

*family*

A D V O C A C Y



## ANNUAL REPORT 2009-2010



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## **Family Advocacy**

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# Our Vision

Family Advocacy has a vision of families being agents of positive social change so that the inherent value of people with developmental disability is recognised within a just and inclusive society.

# Our Mission

Our Mission is to attain positive social roles for people who have a developmental disability through the development and support of advocacy by families and by strengthening the knowledge, role and influence of the family.

# Advocacy is....

Advocacy is speaking, acting and/or writing with minimum conflict of interest on behalf of the sincerely perceived interest of a person or persons with disability in order to promote, protect and defend their interests, rights and needs.

Advocacy strives to be emphatic and vigorous and is, or is very likely to be, costly to the advocate.

This definition of advocacy has been adapted from the original Wolfensberger definition so as to make it specific to social advocacy with, and for, people with disability.

# Who we are

Family Advocacy is an independent, state-wide, community-based advocacy organisation which promotes and protects the rights, needs and interests of children and adults with developmental disability.

Family Advocacy bases its work on the belief that:

- > All people with disability are full members of the community;
- > Good communities are made up of a diverse range of people;
- > People who have a disability have contributions and skills to bring to society.

The organisation recognises that society has, as a matter of public policy, segregated people with disability from the mainstream of society. It recognises the extreme harm caused to people with disability and their families by segregationist policies, and supports the policies embodied in the *Objects and Principles of the Commonwealth Disability Services Act, 1986*, and the *Objects, Principles and Applications of Principles of the NSW Disability Services Act, 1993*. Regulatory processes designed to ensure that direct services adhere to these Principles are also critical.

## OUR PRINCIPLES

### Principles about People:

- > All people, regardless of gender, age, disability, ethnicity, sexuality or religion, have the same human, social and legal rights.
- > People who have a disability are contributing members of the whole community.
- > All people, regardless of the nature and degree of disability, have the capacity to learn and develop throughout their lives.
- > People who have a disability are vulnerable to oppression, exploitation, discrimination, segregation and rejection by society.

### Principles about Families:

Except for advocacy by individuals who themselves have a disability, advocacy by families constitutes the single most important safeguard to protecting and promoting the rights and interests of people who have a disability.

The family is likely to be the most enduring and constant form of relationship in a person's life and, as such, is the first line of defence of the interests of a person who has a disability.

The family provides the most natural and powerful environment for growth and development.

The family is the focus for the development of a range of relationships which lead to inclusion in the life of the community.

While the nature of family relationships changes as a person grows, for all adults, the family continues to act as an important emotional and strategic link into the community.

Positive growth and development is most likely to occur within a family in which each member is esteemed as valued.

### Principles about the Community:

Strengthening individual natural and informal relationships is the most powerful way to maintain, develop, or enhance the inclusion of people who have a disability in the community.

## OBJECTS

In carrying out its Mission, Family Advocacy recognises that families often find it difficult to affect ways in which they or their family member with a disability can be supported within the context of family and community. This is because of:

- > lack of information about alternatives to what's on offer;
- > isolation, vulnerability, extra pressures and financial costs;
- > lack of opportunities for community members to get to know and value individuals who have a disability;
- > diminished expectations by family about its role and influence in the life of the person with disability;
- > lack of flexible, family-focussed supports;
- > segregated service systems which lessen opportunities for people who have a disability to be included in the ordinary life of the community;
- > lowered confidence to tap into ordinary community resources;
- > underdeveloped skills and expertise to perform an advocacy role;
- > lack of independent, organised formal advocacy which supports their individual or local advocacy efforts on behalf of people who have a disability.

As a result, the Objects of the Organisation are:

- (a) to provide families in which there is a person with developmental disability with information, resources, skills and support in order to perform an advocacy role;
- (b) to encourage the development and effectiveness of family-based advocacy groups;

Our thoughts are a magic part of us, and they carry us to places that have no boundaries, and no limitations.

WAYNE DYE

- (c) to provide an avenue for the development of leadership among families;
- (d) to monitor and, where necessary, make representations about legislation, practices and policies which affect people who have developmental disability and their families;
- (e) to disseminate information about legislation, policies and practices to families;
- (f) to encourage the involvement of people who have a disability, families and friends, in the work of the Organisation.

## ORGANISATIONAL GOALS

For people with developmental disability, Family Advocacy will:

- > enable families to become agents of positive social change in the lives of people with developmental disability;
- > be a credible public voice that defends, promotes and enhances the rights and interests of people with developmental disability;
- > strengthen families to develop and negotiate alternatives to current service practice consistent with building positive social roles for people with developmental disability;
- > broaden and activate the constituency of people who will speak out for the rights and interests of people with developmental disability;
- > strive to enhance the capacity and operation of the organisation to ensure its renewal, viability and effectiveness.

## KEY FOCUS AREAS

### Personalised support

Having control over the what, when, where and by whom of support increases the opportunities for people with disability to lead full and meaningful lives, included in their communities. Personalised support describes an approach that places the individual at the centre of decision making and treats their family members as partners. It is built on planning that is directed by the person and their family/ support network, uses resources that are allocated to the individual and uses paid support to compliment rather than replace informal support.

Family Advocacy seeks to exert influence to enable all people with disability to receive personalised support.

### Solid foundations for children 0-6

Getting off to a good start is vitally important for all children, particularly children with developmental disability. A good start means a start on a path that keeps the child embedded in their family and community. It is too easy to follow the 'special and separate' path which can leave families isolated, vulnerable and disconnected from the typical and ordinary environments other children and families enjoy.

Family Advocacy seeks to exert influence so that all children are supported in age appropriate ways to be active members of their families and communities.

### Welcoming, inclusive communities

Communities are places of great possibility. Much can be gained by supporting families to look to their own neighbourhoods and communities for the natural supports and opportunities they can provide people with developmental disability.

Family Advocacy seeks to support families to build and contribute to welcoming, inclusive communities.

### Meaningful adult lives

Too many people with developmental disability are living lives of little meaning. A schedule full of 'programs' and 'activities' keep people busy, but can serve little purpose.

Family advocacy seeks to exert influence so that all adults with developmental disability have lives that are rich with valued adult roles, opportunities for personal growth and development of lifelong learning and employment and relationship building.

### Advocacy for people with developmental disability

Some people with developmental disability are subject to oppression, exploitation, discrimination, segregation and rejection.

Family Advocacy is proactive and reactive in relation to unfolding issues which may lead to these negative impacts on the lives of people with disability.

### Family Advocacy as a prudent and sustainable organisation

Family Advocacy strives to enhance the capacity and operation of the organisation to ensure its renewal, viability and effectiveness.



# Chairperson's Report

MAREE SALZANO  
CHAIRPERSON



**Family Advocacy continues in its commitment to be a public voice that supports families to speak out around the rights and interests of children and adults with developmental disability in New South Wales.**

The year has seen some significant changes and achievements, all of which are guided by the organisation's Strategic Plan. Our planning process this year was skillfully guided by David White of Zentricity Pty Limited, who steered the process with Family Advocacy on a pro bono basis. Many thanks, David.

Another true highlight for the year has been the implementation and roll out of the Resourcing Families Project. *Resourcing Families* is an initiative of Family Advocacy (described fully in the centerpiece of this Report) which has been funded by Human Services, Ageing, Disability and HomeCare.

Family Advocacy continues to make representation to government around the many important issues facing people with disability and their families. The first six months of this financial year saw a particular focus on supported living with the development of a new workshop entitled

*Moving Out*. Since January 2010, the focus has broadened to include the development of a campaign in the lead up to the next state election, calling for a Supported Living Fund to be included in the roll out of the second phase of the NSW Government's *Stronger Together* commitment.

We have worked with individuals and other organisations to raise the profile of family governed and self managed/individualised support, and as an example co-hosted two events with In Control Australia. It is very pleasing to hear and see a shift in the mindset of many towards a much more person focused and individualised approach.

There are many people who assist us in our advocacy efforts. Particular acknowledgement is due to the many individuals who advocate on behalf of their son or daughter, brother, sister or friend on a daily basis. It is this unpaid, freely given support that warrants greater recognition.

I would like to extend a particular thank you to our many volunteers who give so generously of their time and in doing so play a vital role in maintaining and increasing the capacity of Family Advocacy in its varied roles.

Our Volunteer Session Leaders present at workshops throughout NSW and share their lived experiences, which informs and inspires others.

The strength and credibility of the voice of Family Advocacy is upheld and maintained by the work of many people. Notably, Family Advocacy is privileged to have a team of dedicated staff who work vigorously to accomplish an exceptional amount of work. Your commitment, persistent efforts and daily contributions are highly valued. Our special thanks to Catherine Hogan for her outstanding leadership, professionalism and personal integrity.

My thanks also go to my fellow Management Committee members who have worked so well as a team over the last year. It has been an absolute pleasure to work with a fantastic group of people who have shared values and an enduring commitment to the work of Family Advocacy. Committee members come from varying parts of NSW and bring their individual skills and life experiences. Having undertaken a committee self assessment and the governance workshop, we were in a position to identify the skills of individual members and what particular skills would further enhance the functioning of the committee.

