

family

A D V O C A C Y



Strength of Families



Strength of Communities



Strength of Advocacy

Family Advocacy

Annual Report 2015 | 2016

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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

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, statewide, community based advocacy organisation which promotes and protects the rights, needs and interests of children and adults with developmental disability.¹

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 with 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 with disability are vulnerable to oppression, exploitation, discrimination, segregation and rejection by society.

Principles about Families:

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

¹ Developmental disability includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida and multiple disability.

Objectives

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 disability can be supported within the context of family and community. This is because of:

- lack of information about alternatives to what is on offer
- isolation, vulnerability, extra pressures and financial costs
- lack of opportunities for community members to get to know and value individuals with 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 with 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 with disability.

As a result, the objectives 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
- (c) to provide an avenue for the development of leadership amongst families

- (d) to monitor and, where necessary, make representations about legislation, practices and policies which affect people with 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 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.

Chairperson's Report



Strength of families, strength of communities, strength of advocacy... this is our focus!

2015/2016 was a solid year for the organisation where consolidation and strategic planning were a key focus. Our "strength of" narrative was borne out of our collaborative strategic planning sessions to create a clear and strategic pathway for the coming years.

Cecile Sullivan Elder has continued to lead our organisation through the changing landscape of disability within Australia with a steady and calm approach. The brave new world of disability in Australia continues to reveal itself under the National Disability Insurance Scheme (NDIS) and we have seen more of our members join the rollout locations within New South Wales (NSW).

The future of funding for advocacy for people with disability is still largely at play. However, the united and collaborative approach with likeminded organisations to gain clarity and commitment has been a very positive step forward.

Attaining positive social roles for people with developmental disability through our advocacy and leadership development work is still our core business.

Thanks to our Advocacy Leadership and Development and Resourcing Families work areas, an amazing year of workshops and seminars saw us reach large numbers of participants, often in regions we had never travelled to before.

My personal highlights were the regional conferences *Harness the Possibilities: Enriching Lives in Changing Times* in Coffs Harbour, Wagga Wagga and Dubbo. These were amazing two day events with great participant numbers and fabulous feedback.

Our rundown of events reads like the lyrics of the "I've been everywhere, man" song. To our staff, presenters, support crew, volunteers and families who made the fifty-nine events possible, wow! What an amazing achievement!

Devolution of institutions is still on our radar. Safeguarding the futures of people with disability in NSW is paramount and we must all remain vigilant. Whilst the NDIS is taking much of the focus, we must not lose sight of the work still to be done in this area.

Inclusive education, despite all the years of success by so many members, still remains a hard slog for families.

A concerted and targeted approach to address this is underway both in NSW and Federally.

As I have stated in previous annual reports, Family Advocacy remains steady and strong - a testament to the incredible staff we have in our team.

Our Family Leaders, presenters and volunteers make the impossible seem possible. I particularly loved seeing presenters with disabilities taking centre stage at our sessions. These young adults whose families started on that ordinary path many years ago are now stepping into the self-advocacy role, not just for themselves, but for so many others.

In the 2015/2016 year we farewelled two staff members, Philippa and Claire, and we wish them both well.

A few changes in the Management Committee line up saw Amanda Fletcher and Matthew Dimmock step down and Sharon Williams join the team. Working alongside these three, as well as Meg Sweeney, Alex Purvis, Lesley Light, Linda Hughes and Alison Wilson is always a pleasure. They provide insights, experience and a tenacious commitment to the mission, vision and values of Family Advocacy and make my role as Chairperson an absolute pleasure. Whilst my tenure as Chairperson draws to an end I am confident the Management Committee and the team led by Cecile will continue to work together to ensure we remain as efficient and effective as we can.

To all our members and allies who continue to "change the world", thank you. I'm reminded of a great quote shared by Marshall Ganz, Harvard Kennedy School - "When I was young, I thought the fight for justice was a sprint. In my 30s I thought it was a marathon. Now, I realise it is a relay".

Thank you to all those who fought before us, and those coming along behind. We are making a difference, we will continue to make a difference and we will continue to share the baton until we're done.

