



The Advocate

Advocacy for Inclusion

December 2011

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General Manager's Report

Christina Ryan

This issue we look at self-determination, self-advocacy and supported decision making. These related areas are the new frontier for people with disabilities as they work towards greater control over their lives and their direction.

Karen provides insights into self-determination and its relationship to mental health and wellbeing. She also gives an update on the Nutrition Project and recent training. Our advocates have a very different experience of

self-determination and explain how the lack of it creates the need for advocacy support. We also look at the latest expectations from the United Nations about supported decision making.

Advocacy for Inclusion is part of preparations for the National Disability Advocacy Conference to be held in Canberra 30 April & 1 May 2012. Anyone with an interest in disability advocacy and the rights of people with disabilities is encouraged to attend. For more information see the DANA website at www.dana.org.au.

We have also been a part of national discussions on the implementation of the

National Disability Insurance Scheme and consultations with disability representative and advocacy organisations.

Our small team is growing as we roll out new projects in human rights education and self-advocacy. We welcome three new members to the team: Libby Grant (training support officer), Tehmi Mukadam (administration and communications officer), and Kate Stevens (human rights project officer). Our new office is filling rapidly. We farewelled Leko McCulloch in October and wish her all the best for the future.

The training work of Advocacy for Inclusion is growing. Our new training calendar appears later in this newsletter, with specialist training for women's services workers and supported accommodation workers, plus more self-advocacy courses.

It's been an enormous year for our small, but growing, organisation. Advocacy for Inclusion is settling well into our new office in the Griffin Centre. We had a wonderful AGM on 17 November with an official office opening and ribbon cutting. New board members have also been elected. Many thanks to Marcia Williams and Sue Carbone who stepped down from the Board at the AGM. A full report and photos are later in this newsletter.

The AGM also gave us the opportunity to award life membership to Ann Proctor, one of the founding members of Advocacy for Inclusion. Ann has contributed so much over the years and continues to advocate for a more inclusive community for people with disabilities. Our first Executive Officer, Liz Blakey, presented Ann with her certificate. Ann is a very worthy recipient of our inaugural life membership – congratulations Ann!

Our thanks over recent months are many, but special mention must be made of Genevieve Jacobs for MC duties at the AGM, Jon White for his superb returning officer skills, the Mental Health Consumer Network for serious support for our AGM, the Mental Health Community Coalition for their support, and our

partners for the women's services training – Women's Centre for Health Matters and Women with Disabilities ACT.

Finally, we wish you all a fabulous Christmas and look forward to working with you again in 2012.



The move to supported decision making

Christina Ryan

The *Convention on the Rights of Persons with Disabilities* (CRPD) carries an expectation that people with disabilities will be afforded the same “respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons” (CRPD article 3).

Alongside this expectation is the obligation of countries that have ratified the Convention (including Australia) to support people with disabilities to exercise these rights and to adjust legal frameworks to ensure the CRPD becomes reality.

Australia, and the ACT, work within a system of substitute decision making. In other words: guardianship. This is a system which assumes that a person with disability is unable to, or cannot be trusted to, make their own decisions and someone else must do it for them.

In the experience of Advocacy for Inclusion many ACT guardianship orders are currently “plenary” orders, or full orders. This means that the guardian has full substitute decision making over the person with disability for all aspects of their life. These arrangements can

be in place for 40 or 50 years throughout the adult life of the person under the order.

Additionally, in our experience, many people with disabilities may not require such guardianship orders but could be served by limited orders covering specific issues or aspects (for example, legal or financial matters), alongside mechanisms to support their other decision making.

Recently the UN Committee which oversees the CRPD examined how Spain is implementing the Convention and provided Concluding Observations recommending a way forward. A significant statement within those Observations was:

“that the State party review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to **replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences.** It further recommends that training be provided on this issue to all relevant public officials and other stakeholders.” (para 34, *CRPD Concluding Observations Spain* – September 2011.)