The committee was fortunate to gain a new member, Lyn Bruce, who has skillfully fulfilled the role of Treasurer and, in addition, provided much valued financial training which added to the expertise of the committee.

Finally, thanks to our members and friends throughout NSW. Your support and encouragement continues to energise and inspire us.

MAREE SALZANO  
CHAIRPERSON

Strategic Planning led by David White, Zentricity.



# Highlights of the year

CATHERINE HOGAN  
DIRECTOR



Family Advocacy began a two year demonstration project called the *Resourcing Families Project*. The project, funded by ADHC, is fully described in the Centrepiece of this report.

Family Advocacy hosted two very successful In Control Australia events showcasing self directed supports and planning is well underway for a third event to be held in August, 2010.

The concept of supported living gained some support from within government and bureaucratic circles.

Family Advocacy's campaign for a Supported Living Fund is underway and gathering support and momentum.

Within the reporting period, 55 face to face events, covering numerous topics, were held across NSW.

We don't receive wisdom;  
we must discover it for  
ourselves after a journey  
that no one can take for  
us or spare us.

MARCEL PROUST

## Snippets from parents over the year

### Events, workshops and information sessions

'It was a Family Advocacy workshop about visioning our son's preferred future that helped us...'

'It was terrific to meet you at last at the seminar in Newcastle! It was an excellent event and gave me LOTS of Food for Thought!

Thank you! and also for the great handouts.'

'It was a pleasure to meet you and the ideas you shared will, I'm sure, not only change perspectives for families but have definitely influenced our practice professionals. I will definitely share this idea with my families. We will also be in touch to purchase resources especially the Odyssey DVD.'

'Thanks again for a very empowering workshop. I have much to read and get up to speed now and am feeling more confident in navigating the enrolment process for our local public school.'

'Just wanted to say thank you again for the informative workshop today. I really enjoyed it especially the information that I gained and also meeting the other parents and listening to their experiences. I now know I am not alone.'

### Advocacy related advice and information

'Thank you so much for the information you sent me regarding moving out - it has given me much food for thought and some very useful web links.'

'Thanks for the support that you and Family Advocacy have given us. The practical support, knowledge and moral support we have gained has been invaluable to us in pursuing our goals for A.'

'I regularly give your info to a number of families at our preschool. I don't know that they have acted upon them yet but I just remember how much you helped and inspired me when my daughter was just starting on the preschool/school journey. She has just celebrated her 21st birthday with a wonderful party with tonnes of family and friends!'

### Resources from Inclusion Collection

'I really appreciate all the support Family Advocacy provides to me thanks. I will also check out the web sites thanks.'

### Family Advocacy's Systemic Advocacy work

'Just to let you know that after our phone-in workshop on Supported Living, our family started talking about how we could make this work, and took the advice of don't wait create. If we hadn't taken that first step, house hunting, none of it would have happened. So thank you so much for your advice so far, and we will keep in touch regarding the bumps in the road ahead. I found many of your stories about how others had achieved this inspiring and helped my husband to accept that we have to let her try independent living; 12 month lease! We would like to keep up with the campaign for a Supported Living Fund.'

'I really enjoyed the forum and left feeling very energised and excited about being part of this changing culture. I was so happy to see such a large group of people who share our values, or who are at least open to change. There really is hope.'

# Family Advocacy at a glance

## WHERE WE HELD FACE TO FACE EVENTS



Number of face to face events run	55
Number of people attending Family Advocacy events	898
Number of financial members	156
Hits on the website 2009/2010	9,216



# Advocacy and Leadership Development

## ADVOCACY DEVELOPMENT



KIM ROOTS  
ADVOCACY DEVELOPMENT COORDINATOR



KAREN TIPPETT  
ADVOCACY AND LEADERSHIP WORKER

The advocacy and leadership development work of Family Advocacy involves:

- working with families to help increase their understanding of how to bring about positive change in the lives of children and adults with developmental disability;
- enabling families in NSW to have opportunities to develop and enhance their advocacy skills;
- providing avenues for the development of advocacy related leadership among families.

2009/2010 has been a busy period in the area of Advocacy and Leadership Development at Family Advocacy. Highlights have included the development of new workshop about supported living, the development of a new workshop about families preparing for their child starting school in an ordinary class, a new Project called *Resourcing Families* and guest speakers from interstate and overseas.

There were also additions to the staff working in the area of Advocacy and Leadership Development, with Rick Hansen and Chris Jackson joining the organisation. This has increased the capacity of Family Advocacy to run events and create new resources of relevance to families in NSW and has opened up new and exciting opportunities.

### FACE TO FACE EVENTS

#### After school - what then?

July 2009 - Forestville, Penrith, Campbelltown, Fairfield

August 2009 - Gosford

September 2009 - Orange, Dubbo, Albury, Wagga Wagga

November 2009 - Bonnyrigg

Family Advocacy presented ten *After school - what then?* workshops across the State.

The workshop assists families to consider the preparation and planning that will be useful when a student with disability, who will need ongoing support, leaves school.

Topics covered at the workshop include the different forms of support arrangements that are available, how to make informed choices about the future, government guidelines and how they affect school leavers.

Catherine Hogan and Kim Roots presented at each of the workshops along with Volunteer Session Leaders Marianne Brazier and Amber Paisley-Topp in Forestville, Penrith, Campbelltown and Fairfield. Amber also led in Albury and Wagga Wagga.

Families who attended were provided with up to date resources and articles to take away and consider after the day.

In preparation for the workshop that took place in Bonnyrigg, materials were translated into Vietnamese as many of the families attending spoke English as a second language with Vietnamese as the primary language.

Family Advocacy received a contribution from Ageing, Disability and Home Care to assist with the running of these events.

Some of the comments from participants are included below.

'Thank you for bringing this information to a rural area. We probably couldn't make it to Sydney for this workshop.'

'The presenters were fantastic. They were extremely helpful and informative and could really identify with us.'

'Excellent opportunity to find out what is available. Very informative day.'

'I had no idea of what was available and appreciate finding out there is help.'



Interpreter, Tinh Van Vo-Nguyen assisting us to translate workshop material



CHRIS JACKSON  
ADVOCACY PROJECT OFFICER



RICK HANSEN  
ADVOCACY DEVELOPMENT AND LIAISON OFFICER

## Planning for now, tomorrow and the future

### August 2009 - Sydney

One of the most common concerns for families is uncertainty about the future for their family member with developmental disability.

*Planning for now, tomorrow and the future* explored a range of issues and ideas around preparing and planning for the future and keeping a person with disability safe in the long term. Legal avenues and planning strategies were discussed.

The workshop was hosted by Sydney lawyer, Stephen Booth and Catherine Raju, Manager of Pave the Way, a project that works with families throughout Queensland to clarify their vision and to plan for a good life and a secure future for their relative with disability.

The workshop proved popular with 85 people attending.

Some of the comments from participants are included below.

'Both speakers were easy to listen to, spoke clearly and well with warmth and with knowledge of their subject. The element of parent experience was additionally helpful.'

'Some very practical and useful ideas.'

'It put into words the thoughts I had in my head but wasn't able to express.'

'It was extremely informative. Both presenters were practical and spoke in language that was easily understandable. Thank you.'

## Building supportive communities for people with disability

### Presented by Bob Lee

### October 2009 - West Ryde

Bob Lee has been involved in providing services for people with disability since 1978 and since 1984 has been actively involved in advocacy efforts aimed at protecting and defending the rights of people with disability.

Bob argued that the community has an indispensable role to play in safeguarding the lives of vulnerable people and explored the way that families and workers can embrace opportunities to remove rather than construct barriers.

Some of the comments from participants are included below.

'It was brilliant! Bob, you're an amazing and inspiring speaker with a very friendly and approachable manner. I was so glad I was able to attend today's presentation. Thank you!'

'A very powerful talk that gives me an idea on how things could be done better on the ground.'

'Great workshop which has given me ideas to make changes and raise awareness.'

## In Control

### November 2009 - Sydney

### March 2010 - Burwood

## Family Advocacy co-hosted two events with In Control Australia

In Control Australia is a foundation member of In Control International with close links to In Control UK. Through a partnership with In Control UK and other In Control groups around the world, In Control Australia shares information, research and stories, and develops tools to use for self directed funding.

The first event, held in November 2009, was titled *How does self directed support work in practice?*

An array of presenters shared their insights into the experience of self directed supports in other jurisdictions and what is currently happening in NSW.



Stephen Booth



Bob Lee





Judith Ellis and Margaret Ward

Presentations included Peter Shergold, Chair, Centre for Social Impact, UNSW speaking about the ethical imperative for self directed support; Maureen McLeish, a mother, talking about the benefits of direct payments for her daughter; Lara Friedman, a woman with disability sharing insights about using a self managed package and Judy Harwood, Director, Reform and Development, ADHC, who spoke about NSW initiatives in self directed support in NSW.

