

# The Advocate



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**Advocacy for Inclusion**

**December 2012**

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## General Manager's Report

2012 has been an enormous year for Advocacy for Inclusion. At one stage we had eight staff working on a range on advocacy, projects, and training and our new small office was full.

It has also been a year of sadness. The team pulled together as we marked the deaths of the wonderful Roxy Le Cornu, and two of our consumers. We would like to thank the Critical Incident Stress Management (CISM) team who helped us through this really hard time. Their work is fully voluntary and should be better supported. They are genuine unsung heroes of the community sector.

This edition of the newsletter sees some reflections on our big year from across the team.

Karen summarises the enormous amount of work that the training team has put in. We were sad not to get ongoing funding to retain Libby Grant, but thank her enormously for the incredible amount of work she did to establish our training work for the future. Her departure has resulted in a reduction in our capacity to deliver training, but we have managed to continue our self-advocacy training with some donations and the fees from other workshops. Further donations are always welcome for this important work, and can be made through our website.

Jamelle summarises the individual advocacy work we have undertaken and identifies some key areas which remain perennial barriers for people with disabilities. Once again our funding has demanded a restructure of our advocacy capacity. This highlights the continuing strong demand for advocacy and the importance of advocacy being available as the NDIS is rolled out. The ACT remains one of only two Australian jurisdictions which does not fund individual advocacy for people with disabilities, so the

capacity of local advocacy organisations is substantially less than our interstate counterparts.

Ellen provides a short outline of the National Disability Insurance Scheme and how it might look (from information available so far). With a launch in the ACT from July 2013 the workload for everyone in the disability community has increased dramatically as we all contribute to getting the NDIS up and running in a way that will improve the lives of people with disabilities. As we end the year we are participating in a Disability Advocacy Network of Australia consultation process on the NDIS legislation which was tabled in Federal Parliament last week. This legislation contains the basic information on who will be eligible for the Scheme, what processes might be put in place, and how support is provided. It is a crucial time for input from the community.

Our policy work has grown substantially in the past year as various projects were undertaken. The major paper on Supported Decision Making was well received by advocates globally and has laid the ground work for further work on guardianship, the NDIS, and the implementation of the *Convention on the Rights of Persons with Disabilities*. Ellen is currently researching the level of choice and control available to people with disabilities in the lead up to the NDIS, drawing on the expertise of many of our consumers and students. We thank them for their valuable time.

Other current work includes a submission to the Senate Community Affairs Committee inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia. We are also part of the Mental Health (Treatment and Care) Act review advisory committee which is responding to community submissions on the exposure draft

prior to a second draft bill going back to the ACT Cabinet shortly.

Finally, we'd like to thank the volunteers who have assisted us at the Charity Christmas Card Shop: Robyn, Margaret, Jane and Jenni. Thank you so much for your contribution and enthusiasm.

We wish everyone a safe and happy Christmas and hope that 2013 is a good year for you.

Christina Ryan  
General Manager

## 2nd World Congress on Adult Guardianship

Several Advocacy for Inclusion staff attended this two day congress in Melbourne in October. We all enjoyed many interesting sessions, gaining further understanding of guardianship around the world, and the latest developments in Supported Decision Making.



Christina presented our paper 'Developing Supporting Self-advocacy Training – why and how'. You can read it here:

[Word](#) | [PDF](#)

### Highlights:

Jen Cousins from TAFE SA, who spoke about learning from teaching about guardianship. She asked a number of thought-provoking questions including "Who would you give all your decision making powers to?" She also stressed the importance to ensure that we "walk the talk" and our actions support what we are saying.

Justice Michael Kirby delivered the opening keynote address. He said "human rights matter most in practice when they are accorded under the hardest of circumstances". This was a good message to take away from the Congress and reminds us that our work is necessary even if it is sometimes unpopular.

[Oliver Lewis](#) from MDAC (**Mental Disability Advocacy Center**) shared the story of [Rusi Stanev](#), who was provided with a guardian without his knowledge, thus removing his right to make decisions about his life. After appearing before the European Court of Human Rights he was found not to need a guardian. He was also deemed to have been "detained" in an institution that his guardian had put him in.