These Observations provide clear guidance on how to interpret the CRPD. They also are clear on how to implement the Convention.

Advocacy for people with disabilities is part of supported decision making frameworks. Providing mechanisms which ensure the voice of people with disabilities is their own, and supporting people to make decisions are core features of disability advocacy.

Moving towards a community where supported decision making is the daily experience of people with disabilities will take time, training, and commitment, but there is an expectation on Australia to do this as we implement our obligations under the *Convention on the Rights of Persons with Disabilities*.

The Importance of Self Advocacy Training for the Health and Wellbeing of People with Disabilities

Karen Hedley

... *self-advocacy* ... *self-determination* ...
supported decision making...

The ability to develop and utilise these concepts are proven to have a positive impact on the lives of people with disabilities.

People with disabilities do not pick these skills up by observation alone, and are not provided with planned opportunities to learn and develop them. Many Advocacy for Inclusion consumers have not been given the chance to make day to day decisions in their lives, let alone important, life-changing decisions.

With the international move away from substitute decision making¹ towards supported decision making, as recommended by the UN *Committee on the Rights of Persons with Disabilities*², and the National Disability Insurance Scheme (NDIS) likely to be implemented shortly, it is essential that people with disabilities are able to learn and practice self-advocacy and self-determination.

Self-advocacy training does not only lead to improved decision making skills. Increased self-advocacy skills and levels of self-determination result in:

¹ Substitute decision making is when a person’s decisions are made by another, usually a guardian, often a support worker.

² United Nations Committee on the Rights of Persons with Disabilities (2011), *Concluding observations of the Committee on the Rights of Persons with Disabilities: Spain*
http://www.ohchr.org/Documents/HRBodies/CRPD/6th_session/CRPD.C.ESP.CO.1_en.doc

- “Greater control & responsibility over life”³
- Greater academic success
- People more likely to achieve goals
- Better mental health and general health⁴
- Higher levels of pay⁵
- Increased levels of employment
- Increased levels of independent community living^{6,7},
- People who can set career goals
- People who can problem solve successfully at work
- People who can advocate for better job conditions and the support they need⁸
- The need for “less supervision
- Increased trust and respect between self-advocates and staff
- More satisfying work for staff”⁹

The health and wellbeing of people with disabilities is directly related to their ability to use self-determination skills, and experience autonomy. “...When humans feel their psychological needs are being supported this has been associated with better mental health

³ Cooper, Carmel (2009). *Productive Pathways: Students with disabilities*

⁴ Ryan, Richard M, Patrick, Heather, Deci, Edward L, Williams, Geoffrey C. (no date, accessed August 2011) *Facilitating health behaviour change and its maintenance: Interventions based on Self-Determination Theory. The European Health Psychologist, Volume 10 March 2008*

⁵ Field, Sharon (2005). *Self-Determination: What Is It? Why Is It Beneficial? How Is It Best Taught?* Michigan Department of Education, Office of Special Education and Early Intervention Services, *Focus on Results*

⁶ American Psychological Association (APA) (2004, accessed June 2011). *Increasing student success through instruction in self-determination*

<http://www.apa.org/research/action/success.aspx>

⁷ Field, Sharon

⁸ Wehmeyer, Michael L. (no date) *Self Determination, Transition and Employment Supports*
<http://www.ed.uiuc.edu/illinoisrcep/activities/ppt/selfdeterwehmeyer.ppt>

⁹ People First of Minnesota (April 25, 2009) *Self Advocacy and Direct Care Professionals*
<http://ici.umn.edu/para/New/pdf/Selfadvanddircare.pdf>

(less depressive symptoms, anxiety, and somatization), greater quality of life, and better health-related outcomes, such as greater intake of fruits and vegetables, reductions in smoking, better glycaemic control for patients with diabetes, more physical activity...”¹⁰

According to the Australian Institute of Health & Welfare¹¹ people with disabilities report far higher levels of mental health problems, higher rates of long-term health conditions, and lower rates of general health than people without disability. Those with “severe or profound disability”¹² fare worse than others.