The March 2010 event was titled *What does self directed planning, funding and support mean for people with high and complex needs?*

Speakers including Margaret Ward, a parent from Queensland, Judith Ellis, a parent and consultant from NSW, Trudy van Dam, former service provider, now at *Australian Catholic University* and Karen Fisher, Social Policy Research Centre, talked about the lived experience of self direction and important elements associated with it.



Participants at the Burwood event

### **Moving out...from planning to action**

**November 2009 - Hornsby, Newcastle, Burwood, Wollongong**

**March 2010 - Penrith, Castle Hill, Gosford**

**May 2010 - Yass, Cowra, Bathurst, Katoomba**

In 2009/2010 a new workshop was developed to assist families to start thinking and planning for their family member with disability to move out of home with appropriate support. This workshop came about due to a lack of information available to families about a move from home that could be planned and which focused on the needs and interests of the person moving.

The people who attended included those well known to Family Advocacy, as well as people who had heard of Family Advocacy for the first time.

Catherine Hogan and Kim Roots of Family Advocacy presented along with Volunteer Session Leaders Wendy McGlynn and Marianne Brazier.

Given that *Moving Out* is a new workshop, it was particularly beneficial for experienced Volunteer Session Leaders to be present to share ideas after each workshop to continually improve the content of the event.

Some of the comments from participants are included below.

'Workshop was very helpful and positive and planned perfectly.'

'Very friendly and welcoming day.'

'Have more workshops like this.'

'Keep up the good job of supporting families and assisting them with advocacy issues.'

The journey of a  
thousand miles begins  
with a single step.

LAO TSE

### **Inspiring Communities**

**Presented by Ted Smeaton**

**February 2010 - West Ryde**

Family Advocacy hosted a presentation by Ted Smeaton that explored ideas and strategies for building inclusive communities for people with disability.

Ted has over 20 years experience in supporting the development of inclusive communities in Australia and internationally and explored how Asset Based Community Development (ABCD) can provide a useful approach to developing welcoming communities where everyone has a place.

Some of the comments from participants are included below.

'It was a great day. Loved the story telling and the relating to real lives plus the theory and handouts etc.'

'Great inspiration.'

'Loved family input. Very honest and clear and from the heart.'

'Gave me a needed push to get inspired by inclusion again.'

### **Creating the life you want.**

**People with disability and services working together**

**Presented by Jeff Strully**

**May 2010 - Epping**

Jeff Strully has been involved with people with developmental disability for over thirty years. Jeff has written numerous articles and presents workshops on a myriad of different subjects including friendship, inclusion in adult life, supported living and person centered planning. He is currently the Executive Director of Jay Nolan Community Services (JNCS) in Los Angeles. JNCS is an agency that supports people with autism including people with high support needs.

After years of providing more traditional services to people such as group homes and day programs, Jeff realised that these programs were not being very successful and were not providing what people with disability needed.

Jeff discussed the changes that have been made as well as why these changes were felt to be necessary, how these changes have impacted the mindset and planning of families for the future and how the roles of those who provide support have changed.

Some of the comments from participants are included below.

'It was great. Life experiences brought realism to the workshop.'

'Jeff is a brilliant speaker and he is able to present complex ideas but still entertain.'

'I found it extremely useful.'

'Jeff was excellent at challenging preconceptions and very entertaining! We really appreciated his open and insightful way of communicating.'

### **ADVOCACY RELATED ADVICE AND INFORMATION**

Throughout 2009/2010 Family Advocacy has provided advocacy related information and advice to the families, friends and allies of people with disability primarily over the telephone and via email. Some people have also come to the Family Advocacy office to receive information and advice.

Family members and others have made contact to strategise and receive information around matters relating to the interests of the person with disability on a confidential basis.

This has been a useful way for people who have attended workshops to talk through information received on the day of the workshop and to receive additional information - particularly those living in rural and remote locations.

Throughout 2009/2010 people heard about Family Advocacy in a number of ways including: when they received a flier about an event, when they read about Family Advocacy in a newsletter or newspaper, via ongoing contact as part of the mailing list, referrals from other organisations, by viewing the website, via word of mouth from other families, perusing directories and after seeing a Family Advocacy poster.

Recognising that telephone charges can create a financial barrier for people living outside of the Sydney metropolitan area, there is a free call 1800 number to call and discuss issues.

People can call or email as often as they need to and this varies according to the nature and the level of complexity of the issue or issues.

## LEADERSHIP DEVELOPMENT

Advice and discussion over the year has covered a wide variety of life experiences including: preparing a vision for the future, establishing a network of support, planning for starting school, preparing for school transition points, such as the move from primary to high school, considering leisure opportunities, working effectively with schools, thinking about life after school, supporting a family member to develop relationships, planning the move from the family home and making long term plans around the person with disability.

Response to phone calls has varied depending on the circumstances but has included:

- > working with the caller to formulate a course of action;
- > sending resources such as articles or brochures to supplement knowledge and make the possibility of coming to an informed decision more likely;
- > providing contact details for other organisations where the information required is outside the areas of expertise of Family Advocacy, such as legal matters;
- > completing research around an issue to ensure that the caller has the most up to date information or new perspectives about an issue; and
- > making contact with a senior decision maker where an issue is of systemic significance.

This contact, with a wide range and large number of callers from around the State helps to inform Family Advocacy's planning around the workshops and the resources that are likely to be most useful for families. It also helps the organisation to be aware of issues that may be of systemic significance, either within a region or across the State.

**A vital focus of Family Advocacy is supporting families to develop their advocacy and leadership skills and to increase their understanding of how to bring about positive change in the life of their family member with disability.**

Recognising that all families are unique and have different skills, interests and time constraints, the organisation nurtured leadership via a number of different avenues.

Family Advocacy supported family members to:

- > attend events sponsored by Family Advocacy;
- > enhance their skills and knowledge by undergoing specific training;
- > present and assist at Family Advocacy run workshops;
- > contribute articles to the Family Advocacy Journal;
- > attend and participate in meetings with politicians or senior bureaucrats; and
- > facilitated interactions with people with fresh ideas and expertise around supporting people with developmental disability.

### LEADERSHIP TRAINING

#### Developing the skills of presenters

Family Advocacy encouraged those that expressed an interest in becoming a Volunteer Session Leader to gradually develop their skills, competence and confidence.

Being a Volunteer Session Leader involves verbally presenting material and assisting with group work at workshops run across the State.

For those who take on this role, training is of an ongoing nature with Volunteer Session Leaders gradually increasing their level of participation. To ensure that they could be as prepared and as professional as possible, materials relevant to the applicable events are provided and discussed in advance. Self evaluation is encouraged and feedback is also provided.

Being a Volunteer Session Leader provides a great opportunity to meet a wide range of people, exchange ideas, have access to the latest resources and to gain experience presenting to groups of various sizes. Presenting involves the use of a range of equipment that Volunteer Session Leaders are supported to master.

As well as adding to the breadth of experiences able to be shared at Family Advocacy workshops and hence adding to the value of these workshops, these skills and experiences are useful to Volunteer Session Leaders when promoting the rights and interests of their own family member with disability and when planning for his or her future.

#### Family Advocacy Leadership Training

##### Conversation with Bob Lee

October 2009

Several families took part in a conversation with Bob Lee; a respected colleague from Queensland with many years experience promoting the rights and interests of people with disability. The conversation grappled with how Family Advocacy can better support families so that people with disability can be welcomed in their communities.





Staff and attendees at Leadership event

## Inspiring Communities Skill Development Event

February 2009

Family Advocacy hosted a skill development event for people who had taken on leadership roles at Family Advocacy in the past and for those who have expressed interest in doing so in the future.

The event was attended by 12 people over the two days, with several attendees being sponsored to travel from across the State.

On 12 February, participants attended Inspiring Communities followed by a discussion about the day. The workshop and discussion was followed by an informal dinner where participants had the opportunity to meet others and develop connections.

On 13 February there was discussion around:

- > Family Advocacy and its leadership strategy;
- > the current political landscape;
- > Family Advocacy's key focus areas; and
- > working towards welcoming and inclusive communities: Thinking, planning and discussing how Family Advocacy could harness ABCD methodology to help progress community inclusion for people with disability.

Following the workshop, participants have provided feedback about how they would like to be involved with Family Advocacy in the future.

## OTHER LEADERSHIP OPPORTUNITIES

### Attending Events

Part of the way that Family Advocacy assists those taking on leadership roles is to support them to attend training run by other organisations. This offers exposure to fresh examples and ideas as well as networking opportunities.

### Social Role Valorisation: Towards a Better Future

July 2009

Social Role Valorisation theory underpins the work of Family Advocacy and it is very useful for those taking on leadership roles with the organisation to have an understanding of it.

The workshop was presented by Senior Social Role Valorisation Trainer, John Armstrong, and five families were sponsored to attend.

## Conversations, Connections, Communities

April 2010

Four international leaders in Person Centered Practice - John and Connie O'Brien, Jack Pearpoint and Lynda Kahn, facilitated two days of presentation and conversation about supporting people with disability to lead full lives in the community. Two families were sponsored to attend.

### Disability Advocacy Network Australia (DANA) Conference

June 2010

DANA's third national disability conference was held on 15 and 16 June 2010 in Canberra.