Wishing everyone the very best for the forthcoming 2016/2017 year.

Gina Wilson-Burns
Chairperson

Highlights of the year 2015/2016

The 2015/2016 year has been such a busy and productive year it is worth noting some particular events that have led to many families connecting with Family Advocacy to deepen their thinking and to expand collective knowledge in promoting the rights and interests of people with developmental disability.

In February, Family Advocacy hosted a three day *Strengthening Social Advocacy* event with John Armstrong (Social Role Valorisation senior trainer) and Bob Lee (Sunshine Coast Citizen Advocacy). This workshop provided space for some critical thinking, robust conversations and powerful strategies to revitalise advocacy efforts both privately and more broadly.

In this time of sector change it is important to remain ever vigilant in our advocacy efforts to best shape and influence opportunities for people with disability. With this in mind we developed a one day workshop, *Families getting NDIS Ready*. The workshop involved two guest speakers; a family member sharing their NDIS experience and a representative from the National Disability Insurance Agency (NDIA) to answer participants' questions and provide some process details for families. A preplanning session and an advocacy tools session also formed part of the *Families Getting NDIS Ready* workshop. The participant feedback from these workshops was positive and well received and we will continue to deliver them across NSW throughout the 2016/2017 year.

Our ongoing focus on inclusive education of students with developmental disability led us to rewrite our one day workshop for families, *One of the Kids*. The strong values content of this workshop challenges current segregated options by clearly indicating evidence based research on the ongoing benefits of inclusive education for ALL students (with disability and without). Participants have the opportunity to share their own experiences and hear from a parent whose child is in the regular class at school, allowing for learnings around the challenges and importantly the possibilities.

All Students Learning Together – Taking Action on Education booklet was created to be part of the resource kit provided to participants at the *One of the Kids* workshops. This new resource has been well received and is a strong addition to our free resources for families seeking an inclusive education for their children. The booklet was reprinted to keep up with demand and we have been pleased that educators and early childhood professionals have been keen to have copies. We trust this leads to positive outcomes for students and good relationship building between families and educators.

Family Advocacy also linked up with Sydney law firms and family presenters for the *Future Planning* workshops. This was an effective approach to provide much wanted information and ideas around planning for the future. These workshops were delivered in Sydney and in three regional communities generating a lot of interest and practical strategies. Often future planning discussions are left too late, so in the *Future Planning* workshops we aimed to help families open up these conversations in a positive and continuing manner.



Highlights continued

Resourcing Families launched one of its most ambitious projects yet; three regional conferences held in Coffs Harbour, Wagga Wagga and Dubbo. Each two day event had an excellent array of speakers with experience, passion and insight for creating valued lives for people with disability. It was a wonderful opportunity to be able to bring such a quality event to regional centres across NSW. Generous funding for sponsorship enabled people with disability and family members to attend from rural and remote areas and join the conversation about raising expectations for people with disability through an individualised approach to life and support.

Other events continued to assist families to consider the importance of personalised supports for more meaningful lives for people with disability. Events shared strategies for self directing support, creative thinking, planning beyond traditional service models, employing staff, reshaping the paid support role, supported decision making and crafting valued roles for people. All of which were able to equip many to feel better prepared and ready to make the most of the opportunity to self direct individualised supports through the NDIS.

The Final Evaluation Report of the Resourcing Families Capacity Building Project from Griffith University and Queensland University of Technology was presented. It highlighted the importance and effectiveness of ongoing capacity building work to assist families to have the confidence and skills to make positive life changes on behalf of their family member with disability through personalised supports.