MDAC's position is that plenary guardianship is oppressive, removes people's rights, and should be replaced by other processes. Oliver's full presentation can be found [here](#).

We were fortunate to hear from Professor Ron McCallum, who currently chairs the UN Committee on the Rights of Persons with Disabilities. Ron quoted the Committee's recent observations for Hungary "disability should not be the ground for incarceration", which reminds us that there is still a great deal of work to do in abolishing the segregation of people with disabilities.

Similarly, Ian McKinlay, a community guardian in the Northern Territory, spoke passionately about

the indefinite detention of Aboriginal Australians with disabilities. In remote areas Aboriginal people with disability are detained indefinitely for petty crimes as there are no supports available to them in the community. This lack of support results not only in a shockingly unjustified deprivation of liberty, but it has also resulted in terrible outcomes for these individuals and their communities. His speech highlighted how Aboriginal people with disabilities experience multiple and compounding layers of disadvantage, which can result in extreme marginalisation.

Sue Jarrad from Flinders University in South Australia, presented her interesting study on decision making for older people whose capacity is in question in the hospital. The six cases she looked at showed a very strong orientation towards a deficits based approach in the hospital, where patients were assumed not to have decision making capacity. She found that most attempts to consider the person's wishes were tokenistic or aimed at confirming professional opinion. She described some pockets of supported decision making approaches, which were undertaken by hospital workers who held more of a holistic 'world view', such as social workers. A major barrier to supported decision making practices was the fast pace of the hospital environment, wherein workers often did not take the time to seek the person's views and support them to active them.

Diane Chartres reported on [findings from her 2010 Churchill Fellowship](#) into Supported Decision Making and guardianship. She believes that a non-statutory (informal, no legislation) system of decision making supports would be far more effective than a formal system. She stated that decision making is a rite of passage as we become adults and that people with disabilities and their families should learn how to support this process.

Professor Bernadette McSherry from Victoria delivered a very interesting paper on capacity which considered legal capacity as a social construct, and as not the same as mental capacity. Perhaps we should remember this more often.

Jim Simpson from NSW Council for Intellectual Disability argued passionately for more inclusive tribunals. When someone is in the room as an active participant the proceedings have a different flavour as the focus is on them, not on other people and their interests.

It was terrific to catch up with Colleen Pearce, the Victorian Public Advocate, as we move towards the implementation of an ACT Official Visitor for people with disabilities from July 2013. Victoria has had a scheme for some time and Colleen had many useful tips.

The opportunity to meet and talk with people from around the world doing similar work and research was also invaluable.

Thanks to the Congress organisers and the ACT Government - Community Services Directorate (Disability ACT) for assisting us to attend.



### Individual Advocacy for 2012

It has been another busy year of people with disabilities contacting us with a diversity of issues they need advocacy support for. Many of the issues that people have needed our support with have been centred on the lack of opportunities and choices that are given to people with

disabilities. Some of the issues that we have been supporting people with include: right to parent, decision making and accommodation.

Many issues that we provide individual advocacy support for are also centred on people's rights not being adhered to as it is often not acknowledged that people with disabilities have the same rights as everyone else.

Accommodation issues remain one of our biggest issues. We still need better recognition that people with disabilities have the right to feel safe in their living environment, the right to have a choice in where they live and the right to choose who they live with. There needs to be greater awareness of the lack of accommodation choices available to people with disabilities. People are housed together in the anticipation that it will be successful. We have seen cases where this has not been successful and often ends up in a situation of violence as a result of distress and frustration.

Unfortunately one of our consumers passed away in June of this year. She had been inappropriately accommodated in an aged care facility. Even though we had been supporting her to find more appropriate accommodation, it was not thought as an urgent matter as she had accommodation and support where she was. There still needs a lot of work to get more appropriate accommodation and support options for people with disabilities, especially as they age and their parents age. Aged care facilities are definitely not the answer nor are they an appropriate form of accommodation for a younger person with disabilities.

Despite this there have been a couple of gold star moments with two young men finding appropriate accommodation. However it did take a couple of years work with one of the young men to have his accommodation issue resolved.