Staff members along with Management Committee Members Meaghan Sweeney and Amanda Fletcher attended.

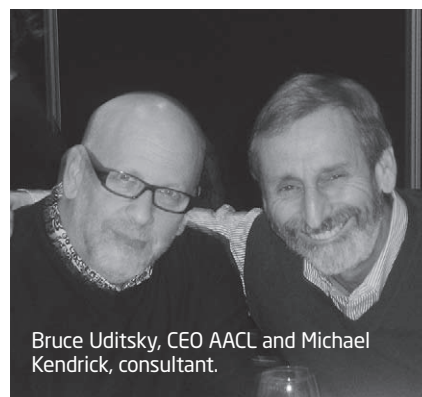
In addition, Family Advocacy sponsored four families to attend.

The conference was a terrific opportunity to hear from key political figures (Parliamentary Secretary Bill Shorten, Senator Mitch Fifield and Senator Rachel Siewart) and from significant members of the advocacy community. Key note addresses were presented by Dr Michael Kendrick and Bruce Uditsky.



Parents and staff sponsored to attend the DANA conference:

Left to right back: Di Samuels, Gina Wilson-Burns, Sue Blackeby, Trisha McLroy, Meg Sweeney  
Front: Shari Raymond



Bruce Uditsky, CEO AACL and Michael Kendrick, consultant.

## EVENTS WE HAVE RUN THIS YEAR

### 2009

July	Information session	Thornleigh
	After School - What Then?	Forestville, Penrith, Fairfield, Campbelltown
August	Information session	Randwick
	Information session	Bankstown
	Planning for now, tomorrow and the future – Catherine Raju and Stephen Booth	West Ryde
	After School - What Then?	Gosford
September	After School - What Then?	Orange, Dubbo, Albury, Wagga Wagga
	Supported Living Information session	Corrimal, Nowra, Dapto, Wollongong, Kiama, Epping
	Information session (Korean)	Ryde
October	Building Supportive Communities - Bob Lee	West Ryde
October/ November	Supported Living Info session	Goulburn, Bowral, Wollongong, Campbelltown, Tura Beach, Bega, Batemans Bay, Ulladulla
November	Moving Out	Hornsby, Newcastle, Burwood, Wollongong
	After School - What Then? Vietnamese workshop	Bonnyrigg
December	Supported Living Information session	Sutherland

### 2010

February	Inspiring Communities - Ted Smeaton	West Ryde
	Leadership development	West Ryde
March	Moving Out	Penrith, Castle Hill, Gosford
	In-Control forum	Burwood
April	Information Tour	Broken Hill, Ivanhoe, Menindee, Cobar, Nyngan, Dubbo
May	Creating the life you want - Jeff Strully	Epping
	Moving Out	Yass, Cowra, Bathurst, Katoomba
	Information session	Cowra
June	Supported Living information session	Sutherland, Eastern Suburbs, Bankstown

# Resourcing Families

Family Advocacy is excited to announce a new initiative that aims to support families that include a child or young person with developmental disability to establish community connections, develop networks and have skills and ideas to direct any necessary supports.

*Resourcing Families* reaches out to families of children and young people with developmental disabilities up to 18 in NSW.

## WHY NOW?

There is an increasing awareness in Australia and around the world of the benefits of people with disability and their families having more control over their lives and opportunities to build a positive vision for the future. It can be difficult, however, for families to know what options are available and how to go about exploring some of the emerging possibilities.

Family Advocacy recognises that there is little support or information available to families around nurturing community connections, developing valued roles and having more choice and control over supports.

In response, Family Advocacy has established *Resourcing Families* as a demonstration project which receives funding from Ageing, Disability and Home Care, Department of Human Services NSW.

*Resourcing Families* provides information, ideas and strategies to help families make decisions, use initiative and have the confidence to consider such options as adopting a self directed approach.



## RESOURCES TO HELP

A number of resources are offered to families to assist them to build a rich and full life with and for their family member. These resources will also help families recognise the trends that are beginning to emerge, which they might like to consider as they plan for the future.

### 1. Information and advice

People are invited to contact Resourcing Families via phone or email to talk through issues relating to their family member. Families can identify issues that they are experiencing, and be supported to work towards positive outcomes. Where Resourcing Families is unable to assist on a relevant issue, appropriate referrals will be made.

### 2. Workshops and other events

These will cover a range of topics, including:

- > community inclusion
- > vision building
- > networks of support
- > developing valued roles
- > building informal supports
- > developing, implementing and sustaining individualised, self directed supports

These workshops and events are an opportunity for families to come together to learn more about issues relevant to their own circumstances, obtain practical advice and have their questions answered. Guest speakers from a variety of backgrounds will also be invited to share their expertise and insights.



### 3. A mentoring program

This will support networking and sharing of information, experiences and inspiration. It will be especially relevant to families with experience or interest in creating circles of support, developing a positive vision for the future, building informal networks to compliment paid support, and adopting a self directed approach. With permission of those involved, some of the ideas and stories of mentors and mentees will also be made available to other families who are not participating in the program.

### 4. A web site with useful resources and information

The website contains a number of articles, fact sheets and other resources that help families consider options available to them and make informed decisions. Families are invited to contribute their own stories to help save others from having to reinvent the wheel. This website is intended to be as user friendly and accessible as possible, and to reflect the diversity of families across NSW. [www.resourcingfamilies.org.au](http://www.resourcingfamilies.org.au)

## LEARNING AND SHARING TOGETHER

A key focus of *Resourcing Families* will be facilitating families to learn from each other, and to provide an opportunity for people to share their own successes and challenges. This will make it easier for the families to support their own family member to develop meaningful connections and have more control over

the future. The more useful the information that can be gathered and shared, the more likely it is that young people with disability will be able to explore a good life of their choosing.

In order for *Resourcing Families* to be most useful, there will be opportunities for ongoing interaction and support. *Resourcing Families* encourages the involvement of mothers, fathers, brothers, sisters, aunts, uncles, grandparents and other relatives and friends of people with developmental disability to contact us, come to workshops, become informed and harness the opportunities for children and young people with disability in their family.

External stakeholders and organisations will also be consulted so that they can help make families aware of the resources provided by this new initiative. Liaising with these organisations will also assist *Resourcing Families* to gather useful and relevant information that can then be provided to the families that it supports.



## BUILDING A POSITIVE FUTURE

A good quality of life in connection with family, friends and community is unlikely to **just** happen for children and young people with disability. Developing a vision, building support networks and exercising more control over paid support can help families create the kind of life that they want for their family member. Finding out more about these possibilities and knowing where to start can be a daunting task. *Resourcing Families* aims to provide that information so that families can build a future where their family member is included, valued and able to access supports and services that meet their individual needs.

All families dream of meaningful and fulfilling life for their family member with disability. *Resourcing Families* intends to give families the knowledge, skills and confidence they need to help turn these dreams into a reality.

**'There is now so much more to our daughter's world than paid support. She has friends, family, and a valued place in the community.'**

Parent

**'Having clear information and good ideas has really helped us plan for a great future.'**

Parent



# Working to change the system

## – Systems Advocacy



BELINDA EPSTEIN-FRISCH,  
SYSTEMIC ADVOCATE



SHARON WILLIAMS,  
PROJECT WORKER

The systems advocacy work of Family Advocacy aims to remove barriers and facilitate opportunities for children, young people and adults with disability to lead good lives as active members of their community.

### KEY FOCUS AREA: PERSONALISED SUPPORTS

#### Self directed approaches

A self directed approach to providing services and supports to people with disability is being adopted by many jurisdictions, both within Australia and internationally. The main benefit is that by being person centered, a self directed approach can deliver more flexible and appropriately targeted services that make a difference in the lives of people with disability and their families. At the same time, it can lead to better utilisation and effectiveness of limited resources.

Family Advocacy believes that all people with disability and their families must have the choice to use a self directed approach. All people must be given the authority and the support to direct the resources targeted to their assistance.

Family Advocacy's position on key strategies to enhance the opportunity for success of a self directed approach includes:

- > a spectrum of funding, planning and support options via which the person with disability and their family can choose the level of responsibility and that level of responsibility can change over time;
- > government funded mechanisms that can be accessed by the person with disability and their family to assist them to plan and implement supports;

- > capacity building for people with disability and families to assist them to take advantage of the opportunities presented by a self directed approach; and
- > support for, and commitment to, service transformation.

#### Concern

In the past 12 months, there has been a significant shift in the language of individualised and person centered support. Ageing, Disability and Home Care (ADHC) policy and guidelines have adopted a person centered approach. Training in person centered planning abounds and Individual Service Plans have given way to Person Centered Plans; Supported Accommodation Policies have been morphed into Policies of Lifestyle Support and the ADHC bureau overseeing Large Residential Centre's now has the name Supported Living in its title.

In addition, whilst the menu of service types has increased, people must still choose from the limited menu and have little control over the what, when, where and by whom of support. Consequently, paid support often does not make a difference in the lives of service users because it replaces rather than compliments the informal support provided by family and friends.