People with disabilities are “more likely to do a very low level of exercise or no exercise (43% versus 31%); to be current daily smokers (31% versus 22%)...” Around 69% of adults with disabilities are overweight or obese, compared to 58% of the general population.¹³

It is clear that the health and wellbeing of people with disabilities is of great concern, and while there are no doubt other issues to tackle, it is clear that learning and practicing self-determination skills is essential for any positive change to occur.

Many people with disabilities require ongoing education and opportunities to practice new skills, self-advocacy included. Self-advocacy courses are extremely important in order to learn essential new skills. Advocacy for Inclusion provides self-advocacy courses to people with disabilities at no charge to them. Courses include topics proven to strengthen self-determination skills, including:

- Social skills
- anger management
- relaxation
- stress management

¹⁰ Ryan, Richard M et al

¹¹ Australian Institute of Health and Welfare (AIHW) (2010) *Health of Australians with disability: health status and risk factors*

¹² AIHW

¹³ AIHW

- and assertiveness training¹⁴
- increasing self-awareness
- decision-making, goal-setting skills
- communication and relationship skills¹⁵

Equally important are opportunities to discuss and practice these with peers, and knowing that those people around you will support these new found skills – hence Advocacy for Inclusion is also providing:

- Our new peer network, for self-advocacy course graduates
- Supporting Self-advocacy courses for support workers and community workers to learn strategies to create a supportive environment within which self-advocacy and self-determination can be practiced.

Self Determination in our Advocacy Practice

Ellen Read
Janelle Boettcher

A central part of the advocates' jobs at Advocacy for Inclusion is supporting consumers' self-determination, which is a basic human right. All of our consumers experience day-to-day barriers to achieving self-determination. These barriers are mostly to do with societal and service provision issues rather than the individual's disability. Here are some examples:

Sally lives in supported accommodation. Last week a house mate moved in with her. Sally was told by the service provider that she was getting a new house mate, not asked.

Basim likes to get out in the community to see his friends spontaneously at the weekends. To do this he requires an accessible bus.

¹⁴ Disability SA, Department for Families and Communities (2008). *Intellectual disability and mental illness (dual disability)*

¹⁵ APA

Accessible buses don't go past his stop very often.

Kara is unhappy in her current employment. It doesn't suit her personality. She needs some assistance with job seeking but her current employment agency will not assist her because she is already employed.

Roya can't enjoy a glass of wine at home because the rules in her supported accommodation home won't allow her. She did not set the rules.

Tom is often asked by service providers "who is your guardian? Who makes decisions for you?" Tom doesn't have a guardian. He makes his own decisions.

Claudia just had a baby. She is offered monitoring rather than support by the services around her. They keep a very close eye on her because she has a disability. Many of the people around her were disapproving from the start instead of excited and happy for her.

Experiences such as these prevent a person from having self-determination from the simplest day-to-day activities to major life decisions. Other members of the community might never experience the scenarios such as the ones above. However, many of our consumers experience this every day.

A major factor involved in having self-determination is speaking up and being heard. Our consumers are often not listened to and are not encouraged to speak up in the community. It is commonly assumed that because the individual has a disability, someone other than the individual will know better. At Advocacy for Inclusion we support people to achieve self-determination first and foremost by listening to what the individual wants. We encourage them to voice and act on their wishes. When the person is supported to do so, it is amazing what they can achieve. We all have the right to self-determination, disability or no disability.



Nutrition Course Report

Karen Hedley

The Nutrition and Self-advocacy courses have now finished for this year.

In our third course we had 4 participants and feedback was very positive. We talked a lot about rights and how to deal with problems. We made wonderful food like Asian Noodle Salad, Pita Pizzas and Noodles with Tofu and Vegetables.



Course 4 was fully booked but unfortunately only 2 of those interested have been able to attend. It is often difficult for people to get to the course without the support of those around them.