We have also been working with people who have been living in an institutional type of residency and they have spoken up about no longer wanting to live in that environment. They are now being quite involved in making decisions on where they want to live, who they want to live and how they live. It has been a lengthy process, but for them to be involved in planning all aspects of their future accommodation and support is exciting.

Another gold star moment includes the restoration of a mother's children. It has been a long battle for the mother with Care and Protection pushing for 18 year orders for the children as the mother was deemed unfit to parent due to her disability. Now with a new case worker and appropriate supports in place, a restoration plan is underway with the oldest child to be fully restored by mid-January.

Red Tape and bureaucracy can make a simple decision, which many people take for granted, into a long hard battle for many people with disabilities who are only trying to have their voices heard, rights acknowledged and to live with the freedom of making personal choices about their lives. This can also see a push by some services to ensure that the person they are supporting has a guardian. We have seen this being implemented when the person is being 'non-compliant about something the service is requesting. We have been working with consumers in this situation to be supported in a decision making framework, according to their wishes, rather than under a guardianship order. This is their right under the *United Nations Convention on the Rights of Persons with Disabilities*.

2012 has been a very busy year which highlights the importance and need for individual advocacy. I would also like to take this opportunity to thank

my team for their ongoing support over the past 12 months.

Jamelle Boettcher  
Advocate



### New on our Website

We recently added the following to our website:

- Presentation to the World Congress on Guardianship – Melbourne, October 2012
- Developing Supporting Self-advocacy Training – why and how  
[Word](#) | [PDF](#)
- Advocacy for Inclusion Submission to NDIS Eligibility - September 2012  
[Word](#) | [PDF](#)
- Advocacy for Inclusion submission to ACT Mental Health Act - Draft Submission - September 2012  
[Word](#) | [PDF](#)

*Media –*

- [Call for Review of Guardian Laws](#)  
[A Plea to Live a Free and Independent Life](#)  
Canberra Times, September 17, 2012

### Charity Christmas Card Shop

The card shop is on again and Advocacy for Inclusion is joining in.

If you would like to buy your cards from us in person then drop by to the foyer of the City Uniting Church Pilgrim House, 69 Northbourne Avenue, from 29 October to 13 December 2012. The shop is open Monday to Friday from 10 am to 4 pm.

Our beautiful new cards will be on sale, plus some limited stocks of our earlier card “In my thoughts I have many friends”.

The Charity Card Shop has about 16 organisations participating so there is plenty to choose from. We’d love to see you there

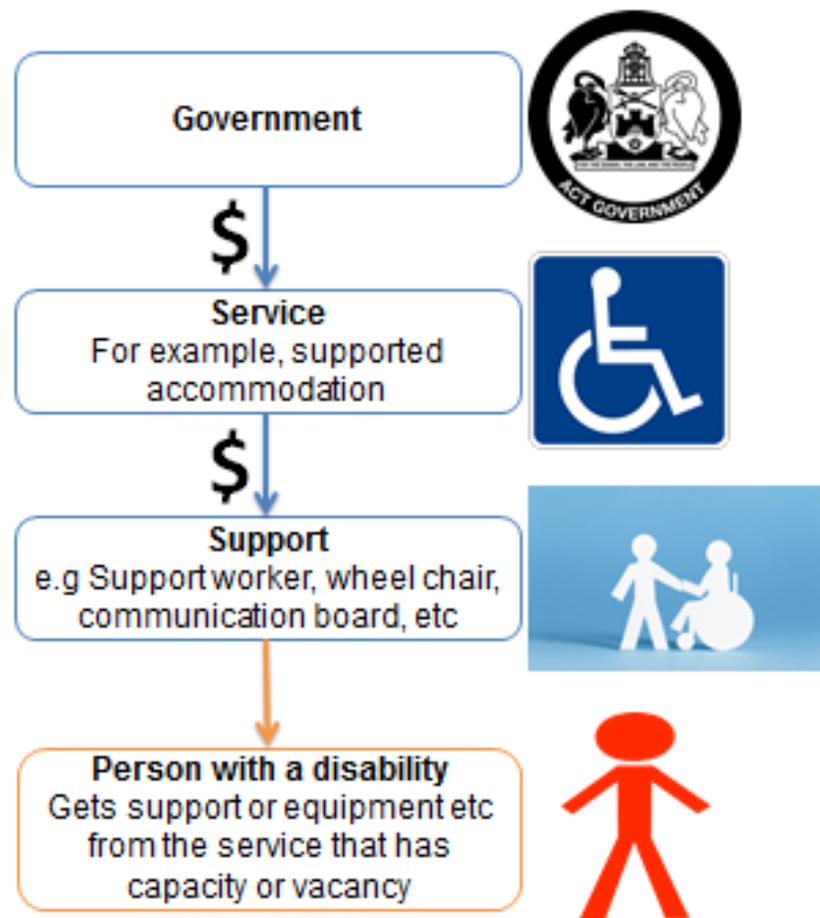
## Looking forward to 2013 – the NDIS begins in July next year!