Family Advocacy supports the general direction underpinning these policies, but believes that they do not address the serious challenges that will exist in implementing this approach in congregate services. Without addressing these issues, there is a very serious risk that the language will change without real and positive changes in the lives of people with disability.



An authentic commitment to a person centered approach requires an organisation to have:

- > a strong mission and values that rests on the United Nations *Convention on the Rights of Persons with Disabilities* (2006);
- > a commitment to enhance the capacity of people with disability and their families;
- > a willingness to share authority and responsibility;
- > a commitment to change when current structures, policies, processes and activities hinder the implementation of people's goals and aspirations; and
- > a change in organisational culture and significant development for staff to understand and implement a new approach.

Family Advocacy's strategies in this Key Focus Area have been towards achieving improved quality of life for people with disability commensurate with the changed language.

#### **Outcome**

ADHC has an increased understanding about self directed support and its implementation in many areas of service provision.

#### **Strategy**

Family Advocacy was a member of the ADHC Evaluation Steering Group which oversaw a study evaluating services accessed by ADHC clients. This group then became part of the ADHC External Advisory Group on Individualised Support that is overseeing action research that will document and draw emerging knowledge from the experiences of the four ADHC pilot projects in the area of individualised support.

Family Advocacy represents In Control Australia as a member of the ADHC External Advisory Group on Individualised Support.

Family Advocacy met with senior ADHC staff in the Accommodation, Prevention and Pathways and Reform and Development sections.

Family Advocacy provided teleconference training to support planners involved in one of the pilot projects.

#### **Outcome**

People with disability, families, advocates and some services have improved their understanding of self directed support.

#### **Strategy**

Family Advocacy worked within the framework of In Control Australia to broaden the base of individuals and organisations that aim to bring about systemic change throughout Australia to enable people with disability and families to manage their own support.

Family Advocacy hosted two In Control seminars about self directed support in order to encourage people with disability, families and services to exchange ideas and pressure the NSW Government for change.

The first seminar, *How does self directed support work in practice?* was held on 24 November 2009 and showcased the transformation taking place in Victoria to provide opportunities and assistance for people with disability and their families to direct their own support.

The second seminar, *What does self directed planning, funding and support mean for people with high and complex*

*needs?* was held on 22 March 2010. This full day seminar examined what is required by services and government to achieve a self directed approach.

Preparation is underway for the third Family Advocacy/In Control Australia seminar to be held in August 2010 on the theme of *Supported living as self directed support in action*. Speakers include Greg Lewis of My Place WA and Jill Hole of Homes West, two services supporting people with disability to live in their own homes, and Eddie Bartnik of the Disability Services Commission of Western Australia to look at the role of government in facilitating these opportunities.

Family Advocacy participated in In Control Australia NSW meetings, which aimed to coordinate activities in NSW, advocate for a self directed approach in *Stronger Together 2*, the second stage of the NSW Government 10 year plan for disability services, and develop a joint submission to the Productivity Commission Inquiry into Long term Disability Care and Support.

#### **Outcome**

The Minister and Shadow Minister for Disability Services have an increased understanding of self directed support.

#### **Strategy**

Family Advocacy developed a position paper *Moving toward a self directed approach in NSW* and used it as the basis for discussion with politicians and bureaucrats. The paper contributed to the Coalition consultation on policy.

Family Advocacy met with Minister Primrose once and the Shadow Minister, Andrew Constance on two occasions.

## SUPPORTED LIVING

### Concern

The NSW specialist disability service system is not effective in preventing crises and in fostering family initiative. It encourages families to become dependent users of services who rely on government funding to fix their situation. Accommodation support is crisis driven. It is allocated at the point of family breakdown and teaches families that crisis is rewarded with a bed. A system built on such crisis intervention has many risks and unintended consequences including:

- > people believing that crisis is the only way of moving from the family home;
- > a reluctance to plan for, or trial arrangements without having first secured funding;
- > a generalised reduction in community capacity arising from too great a dependence on funded supports that push out welcoming inclusive practices and leave people with disability isolated;
- > trauma and mental health problems for people with disability as well as their families;
- > growth of unmet need to such levels that addressing it seems overwhelming for government policy makers and funders;
- > people living in accommodation that is inappropriate to their needs; and
- > people being moved between vacant beds in a way that is dislocating, destabilising and dehumanising.

The supported accommodation on offer in NSW does not lead to good lives for people with disability. Accommodation is usually distant from family and community and people have no control over where they live, with whom they live, their lifestyle, who visits and how they are supported.

Family Advocacy argued that if the NSW Government wants to move from crisis intervention to prevention and from having sole responsibility for long term care and support, to being a partner in care and support, it must encourage and support family initiative while families still have the capacity to partner.

When adults with disability are in their 20s, their families still have capacity and energy to support them into homes of their own. Assistance at this time is part of the normal life course. As time goes on, parents feel less able to take the steps that are necessary. Their confidence in their own capacity diminishes and they are less willing to try innovative solutions.

Family Advocacy has developed a major campaign to secure a Supported Living Fund for NSW. This is a proposed stream of government funding that would enable people with disability to have a home of their own while families still have capacity to support the transition and be part of the solution.

### Key features of the proposal

- > the Supported Living Fund provides a new avenue of growth funding;

- > the target group is adults with disability who meet the established criteria for specialist disability services and are interested in having their own home with the assistance of formal and informal supports. The feature differentiating the target group from the current ADHC system is that their families are not in crisis;
- > families are given encouragement and support to plan. This includes information to guide and inspire, and assistance with planning, facilitation and support coordination;
- > government provides recurrent funding from the *Supported Living Fund* to pay for support that compliments the freely given relationships of family and significant others. Government thereby provides incentives for families to plan and put informal support in place;
- > people with disability, their families and support networks are able and helped to direct their own support. Funds are not used to purchase a bed in a group setting; and
- > the Supported Living Fund is part of an identifiable strategy that rebuts the notion that the only way for people with disability to move out of the family home is for them to move into a government allocated place. The identifiable strategy includes investment in vision and capacity building, support for high quality planning and individual service design, removal of disincentives and the development of acquittal and accountability mechanisms appropriate to a self directed approach.

## Anticipated benefits of the Supported Living Fund

People with disability will:

- > have a life of their own in a home of their own.

Families will:

- > feel able to plan, leading to new pathways that build on people's strengths, relationships and resources and reduce reliance on crisis pathways;
- > regain control of their lives with the concomitant improvement in health and wellbeing; and
- > be supported in their efforts leading to empowerment rather than passive dependence which is currently fostered by the system.

The disability service system will see:

- > a reduction in crisis as people see clear pathways that support their initiative;
- > an increased range of supported living options;
- > the development of expertise in supported living to inform directions on building capacity;
- > the development of expertise in supporting families to use their own initiative, thereby reducing reliance on the service system;
- > the development of an evidence base around individualised support and supported living; and
- > funding being used in ways that facilitate and assist to build new relationships and increase community inclusion with a shift away from the more traditional fee for service approach provided in current Business Rules.

A Supported Living Fund has the capacity to move families from a position of dependence, stress and crisis to people with capacity whose initiative is rewarded. The Supported Living Fund also has the capacity to move the NSW disability service system from crisis intervention to prevention.

### Outcome

An increased number of families know about supported living and want their family member with disability to live in their own home with a lifestyle of their choosing.

### Strategy

Family Advocacy ran workshops, information sessions and teleconferences on supported living for families across NSW.

Family Advocacy supported families who were helping their sons and daughters with disability to move into their own home through telephone discussions and face to face meetings.

Family Advocacy produced a resource booklet *A Home of My Own* that provides values based insights, ideas and practical strategies on housing and sustainable support for people with disability in NSW.

### Outcome

The concept of a Supported Living Fund was widely discussed in NSW.

### Strategy

Family Advocacy developed a position paper that was widely circulated through our Journal, *Families for Change*.

Family Advocacy held meetings with the CEO and many senior staff of ADHC to discuss the concept and its implementation.

Family Advocacy held meetings with the Minister and Shadow Minister for Disability Services.

Family Advocacy sought endorsement for the concept from service providers and advocacy organisations, forming a coalition of 16 organisations that advocated for the implementation of a Supported Living Fund as part of *Stronger Together 2*.

Family Advocacy developed a Campaign for a Supported Living Fund for NSW.

### Outcome

Supported accommodation approaches used by ADHC were critiqued.

### Strategy

Family Advocacy provided feedback on ADHC's *Lifestyle Planning Policy* for people in supported accommodation.

Family Advocacy held meetings with senior ADHC staff responsible for accommodation.

Family Advocacy held meetings with the NSW Ombudsman to provide feedback in relation to ADHC provided and funded accommodation services.

### Outcome

The work of People with Disability Australia, in relation to the redevelopment of Large Residential Centres, was supported. This work is focused on preventing the redevelopment of Large Residential Centres into accommodation models that congregate people with disability and segregate them for the community.

### Strategy

Family Advocacy continues to be a member of the People With Disability Devolution Portfolio Advisory Group.

The best way to predict the future is to invent it.