Our 2 participants have been enjoying the course and we have been focusing on creating healthier versions of their favourite foods. Spaghetti Bolognese, fish and chips and chicken nuggets have been on the menu. We have had some fabulous guest speakers as the highlight of this course.

Course 3 was run from the fabulous Nutrition Australia kitchen at the Chifley Health and Wellbeing Hub, and we'd like to thank Lyn and the team for all their support during the courses. Course 4 has been held in the Holy Cross Lutheran Church in Belconnen and thanks go out to them for making the venue available for our use.

We'd also like to thank our guest speakers Jane Thomson and Kelly Swan from the ACT Human Rights Commission, and Prue Spence from the Australian Red Cross.

Nutrition Courses We want you!

Do you:

- Want to learn more about speaking up for yourself?
- Want to learn more about eating healthy food?
- Want to learn more about taking care of yourself?
- Want to learn more about cooking fantastic meals and snacks?
- Have disability and live in supported accommodation?

If so then we want you to come along to our **Nutrition & Self-advocacy Course!!**

We have one more course planned for early next year. The location will depend on where the people are who want to do the course so if you are interested please put your name down as soon as you can and we can get planning!

Each course is for 4 - 6 people, and runs for 8 weeks. If you require support to attend you will need to provide your own, but please contact us if you are having trouble finding someone to support you, we may be able to help.



Topics covered in the course will include:

- What is self-advocacy?
- What is nutrition?
- Eating healthily
- Exercise & being active
- Reading nutrition labels
- Human rights
- Hygiene & kitchen safety
- Assertiveness & respect
- Meal planning
- Shopping & saving
- Making decisions & goal setting

Workshops include the chance to cook, and to learn basic cooking and kitchen skills, but are not cooking courses. There will be lots of other things to learn and talk about, to help people become stronger self-advocates.

Courses are supported by the ACT Government under the ACT Health Promotion Grants Program.

Feedback from our courses:

The best thing about the course was:

“learning how to cook healthier”

“all the information and presentation”

“eating the prepared food”

“making friends”

“feeling good about myself and advocacy skills”

“I really enjoyed the group & sad it’s finished”

“Thanks for teaching us about eating healthy, you’re the best teacher in the whole of Canberra”

If you are interested in finding out more about the workshops, or putting your name down to do one, please:

Check our website

www.advocacyforinclusion.org

Email Libby: libby@advocacyforinclusion.org

or call Libby on 6257 4005.

Supporting Self Advocacy Courses for Community & Support Workers

Karen Hedley

Are you working with people with disabilities living in supported accommodation? This course is designed to give you the skills and knowledge to support people to become stronger self-advocates.

In this course you will learn about:

- Advocacy and self-advocacy
- Human rights for people with disabilities
- Balancing duty of care, dignity of risk and supporting self-advocacy
- Strategies to assist people practice self-advocacy skills
- Healthy eating & exercise overview
- Local resources & information

Courses are planned for 14 February and 19 April 2012 and are supported by the ACT Government under the ACT Health Promotion Grants Program.

Feedback from our first Supporting Self-advocacy course:

"I found the session really informative"

"Presenter was clear and easy to talk to"

"As new in this disability field, this training is very informative & useful"

"Presenter provided opportunities for questions and sharing ideas"

"Some areas I felt touched on subjects that were already well known to me, but they were addressed well and would be good for people new to the industry"

Please give Libby a call on 6257 4005 for further information or complete the registration form on our website <http://www.advocacyforinclusion.org> to put your name on the list.

Annual General Meeting

On 17 November 2011 Advocacy for Inclusion held our Annual General Meeting.

This was an opportunity to officially open our new office in the Griffin Centre, and to launch the DVD "Pete and Annie's Dinner Party" which is a self-advocacy tool made as part of our Nutrition Project.

We also took the opportunity to award Ann Proctor with the first life membership of Advocacy for Inclusion in recognition of her enormous contribution and support over many years.