The National Disability Insurance Scheme (NDIS) is a new way of funding support for people with disabilities. Many people with disabilities get help by paid support workers or equipment such as a wheelchair. A lot of this support is paid for by government money.

Most of the time, this government money goes straight to a service. Then the service uses that money to pay for support for a person with disability. For example, the service might pay a support worker to help someone shower or make dinner.

This diagram shows what happens with the funding (money \$) at the moment.

### Current funding system

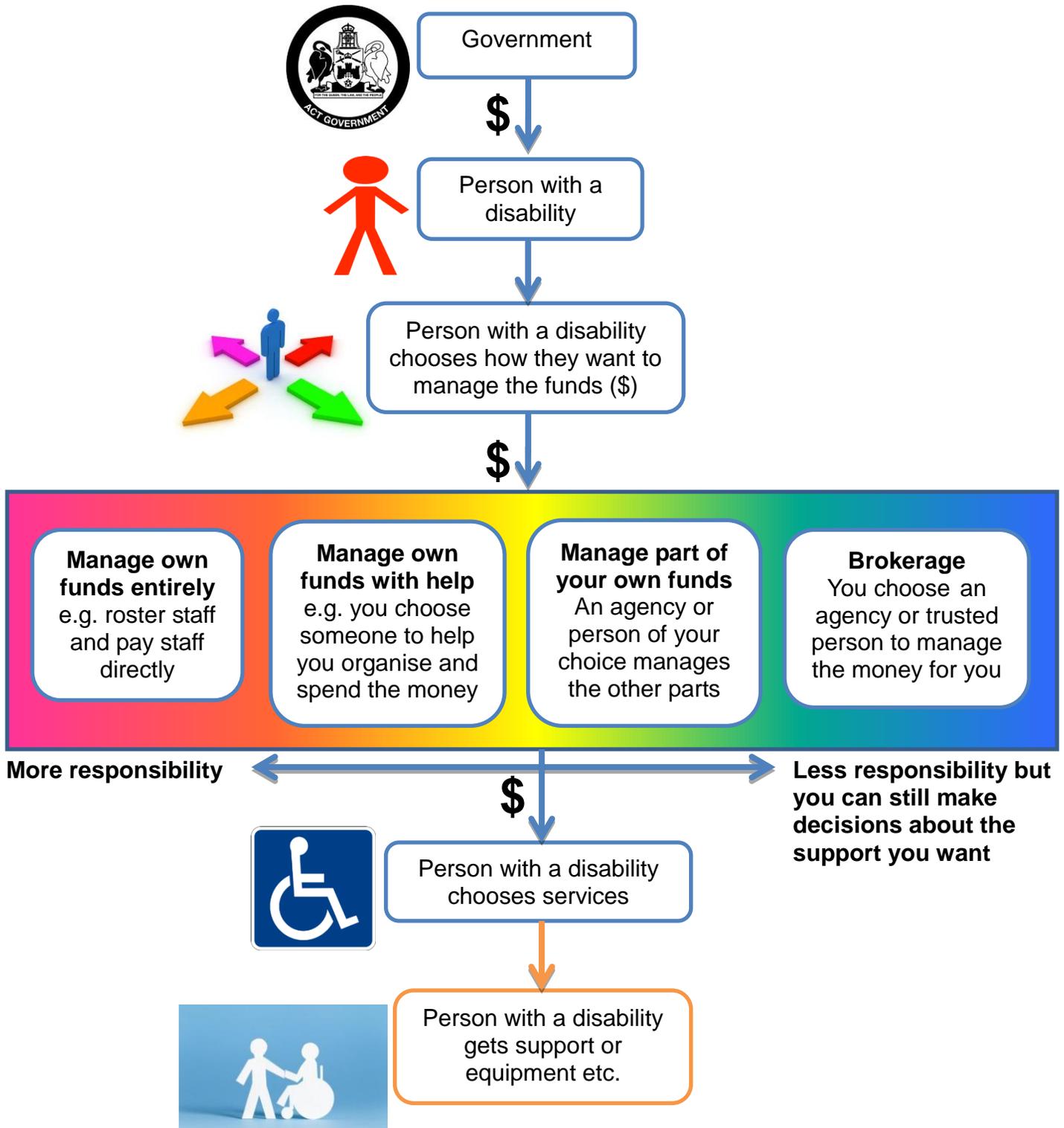


The Productivity Commission talked to people with disabilities and carers. They found out that this system is unfair. People with disabilities often do not get the support that they need and want.

With the new NDIS people with disabilities should be able to choose how much control they want over their support, and what services they want to use. People should have the option to direct their own

funding (\$) if they want to. This is called 'self-directed funding'. The Productivity Commission said that the new system should look something like this diagram.

### How the new funding system might look



Many people with disabilities may want their current supports and arrangements to stay the same. Many others will want to change it some or a lot. These are the choices that people with disabilities can make. People who self-direct their funds will have the maximum level of control over who or what supports them, where, when and how.

Not all people with disabilities will have the option to direct their own funding. This option is targeted at people with higher disability support needs. People with lower support needs will still get support.

No one is exactly sure yet how the new NDIS will work. It is aimed at giving people with disabilities more control over their support and their lives.

This year Advocacy for Inclusion began our research project to help the ACT prepare for the NDIS. It is called *Preparing people with disabilities for the NDIS – Research project*. \* We want to help make sure that people with disabilities do get more choice and control when the NDIS comes.