ALAN KAY

## KEY FOCUS AREAS: SOLID FOUNDATIONS FOR CHILDREN 0 - 6

### WELCOMING, INCLUSIVE COMMUNITIES

#### Children and young people

The emphasis of advocacy in this area involves strengthening opportunities to enable all children and young people with disability to grow up in families that are well supported and as active and contributing members of their communities. This involves being welcomed and supported in age appropriate local opportunities including early childhood formal and informal services and supports, being a member of the regular class of the local neighbourhood school, participating in after school and vacation programs with peers in inclusive settings and having an age appropriate break from their family through the same opportunities as their peers without disability.

#### Outcome

Emerging practice in service provision reflects an increased understanding of ways to embed children in families and in ordinary pathways of life.

#### Strategy

A member of staff is a member of the ADHC Expert Advisory Group on Children and Young People with Disability and their Families.

A member of staff provided the Keynote address at the Conference of Early Childhood Intervention Association, entitled *Strengthening connections and building communities*.

Family Advocacy was part of the reference group that developed a booklet for siblings of children and young people with disability.

#### Outcome

The Government was informed of the concerns of families that the new out of school hours supports for teenagers with disability were only funded in segregated settings.

#### Strategy

Family Advocacy wrote to Minister Lynch to express concern and recommend that support be provided for young people who want after school and vacation support to participate in ordinary community activities.

#### Outcome

The National Framework for Protecting Australia's Children took into account issues relating to children and young people with disability and their families.

In April 2009 the Council of Australian Governments (COAG) endorsed a National Framework for Protecting Australia's Children 2009 - 2020. This was in response to numerous reports documenting the way in which current child protection systems are dysfunctional and promoted moves to assist families in a preventative rather than a crisis driven reactive mode. One of the first strategies for implementing the National Framework is the development of a common approach to assessment, referral and support.

Jenny Macklin, Federal Minister for Families, Housing, Community Services and Indigenous Affairs, and Fiona Stanley,

Australian Research Alliance for Children and Youth have convened the national Common Approach to Assessment, Referral and Support (CAARS) Taskforce to:

- > develop a common approach to assessment and referral; and
- > improve mechanisms for information sharing between primary and secondary level services which may have contact with children who are potentially at risk and their families.

#### Strategy

A member of staff was invited to be a member of the CAARS Taskforce which met on four occasions from July 2009 to June 2010.

#### Inclusive Education

The School Learning Support Program (SLSP) aims to provide more immediate support for classroom teachers, significantly reduce administration for schools when providing support to individual students or groups of students with additional learning needs, increase the expertise of specialist teachers and improve the coordination of support for students with additional learning needs at the school level.

#### Concern

Specialist support for students in the regular class was under threat as a result of a campaign by the Teachers' Federation to reject the SLSP.

#### Outcome

The critical importance of professional support at each local school as provided through the SLSP was promoted to families, departmental staff and politicians.

### Strategy

Family Advocacy wrote to the Minister for Education, Verity Firth and the Director General of Education commending them on the SLSP and making suggestions for its enhancement.

Family Advocacy met with Greens MP John Kaye who was taking a key role in the issue.

Family Advocacy sought a meeting with the Opposition spokesperson on Education.

Family Advocacy developed a submission to the *Parliamentary Inquiry into the provision of education to students with a disability or special needs* and shared the submission with the advocacy sector. We also gave evidence at the Inquiry.

Family Advocacy is a member of the Community Consultative Forum on the SLSP.

### Concern

Special provision in the national standardised numeracy and literacy assessment, the National Assessment Program - Literacy and Numeracy (NAPLAN), in Years 3, 5 and 7 was not adequate. In addition, reporting of the results of NAPLAN on the 'My Schools' website took no account of the number of students with disability in the school leading to a concern that inclusive schools that had children with disability enrolled in the mainstream classes would be disadvantaged.

### Outcome

The Australian Curriculum, Assessment and Reporting Authority (ACARA) and DET agreed to review the nature of special provision and to introduce a mechanism to review additional needs of students that fall outside guidelines on a case by case basis.

### Strategy

Family Advocacy worked with two parents to argue the case with ACARA, which has responsibility for the development of national assessment and guidelines for its implementation, and DET, which has responsibility to implement the NAPLAN tests.

## KEY FOCUS AREA: MEANINGFUL ADULT LIVES

### Concern

Family Advocacy seeks to exert influence so that all adults with developmental disability have lives that are rich with valued adult roles, opportunities for personal growth and development of lifelong learning and employment and relationship building. Many people with disability end up in programs that roll on from year to year with little change and meaning.

### Outcome

The programs designed for young adults with developmental disability are person centered, meaningful and are reviewed regularly to ensure their efficacy in bringing about good outcomes.

### Strategy

Family Advocacy has remained on the ADHC Transition to Work Stakeholder group to have input into the guidelines that govern the program and to participate in its evaluation.

Family Advocacy met with senior ADHC staff to suggest the development of a Fact Sheet to assist young people and their families in the assessment process leading up to the end of their schooling

life. Family Advocacy worked with ADHC in the development of the Fact Sheet which is now available.

## KEY FOCUS AREA: ADVOCACY FOR PEOPLE WITH DEVELOPMENTAL DISABILITY

### DISABILITY ADVOCACY NETWORK AUSTRALIA

#### Outcome

A body representing and strengthening the disability advocacy sector exists and is building its efforts to act as a voice for the sector as well as acting to bring the sector together.

#### Strategy

Family Advocacy sits on the Board of DANA and has worked with the Board in its efforts to seek recurrent funding for DANA.

DANA coordinated the third National Advocacy conference held in Canberra in June 2010.

#### Other

Family Advocacy contributed to a consultation around the NSW State Plan.

Family Advocacy contributed to discussions on Stronger Together 2, attending meetings, distributing material to families and supporting people to attend meetings.

Family Advocacy contributed to the Senate Community Affairs Reference Committee *Inquiry into planning and services for people ageing with a disability* through the development of a submission.



# Information



WENDY MCKINNON  
INFORMATION COORDINATOR  
UNTIL DEC 2009



TRISHA MCILROY  
INFORMATION COORDINATOR

An important part of Family Advocacy's mission is to strengthen the knowledge of families. Through the Information role and the resources in the Inclusion Collection, Family Advocacy provides families with information that is both relevant and inspiring. Patricia McIlroy commenced work with Family Advocacy as Information Coordinator on 1 June 2010 following the resignation of Wendy McKinnon in December 2009.

## INFORMATION SESSIONS

### About Family Advocacy

In July 2009, Family Advocacy provided an Information Session at the Children's Hospital, Randwick. Family Advocacy was one of nine organisations/services represented on the day to provide information to families, adolescents with cerebral palsy and their caregivers, about what we have to offer, with a specific focus on points of transition. This session was presented by Wendy McKinnon and Kim Roots.

We were invited to Bankstown in August to address their multicultural Community Resource Group and to provide resources and strategies on education options. There was a good mix of parents and workers. This made for a good discussion and, importantly, all workers reinforced the option of inclusion as being a very real option, where all of the families present had been told Special Education classes were their only option. The outcome of this session has been very positive, with several workers requesting further resources to assist families and one worker has provided us with a new resource. A staff member from the Community Resource Group stated: 'We want to support you (Family Advocacy) as we were so impressed with the presentation and available resources. Family Advocacy achieves so much, with such little funding. You really are an inspiration to us all!'

In October 2009, Family Advocacy was invited by the Spastic Centre to provide an Information Session, via teleconference, to five families.

Kim Roots and Wendy McKinnon with members of the Bankstown Community Resource Group



Knowledge is power. Information is liberating. Education is the premise of progress, in every society, in every family.

KOFI ANNAN



Catherine and Diane Newey - Member from Cobar.



On the road again...



Example of resources distributed.

In December 2009, Ethnic Child Care, Family and Community Services invited Family Advocacy to provide an Information Session to Korean families. An interpreter was present to assist us at this session.

#### About Supported Living

Supported Living continues as an important issue for families and people with disability in NSW. To assist families to have a good grasp of the topic, we ran 34 Supported Living teleconferences and information sessions in NSW during this period.

#### Far West NSW, Information Tour

As a statewide organisation, Family Advocacy has a responsibility to outreach to rural and remote areas of the state. This year the decision was made to travel out west to visit some of the more distant and remote towns and provide information about Family Advocacy to parents and services. Catherine Hogan and parent, Amber Paisley-Topp ran 7 sessions in 5 different towns - Broken Hill, Ivanhoe, Menindee, Cobar, Nyngan and Dubbo.

In May 2010, we attended an Early Intervention Expo on the Central Coast. By being present at such Expos, families of young children are made aware of Family Advocacy.

## RESOURCES DEVELOPED THROUGHOUT THE YEAR



In 2009, the topics for the *Families for Change* journal have included: 'Life After School...An Opportunity For Work, Growth and Dreams'. This journal was distributed at workshops on 'After school, what then?' The September and November edition encompassed reflections of parents from the Canadian parent exchange. A decision was made to split the articles into two journals due to the enthusiastic response from parents who participated in the Parent Exchange journey.

