Many children diagnosed with epilepsy will have it throughout their lives while others will be diagnosed during their teenage years.

The teenage years are very important years. It is a time when many major life decisions are made about higher education and career pathways. It is a time for looking forward to being independent.

Epilepsy can affect these life decisions, but it is most important to have the facts and accurate information before any decisions are made. In certain circumstances young people may have to reconsider a first choice of career or the sporting activity, and plans for a driving licence may have to be put on hold for awhile.

Epilepsy can be managed, and while it's a reality that there may be limitations, people with epilepsy will be able to achieve many of their goals.

People with epilepsy are doctors, lawyers, teachers, scientists, actors, writers, elite sportsmen and women—epilepsy need not be a barrier to achievement but attitudes can be!

Treatment in most cases is with antiepileptic drugs (AEDs). These drugs do not cure epilepsy; but they

help to prevent seizures occurring. Many people will achieve total control of seizures, and may think that seizures have stopped forever. But to work effectively, medication needs to be taken exactly as prescribed by a neurologist.

Not taking medication as prescribed could also mean that seizures start again, are more frequent or may last longer than previously. Sometimes the unpleasant effects from medication may be the reason people stop taking it.

Other people may resent taking medication because they are associated with the stigma of epilepsy, or want to avoid explanations to everyone else. It's important to discuss these concerns with a paediatric neurologist/neurologist or a counsellor at Epilepsy Australia.

Stopping medication suddenly can trigger seizures and in some instances cause a medical emergency.

While taking medication is a choice, most teenagers prefer to take their medication rather than have seizures. Seizures can be unpredictable and depending on what activity a person is doing at the time of a seizure, can place them or others, in danger.

People who have epilepsy, may not always have to take medication and a paediatric practitioner or neurologist can discuss the indications and likelihood of a successful withdrawal of medication.

Once seizures are controlled, life carries on. It is important to learn

what triggers seizures and how to manage this. For example, sleep deprivation is a known trigger for seizures, as is alcohol. Remember, AEDs can make people more sensitive to the effects of alcohol, and can reduce the effectiveness of medication. This may mean seizures are more likely to occur.

Drugs such as marijuana, ecstasy, heroin, amphetamines or solvents can trigger seizures and when combined with a change in lifestyle that involves late nights and alcohol, the risk of seizures is greatly increased.

Seizures can be triggered by flashing or strobe lighting, so check for warning signs before entering nightclubs or bars.

Depending on the kind of epilepsy syndrome, getting a licence may not be possible until seizures have been controlled for a specified period of time.

Living with epilepsy is not always easy. Discrimination in some form or another, mainly through ignorance and fear can happen. Managing this can depend on how comfortable people are with their epilepsy. Being frank and open about it will suit some people, while others will feel quite sensitive about being 'different'.

Learning about the type of epilepsy involved can bring confidence in explaining it to others—as can talking to close friends about what to do if a seizure does (or is likely to) happen. It's important to remember that when managed well, epilepsy will become only one part of a person—not defining them.

**Teenage years are a time when many major life decisions are made about higher education and career pathways.**

# Invitation: **accommodation committee** members

## **Individual Support Services (ISS) conducts a joint committee to oversight the accommodation transfers within its supported accommodation or relocation to another service provider.**

The *Accommodation and Support Review Committee* has a formal role in ensuring that throughout the exploration process, the rights of all clients are protected and appropriate processes are followed, and to make recommendations to the Director of Disability ACT, Ros Hayes, to approve outcomes.

The Committee also provides a forum for families to discuss their initial accommodation preferences and to discuss the exploration process once an offer has been made.

The committee consists of key ISS staff and four family/community representatives, and new family or community representatives are now being sought.

People who are:

- committed to assisting people with disabilities and their families to secure accommodation support that is appropriate to their needs.
- committed to a transparent process that safeguards the rights of people with disabilities including those with high needs and difficult circumstances.
- able to participate within a Committee framework to oversight the exploration process and make recommendations for management, including working with the Committee in a program of continuous improvement.

- clear of any potential or perceived conflict of interest and willing to sign a declaration accordingly.
- prepared to attend meetings at least once a month and be willing to serve a twelve-month term, are encouraged to apply.

The maximum tenure for members is two years, and renomination is available.

The Director of Disability ACT and a consumer representative will assess nominations against the above requirements.

If you are interested in self-nominating for the committee, please contact:  
Deborah Mesman,  
Committee Secretariat on 6205 5121 or [Deborah.Mesman@act.gov.au](mailto:Deborah.Mesman@act.gov.au) by 30 April.

ensuring the **rights of all clients** are **protected** and appropriate **processes** are followed

## **Contact details**

### **Disability ACT**

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GPO Box 158  
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Telephone 6207 1086  
[www.dhcs.act.gov.au](http://www.dhcs.act.gov.au)

### **Your mailing details**

Do we have your correct name and address details? Would you like an extra copy of the Newsletter? Do you want to stop receiving the newsletter?

Email: [disability@act.gov.au](mailto:disability@act.gov.au)