Financial members

151 (including 11 life members)

Contacts on our mailing list:

10,917

Number of enquiries:

476

Resources distributed:

71,377

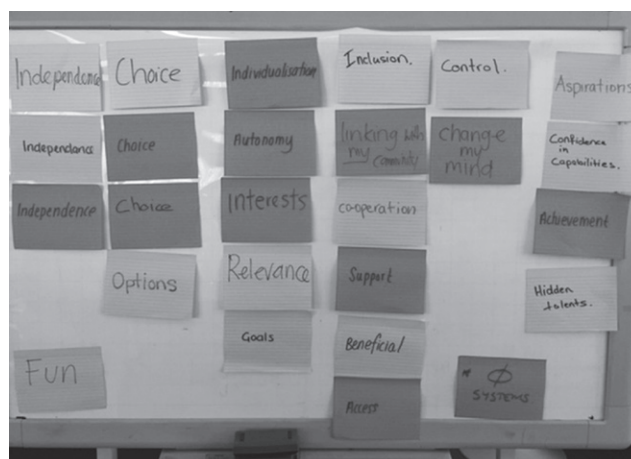
Website visits:

26,738

Number of people we engaged at events:

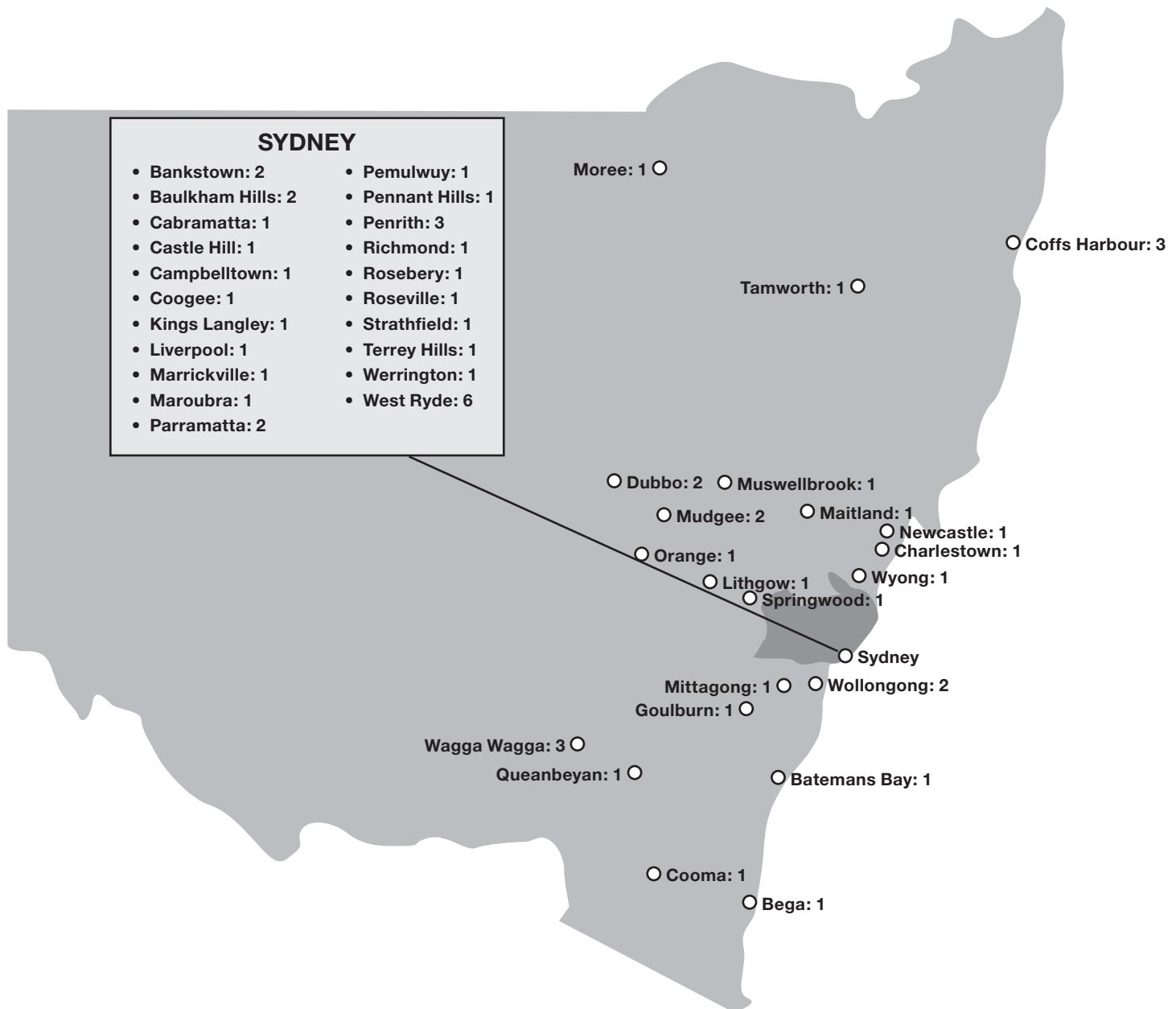
Family Advocacy:	527
Resourcing Families:	573
Combined Events:	391
Total:	1491