### COMMUNIQUE

AN INFORMATION UPDATE FOR NSW FAMILIES



Communiqué, which is published quarterly, contains information for NSW families, concerning policies, changes to legislation and communication between Family Advocacy and government authorities.

Communiqué is sent by post and email to approximately 800 families and allies, an increase of 500 readers since last financial year.

## GENERAL ENQUIRIES AND RESOURCE PROVISION

Providing information and resources to families and workers is a fundamental role of the organisation. Family Advocacy received approximately 1,300 individual requests for books, articles, videos and information packs during the past 12 months.

## THE INCLUSION COLLECTION LIBRARY

During 2009/2010 over 4,300 resources were accessed or borrowed from the library. Families were the main users, but students and workers also accessed information.

No new resources have been added to the library, as the decision was made to give the Library a 'makeover' and out of date resources, containing information that is deemed no longer useful, are being removed. Articles that are relevant and timely will continue to be added as and when copyright allows.

# Management Committee

## GOVERNANCE STATEMENT

Family Advocacy is incorporated under the *Associations Incorporation Act*, and operates under the rules of association adopted by members on 19 June 1991. Under these rules Family Advocacy's affairs are managed by the Committee of Management (the Committee). This governance statement outlines how the Committee discharges that responsibility.

The Committee's primary responsibility is to ensure Family Advocacy stays true to its Vision and Mission, advocates effectively on behalf of people with developmental disability in NSW and achieves the goals set out in the Strategic Plan.

The Committee, which comprises the Chairperson, Immediate Past Chairperson, Treasurer, Secretary and up to a maximum of 12 ordinary members, is elected each year at the time of the annual general meeting. In fulfilling its primary role, the committee meet at least 6 times per year. At these meetings the committee considers:

- > the Treasurer's report, which details income, expenditure and financial position;
- > membership matters;

- > staff and administrative matters;
- > systemic and general advocacy matters;
- > correspondence;
- > complaints; and
- > outcomes of program delivery to families and people with disability in NSW.

The proceedings at each meeting are minuted and kept as a permanent record of the business conducted by the Committee.

The Committee report to members at the annual general meeting. At the annual general meeting the annual report, which includes the audited financial report for the year just ended, is presented to members.

### Annual General Meeting

Family Advocacy held its AGM on 23 October 2009. We were very fortunate to have Bob Lee, co-ordinator of the Sunshine Coast Citizen Advocacy Programme Inc as our guest speaker. Bob spoke eloquently and passionately about the role advocacy can play in building more inclusive communities.

An orientation for committee members re-elected and new, was conducted in December 2009.



Bob Lee and Catherine Hogan





AGM held 23rd October 2009

## GOVERNANCE IMPROVEMENT

Family Advocacy's Treasurer, Lynette Bruce conducted an inhouse training for the Committee Members to strengthen the financial capability of the Management Committee. Family Advocacy thanks Lyn for her time in preparing and presenting the training material.



**Lynette Bruce**  
Treasurer

Lynette brings with her a wealth of executive and change management, financial and project management experience across a range of industries: aged care (current), acute care, retail, legal and local council. She utilises her financial and analytical skills to assess the strengths and weaknesses of organisations and facilitates change when necessary. Being currently an Aged Care CEO in a catholic organisation, she has a firm commitment to social justice and inclusion of people with disability. She also believes strongly that everybody has the right to live as completely as they can with the abilities they have. She endorses the philosophy of assisting people to fulfil their potential and giving them the tools to enable this.



**Anne Chaffey**  
Secretary

Anne and her husband live in Armidale, with their three sons, 23, 21 and 19 and a daughter 13. With a full time aide, her daughter has been able to attend

mainstream school and is now in year 7 at her local high school with her friends. Anne has always been a strong advocate for all of her children, actively supporting inclusion in mainstream schools, and has been involved with many community organisations, the majority of these in the disability field. Anne was a member of the National Disability & Ministerial Advisory Council with the Department of Family and Community Services, Indigenous Affairs. Anne brings her passion, experience and beliefs to this position on the committee.



**Linda Hughes**

Linda is from Newcastle, she lives with her 18 year old son and her partner. Her son has disability with high support needs; he is in year 12 and is studying via Distance Education. The work of Family Advocacy continues to inspire Linda: she is committed to her son having a good life where he is included as a valued member of the community. Linda's association with Family Advocacy began in the early nineties. She has previously served on the Management Committee for four years. After a year off the Committee, Linda returned in 2005 and served as Treasurer in 2006/2007 and Chair in 2007/2008.



**Maree Salzano**  
Chairperson

Maree lives with her family on the Northern Beaches of Sydney. Maree and her family are pursuing their vision of an inclusive and fulfilling life for their son. He is a happy and valued member of his local high school community. Maree is committed to promoting and protecting the rights and interests of people with disabilities. She works in her community advocating for and supporting people with disabilities ensuring their voices are heard and their needs recognized. Maree is committed to social justice and inclusion for all people regardless of ability. Maree has been Committee Chairperson for the past two terms.

Life consists not in holding good cards  
but in playing those you hold well.

JOSH BILLINGS



**Scott Phillips**

Scott and his wife live in southern Sydney. They have two children, aged 9 and 7. In 2007, Scott and his wife turned their efforts towards their daughter's successful inclusion into a typical class at a nearby public school. They have spoken at autism conferences, workshops and work with many families in similar circumstances. Scott was Family Advocacy's past Treasurer for 2 years.



**Alex Purvis**

Alex is a father of four children and lives in Grafton. For many years he has been involved in promoting the rights of his son. His knowledge of advocacy, legal and persuasive techniques were honed through his experiences in encouraging the education system to include all children. He has a particular interest in developing individualised self managed approaches. An innovative support arrangement has given his son a meaningful and enriched life. Alex has previously been on the Management Committee, including a term as Chairperson.



**Meg Sweeney**

Meg has been involved in advocacy for people with intellectual disability for over 17 years. Meg's experience has seen her serving on the Disability Council of NSW, acting as a Community Visitor, and achieving life member with the Institute of Family Advocacy and Leadership Development. She has been busy establishing her family in a new community having recently relocated from Wagga Wagga to Vincentia on the South Coast. Meg is passionate about assisting people to develop and maintain their own unique identity through valued roles and inclusive practice.



**Kate McNamara**

Kate lives in Stanmore with her husband and three daughters. The eldest is 13 and since her birth, Kate's focus and work (both paid and unpaid) has been in the disability field. Kate enjoys reading, tennis and live music and looks forward with interest to an on-going association with Family Advocacy.



**Amanda Fletcher**

Amanda lives in Sydney with her partner and two children, aged five and two. Amanda is currently facilitating enrolment for her daughter in the local school for 2011, with the support of her immediate community. She has had a wide variety of work experience including the childcare and finance areas. Amanda is a passionate advocate for her daughter and strives for both of her children to be valued members of the community. Amanda enjoys walking, baking, gardening, shopping and is known for saying hello to everyone!

**Catherine Hogan  
Public Officer**

Catherine is the Director of Family Advocacy and also holds the Public Officer role.

Seven committee meetings were convened over the financial year and were held as either a face to face meeting or a teleconference.



# Staff and Allies

## STAFF AND VOLUNTEERS

Full time:	Length of Service
Director - Catherine Hogan	14 years (6 years as Director)
Advocacy Development Coordinator - Kim Roots	5 years
Advocacy Development and Liaison Officer - Rick Hansen (from May 2010)	6 weeks
Information Coordinator - Trisha McIlroy (from June 2010)	4 weeks
Administrative Support Worker- Philippa FitzPatrick	7 years
Advocacy Project Officer - Chris Jackson (from June 2010)	1 week
Part time:	Length of Service
Systems Advocacy - Belinda Epstein-Frisch	15 years
Advocacy and Leadership Worker - Karen Tippet	2 years
Information Coordinator - Wendy McKinnon (until Dec 2009)	6 months
Office Administrator - Marybelle Ignacio	3 years
Systems Advocacy Worker - Sharon Williams (until Dec 2009)	10 months
Accounts Administrator - Carmen Daher (from Nov 2009 until Feb 2010)	4 months
Accounts and Administration Officer - Sally Goh (from June 2010)	2 weeks



Volunteer Session Leaders - Amber Paisley-Topp and Marianne Brazier

## CONSULTANTS

### Resourcing Families Project

Alison Plant

Mimi St John-Austin

### Supported Living

Lee-Anne Whitten



Lee-Anne Whitten,  
Consultant,  
Supported  
Living

### Work experience

Courtney Campbell  
(until October 2009)



Courtney  
Campbell

Nothing is particularly hard if  
you divide it into small jobs.

HENRY FORD



Karen Tippet, Sharon Williams, Kim Roots, Belinda Epstein-Frisch, Wendy McKinnon and (seated) Philippa FitzPatrick, Marybelle Ignacio and Catherine Hogan.

## VOLUNTEERS

Family Advocacy values the contribution made by our volunteers over 2009/2010.

There are many ways to volunteer for the organisation. Some people who live near the office offer to help with the administrative tasks involved with sending large mail outs to services and families, about upcoming events. This is invaluable, as Family Advocacy conducts an increasing number of workshops and events through the year.