We are talking to people with disabilities to find out how much choice and control they have now, and what supports people will need to exercise their choices and control with the new system. I will finish the interviews in early December 2012. A report with the recommendations from this research will be released early next year.

Thank you to all of the people who participated in our study ☺

Ellen Read  
Policy Officer

**\*Preparing people with disabilities for the NDIS – Research project was made possible with assistance from the ACT Government under the ACT Disability Grant Program.**

### Annual General Meeting New Board

Advocacy for Inclusion held its Annual General Meeting on 13 November 2012. Our new Board is:

Jane Thomson - Chair  
Vincent McCormick - Deputy Chair  
Melissa Guilfoyle - Treasurer  
Ian Tunstall - Member  
Liam Waldron - Member  
Jenni Vincent - Member  
John Koulouris - Member  
Luke Power - Member



Twitter



Advocacy for Inclusion is now on Twitter. Why not follow us at @adv4inclusion to keep up with our day to day activities and thoughts?

## In-House Training

Let us come to you and train your team or consumers! Workshops available include:

- Inclusion & Awareness
- Access all Services – women's services
- Supporting Self-advocacy
- Self-advocacy
- Nutrition & Self-advocacy

For further information see the training page of our website, or email us at [training@advocacyforinclusion.org](mailto:training@advocacyforinclusion.org)

## Training Report

The past year has been a very exciting one for training at Advocacy for Inclusion. We have completed our Nutrition and Self-advocacy project, developed and run new courses, all with extremely positive feedback.

### Nutrition and Self-advocacy Project

Completed in June 2012, the wrap-up of this project included:

- The final **Nutrition and Self-advocacy course**, January to March 2012
- The second and third **Supporting Self-advocacy** workshops, February and June 2012
- Being selected to showcase our project at our Health Promotion Grants Celebration Forum held August 2012

### Other Training:

The development of a **Women's Self-advocacy course** led to 2 courses running back to back from April to June and again in July to September.