The Board elected at the AGM is:

- Dwayne Cranfield – Chair
- Vincent McCormick – Deputy Chair
- Melissa Guilfoyle – Treasurer
- Ian Tunstall
- Liam Waldron
- Jane Thomson

Jenni Vincent nominated from the floor and was co-opted to the Board at its first meeting on 5 December 2011.

Particular thanks to Marcia Williams (former chair) and Sue Carbone who stepped down from the Board at the AGM.

Thank you to everyone who made the AGM a special event including: Genevieve Jacobs from ABC Canberra, Jon White DPP our returning officer, the ACT Mental Health Consumer Network, and Liz Blakey.



Ann Proctor receiving Life Membership



Cutting the ribbon for the new Griffin Centre office, L to R: Vincent McCormick, Ann Proctor, Genevieve Jacobs

Recent publications and submissions

- ACT Disability Advocacy Network submission to the ACT Legislative Assembly inquiry into social housing
- AFI/ADACAS submission to the ACAT Ruling Tribunal

If you would like a copy of any of our publications or submissions, please email info@advocacyforinclusion.org

Training Calendar for January - June 2012

Nutrition and Self-Advocacy for people with disabilities
8 week course
January to March 2012

Supporting Self-Advocacy for supported accommodation and community workers
Full day
14 February or
19 April 2012

Self-Advocacy for Women for women with disabilities
8 week course
May to June 2012

Inclusion and Awareness Training for Women's Services for women's services workers
Full day
16 February or
27 March or
18 May 2012

To register for any of these courses and workshops please go to our website www.advocacyforinclusion.org to download a registration form and then send the completed form to libby@advocacyforinclusion.org or fax to 6257 4006.

New Peer Network

If you have completed one of our self-advocacy courses then you may like to think about joining our new peer network.

The network is a space to practice becoming a stronger self-advocate and to meet with other self-advocates and work together to make sure you have the same rights, choices, and opportunities as anyone else.

The network meets in the Griffin Centre once a month on a Thursday afternoon, however these times may change in 2012. If you are interested or have any questions please call Libby on 62574005.



Administration and Communications Officer

Hello. I am Tehmi, and I started my new position as Administration & Communications Officer in November 2011. I have been in many fields of work – I started my career as a Personal Assistant and moved up to Administrative Services work. After 21 years in the Australian Public Service, I decided to embark on a career as a Real Estate Agent. More than six years later I have gone back to my first love – Administrative work. So here I am working for Advocacy for Inclusion and loving every minute of it.

No doubt I will be meeting or speaking to you soon. Till then, take care and have a safe holiday time.

Training Support Officer

Hi, I'm Libby and I am the new training support officer. Before starting at Advocacy for

Inclusion in September I worked in a government agency responsible for producing information about people with disabilities in Australia. I also have experience working in a variety of programs at another community organisation in Canberra. I really enjoy working with different people in the community, and am looking forward to the new things that I will learn as I get more involved with the training that Advocacy for Inclusion offers!

Project Officer: My Life, My Rights!

Hi, my name is Kate and I will be working on the "My Life, My Rights!" project at Advocacy for Inclusion. This work will involve developing self-advocacy training with a specific focus on human rights.

I have just moved back to Canberra from Melbourne and will start postgrad study at ANU in 2012. Most recently I have worked in women's health, development and as a Disability Support Worker.

I'm really excited to be working on this project and to be a part of the Advocacy for Inclusion team!

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*
- *the ACT Government under the ACT Health Promotion Grants Program; and*
- *Australian Government Attorney-General's Department*

Order your Advocacy for Inclusion cards today!!!



“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.

To order yours today, please fill in this form and return it to the address below.

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

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Suite 2.02, 20 Genge Street,
Canberra ACT 2601

Name _____

Address _____

Post Code _____

Number of packs _____ x \$10.00
per pack = \$ _____ Total Due



MAKE A DONATION

Advocacy for Inclusion is now 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 this form and return it to the address below.

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

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MEMBER APPLICATION FORM

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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