Regional volunteers have provided important local knowledge and contacts so that we are more effective in reaching families and key organisations around NSW.

Others have assisted by collating survey information into a summarised format for easy analysis.

Contributions to Family Advocacy's *Families for Change* journal provided a meaningful platform to share stories between families around NSW.

Thank you to the following people who have actively given their time to Family Advocacy during 2009/2010.

Paivi Russanen  
Wendy McGlynn  
Gina Wilson-Burns  
Marianne Brazier  
Meaghan Sweeney  
Angela Guo  
Anita Speed  
Di Samuels  
Helen Durbidge  
Shari Raymond

Anita O'Brien  
Amanda Fletcher  
Maureen McLeish  
Courtney Campbell  
Wilma Reed  
Margaret Hardman  
Russell FitzPatrick  
Dianne Newey

Family Advocacy also recognise that there are many people who have passed on fliers and let others know about the work of the organisation and we thank you and appreciate this effort.

**Volunteer session leaders** provide a significant resource for Family Advocacy as they take time to travel with staff to present at workshops and events. The additional knowledge and skills of these session leaders gives a valuable perspective during these face to face events with families. Family Advocacy would also like to acknowledge the support of their families.

THANK YOU to the Volunteer Session Leaders in 2009/2010:

Marianne Brazier  
Amber Paisley-Topp  
Wendy McGlynn

## ADDITIONAL SUPPORTS

### Accounting and Finance

We value the accounting support and professional advice provided by Gary Jones of Gee Jay Computer Services. Payroll and account reconciliation were entrusted to Mussarrat Haq (until Oct 09).

### IT Support

We have collaborated closely with Andrew Kerr who has provided us with advice and support for all our website requirements. We have relied on Patrick Hasbani and his team at PCQuest for IT and computer maintenance support.

### Media Productions and Publications

We appreciate the spirit with which Jon Gallimore and his staff at BEE Printmail produce timely and dependable work in the printing of our brochures, fliers and reports throughout the year.

Thanks also to Paul Hardman of Trademark Design, for the design and layout of this Annual Report.

## STAKEHOLDERS AND ALLIES

Thank you to our colleagues and friends within these other important organisations. Family Advocacy does not function in isolation. Much of what we do and achieve is supported or aligned to the work of others in the sector:

The Australian and New Zealand SRV Group  
The Alberta Association for Community Living  
Michael Kendrick  
Foundations Forum  
ADHC Local Support Coordinators  
NSW Council on Intellectual Disability (CID)  
Disability Advocacy Network Australia (DANA)  
NSW Disability Advocacy Network (NDAN)  
People with Disability Australia  
The Multicultural Disability Advocacy Association

Thanks also to the many organisations that distribute our brochures and fliers.

# Membership

As an Incorporated Association, Family Advocacy has a membership base. Membership is an important factor in keeping community based organisations relevant and strong and Family Advocacy acknowledges and thanks members for their support during the 2009/2010 financial year. Family Advocacy has 156 financial members throughout NSW, from Cobar in the far west to Albury in the south and Tweed Heads in the north.

Membership is open to individuals only (not organisations or individuals representing organisations). The membership fee has not changed and remains at \$10 per person per year or \$20 per person for three years.

Financial membership connects people who share the aims and goals of Family Advocacy. All of Family Advocacy's members are committed to achieving a vision of a genuinely inclusive society and

our Management Committee is drawn from our membership base.

Some of the benefits of membership include:

- > receiving complimentary editions of Family Advocacy's journal, *Families for Change*, *Communiqué* and *Taking Action*;
- > links with others with similar ideas; and
- > the ability to nominate to become a member of the Management Committee.

## LOCATION OF MEMBERS



# Internal Management Accounts and Administration



SALLY GOH  
ACCOUNTS  
ADMINISTRATION OFFICER



MARYBELLE IGNACIO  
OFFICE  
ADMINISTRATOR



PHILIPPA FITZPATRICK  
ADMINISTRATIVE  
SUPPORT WORKER

**Family Advocacy as an organisation is growing and moving in new directions to reach more families. The management and administration team constantly seeks ways to maintain its support to staff and address its role in an efficient and cost effective manner.**

In order to address the needs of the new *Resourcing Families* Project, we have increased our personnel and correspondingly, increased logistics. We are in the process of improving our systems and technology area, while at the same time considering costs and environmental responsibility.

## EQUIPMENT

With the commencement of the *Resourcing Families* Project in the last quarter of the financial year, Family Advocacy geared itself up to address the logistical requirements of the project. Renovation of the office was undertaken to accommodate new staff. A vehicle was purchased to use for workshops, information sessions and other business travel. Additional computers and office furniture were required.

## INFORMATION TECHNOLOGY

### Database

For 2009/2010, there are a total of 10,676 entries in our database, up by 683 from the previous year. The database continues to grow as we receive new requests to be included on our mailing lists through workshops and contact with staff, as well as through the website. With the increase in staff and changing needs of

the organisation, we are looking to either upgrade our database or take up other options that are currently being explored

### Website

Over the past year, we incorporated into the website some online features that we are continuing to improve on, as follows:

- > registrations for various events
- > payments and donations through PayPal
- > subscription and requests to join mailing lists
- > requests for resources
- > sign ups for campaigns

We are in the process of exploring new ways of utilising the website and the internet to assist families to participate more actively, should they wish to, in campaigns and other activities promoted by Family Advocacy.

## OCCUPATIONAL HEALTH AND SAFETY

At Family Advocacy, we place importance on the safety of all staff, volunteers and visitors in the workplace. Regular safety inspections and workstation assessments are conducted. Training is provided to staff on the use of our evacuation chair, which may be required by a person using a wheelchair, in the case of an emergency. The organisation has a Fire Warden and Deputy Fire Warden who undergo emergency procedures and fire warden training, at least once a year. Evacuation drills are subsequently carried out.

## DATA COLLECTION AND CENSUS

In compliance with the requirements of our Federal and State funders, we continue to provide data on the organisation and its advocacy activities, client demographics and census information.

## ENVIRONMENTAL CONSCIOUSNESS

Family Advocacy takes its environmental responsibilities seriously and does its part in implementing practices that would minimise its impact on the environment. Recycled paper is used for internal purposes and all paper and cardboard that is no longer needed is collected for recycling.

For the past two years, emails have been a primary mode for information provision and communication with members, stakeholders and families. Emails have been used for distributing the Journal, Communiqué and Taking Action, event promotions, pre and post workshops communications and reaching out to volunteers. An increasing number of families and service providers have opted to receive information via email as opposed to post. Material that is posted is also minimised through targeting appropriate recipients, i.e. Workshops that cater for families of a particular age group.



# Treasurer's Report

LYNETTE BRUCE  
TREASURER



## I am pleased to present the Treasurer's Report on behalf of Family Advocacy's Management Committee.

Family Advocacy is growing. This year, new funding from Ageing, Disability and Home Care (ADHC) of the Department of Human Services NSW is being utilised for a new project - *Resourcing Families*. The project aims to provide families of children and young people with developmental disability with strategies to develop their vision and support networks, through advice, workshops, resources and mentoring opportunities.

Recurrent funding grants from the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and the State Government Department of Community Services (DoCS) through the Community Services Grant Program are supporting the ongoing programs and operations of Family Advocacy.

This year, Family Advocacy received a number of one off grants from various State Departments. What was previously known as the Department of Ageing, Disability and Home Care

(DADHC) provided a one off grant to provide information to families around the state on post school opportunities. A one off grant from the NSW Department of Education and Training (DET) was also received.

The organisation's liabilities can be fully funded from its accumulated provisions and the organisation continues in a sound financial position. A budget for 2010/2011 is in place.

### Donations

We would like to thank those who have provided their financial support throughout the year through their donations to the organisation:

Alexandra Leafé  
Laurel Prince  
Namira Williams  
George Crowley  
Robyn Steel  
David Phillips  
Doug & Jane Rodgers  
Sydney Taylor  
Alex Purvis  
Sandra Mistler  
Dianne Ward  
Christopher Lee

Greater Bldg Society  
Helen White  
Lyn Macey-Legge  
Beryl Dyer  
Chris Pollock  
Joyce Camilleri  
Jenny Price  
Kevin Lawler  
Mark Gaston  
Anastasia Anderson  
SA Davies  
Tony Wells  
Community Living Project  
Catherine Gale  
Sonia Mara  
Wilma Reibel  
Phillis Setchell  
Jim & Helen Meek  
Anne Cunningham

### Disclosure of Interests

In accordance with the requirements of the Rules of the Association, I advise members that no payments have been made to any committee member other than for reimbursements for out of pocket expenses incurred in the course of carrying out their function as committee members.

LYNETTE BRUCE  
TREASURER

### Recurrent funding and One off Grants for 2008/2009

Revenue from Commonwealth Government	\$232,399
Revenue from State Government	\$238,635
New recurrent funding from ADHC	\$200,000
One off grant from ADHC	\$ 25,800
One off grant from DET	\$ 30,900
Donations	\$ 1,428
<b>Total</b>	<b>\$729,162</b>





*family*

A D V O C A C Y