A **Nutrition and Self-advocacy** short course ran during November with participants learning more about healthy living and speaking up for themselves.

**Supporting Self-advocacy workshops** are proving popular as in-house on demand training with local organisations booking us to run training in September and October.

**Inclusion and Awareness Training for Women's Services** workshops ran in March and May to participants from various women's services in the local area. The June workshop was presented as an in-house workshop for DVCS staff. This project was auspiced by the Women's Centre for Health Matters and the manual is available to download free on our website in the Publications > Resources section.

### Other achievements:

Our **Human Rights** project was completed in the first half of 2012, resulting in several human rights-focused self-advocacy training packages which will be rolled out next year.

The **Self-advocacy Group** (Peer Network) continued, with a core group attending. This group is for those who've completed a self-advocacy course and builds on the knowledge and skills gained.

During 2012 we successfully continued to offer **in-house on demand training** for organisations. All of our training is available in-house at very reasonable fees.

Advocacy for Inclusion was selected to present a paper at the **2nd World Congress on Adult Guardianship** in Melbourne, in October. The paper we presented was 'Developing Supporting Self-advocacy Training – why and how'. You can read it on our website.

### Acknowledgements

With thanks to the following for funding / donations to support our training:

- Disability ACT, ACT Government - Community Services Directorate
- Narrangullen Pty Ltd
- Australian Government – Attorney-General's Department
- Health Promotions, ACT Government – Health Directorate

We also thank:

- The Mental Health Community Coalition for the generous use of their meeting room to run some of our courses and groups
- Nutrition Australia and Holy Cross Lutheran Church Belconnen for their support and hire of their kitchen and rooms
- Project Officers Susan Abbott and Kate Stevens
- Women's Centre for Health Matters and the women's services network

Guest speakers from:

- A Spark of Splendour
- ACT Human Rights Commission
- ACT Legislative Assembly
- Diabetes ACT
- Elections ACT
- Local Area Coordination, Woden Community Service
- NICAN
- PATH, Belconnen Community Service
- SHFPACT (Sexual Health and Family Planning ACT)
- WWDACT (Women with Disabilities ACT)

We miss Libby Grant who was a valuable team member for most of the year, and **Roxy Le Cornu** (1988 – 2012) for her ideas, support and friendship

### Training Update Emails

Keep up to date with:

- ✓ Our training – new and upcoming
- ✓ The latest news in self-advocacy

Subscribe to our monthly updates by visiting the training page of our website, or email us at [training@advocacyforinclusion.org](mailto:training@advocacyforinclusion.org)



### Funding Acknowledgement

Advocacy for Inclusion is currently funded by the:

- *Australian Government Department of Families, Housing, Community Services and Indigenous Affairs*
- *the ACT Government – Community Services Directorate (Disability ACT)*

### Make A Donation

Advocacy for Inclusion is a registered charity. All donations over \$2 are tax deductible.

*We welcome your support.*

All donations support our self-advocacy training for people with disabilities. You will help to buy materials, ensure accessible venues are used, or assist with interpreters or other supports.

All donations directly empower people with disabilities.

To make a donation, please fill in the Order Form and return it to us.

If you would like to make a donation to Advocacy for Inclusion please use the form at the back of this newsletter. All donations over \$2.00 are tax deductible. You can also donate to us via the Hands Across Canberra website at <http://handsacrosscanberra.org.au/give/browse/?id=64>

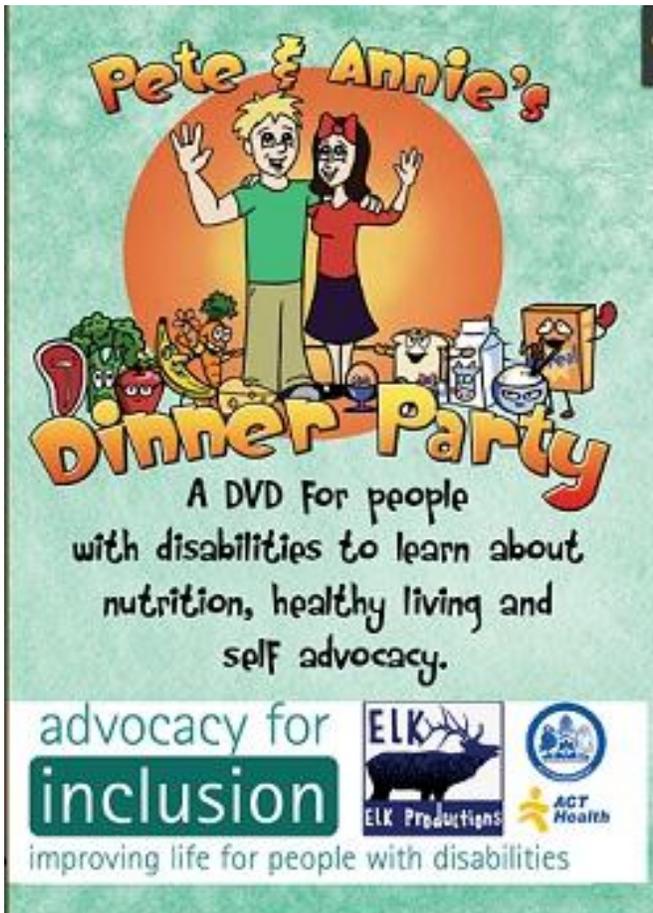
## Pete & Annie's Dinner Party

Our DVD introduces the basics of nutrition, healthy living and self-advocacy and is available for sale now. The DVD includes seven short episodes and a documentary featuring self-advocacy graduates, it is ideal as an introduction to, or to reinforce these essential concepts.

Cost:

\$ 55 - for individuals

\$55+ \$5 P&H for more than one copy and/or organisations



## Order Form:

Product	No. of items	Ea	Total Cost
Andrew Delaney Cards Pack of 10		\$10	
Free Poster – 1 per order with any other item purchased.			
Andrew Delaney – “In my thoughts, I have many friends”			
‘Stars’ Cards. Pack of 10 - Two of each card in a pack		\$10	
DVD – Pete & Annie’s Dinner party		\$55	
Postage & Handling for DVD		\$5	
Donations			
Total			
Your Name:			
Your Address:			

Please make your cheque or money order payable to Advocacy for Inclusion Inc.

Advocacy for Inclusion  
 Suite 2.02, 20 Genge Street,  
 Canberra ACT 2601

## Order your Advocacy for Inclusion cards today!!!

**“like the stars, we are all the same from a distance”**

The Inclusion Art Competition invited artists with disabilities to depict their concept of inclusion. This beautiful new set is based on a themed set of artworks by artists at the Hands On Studio. They are ideal for Christmas cards, or any occasion when you want to send a message of inclusion.

The cards are high quality gloss, post office-preferred size and available in Sets of 10 with envelopes – two copies of each design per set.



**“In my thoughts I have many friends”**

**Artist Andrew Delaney**

Andrew grew up watching his Grandfather doing art and has always wanted to have a go. He has been doing art classes at Hands on Studio since October 2009 and loves to paint; in particular he loves to paint tractors and farms.

**\$10 per pack of 10 cards**

All cards are Post Office preferred size.



## MEMBER APPLICATION FORM

Name

Address

Post Code

Phone

Email

Contact Person (Organisations only)



Full Membership



Associate  
Membership



Please tick if you have a disability (free membership)

To become a member, please fill in this form and return it to the address below.

*Please make your donation, cheque or money order payable to  
Advocacy for Inclusion Inc.*

**Advocacy for Inclusion  
2.02/20 Genge Street  
Canberra City ACT 2601**

### Membership includes:

- Quarterly newsletter
- Policy consultation on key issues
- Representative opportunities
- Connection with local and national networks
- Right to nominate for our Board
- Membership rates for training

### Membership Categories:

- *Full Membership - Individuals*
  - \$10
  - Free for people with disability
- *Associate Membership - Organisations*
  - \$25