Family Advocacy's systemic work continued to emphasise inclusive housing and education systems. We pursued the issue of separating housing and support in the NSW Ageing Disability and Home Care (ADHC) transfer through a number of channels, building relationships from scratch with the Department of Premier and Cabinet, Disability Minister Ajaka's office and the new NDIA Director of Housing, Padmini Saxena. We joined with Council for Intellectual Disability (CID) and People with Disability Australia (PWDA) to call for better outcomes in the transfer. We also co-hosted an inclusive housing event at KPMG with other advocacy organisations, at which our secretary Meg Sweeney and her daughter Joscelyn presented. This strategy led to the two year lease arrangement with not for profits and a distinction to be made in service agreements between support provision and housing provision. In addition, the NDIA announced its view that housing and support should be provided separately and that the agency would not fund housing options with greater than five bedrooms.



Inclusive education remains a challenge for families and this year we reconvened the Education Working Group, a parent group who wish to take further systemic action for inclusive education. Through this group, parent interest in inclusive education as a human right became apparent, meaning we were able to draw on the recent United Nations General Comment on Inclusive Education as a resource. We made a lengthy submission to the Australian Senate inquiry regarding levels of attainment and access for students with disability and supported parents to do the same, as well as provided feedback on the Department of Education (DoE) inclusion plan. Our Chairperson, Gina Wilson-Burns, took a place on a DoE Stakeholder Advisory Group on specialist support provision and the Director of Learning and Engagement committed to meeting with the Education Working Group in the future.

Advocacy and leadership development and Resourcing Families events in 2015/2016



Advocacy and Leadership Development events 2015/2016

2015

July	Information session - Let's Get Started...Getting Ready for School and Life	Pennant Hills
August	Future Planning	West Ryde
September	Vietnamese information session - Importance of Advocacy and a Positive Vision	Cabramatta
October	What Makes A Home	West Ryde
	Life After School - Expanding Opportunities	West Ryde
November	Information session - Advocacy for People with Developmental Disability	Maroubra

2016

February	Information session - Advocacy for People with Developmental Disability	Baulkham Hills
	Strengthening Social Advocacy	West Ryde
March	Information session - Advocacy for People with Developmental Disability	Strathfield
	One of the Kids - Inclusive Education	Wollongong
April	One of the Kids - Inclusive Education	Coogee, Bankstown, Liverpool, Wagga Wagga
	Future Planning	Wagga Wagga
May	Future Planning	Coffs Harbour
	One of the Kids - Inclusive Education	Coffs Harbour, Maitland, Charlestown, Penrith, Castle Hill, Roseville
	Information session - Let's Get Started...Getting Ready for School and Life	Marrickville
	Information session - Let's Get Started...Getting Ready for School and Life	Penrith
June	Future Planning	Dubbo
	One of the Kids - Inclusive Education	Orange

Resourcing Families events 2015/2016

2015

August	Information session - Individualised Funding	Rosebery
	Information session - Getting Prepared - Professionals	Parramatta
September	Circles of Support	Kings Langley
	Information session - Individualised Funding	West Ryde
	Information session - Community Connections	Werrington
	Information session - Individualised Funding	Pemulwuy
October	Ideas for Self Directing Supports	Batemans Bay, Bega, Cooma, Queanbeyan and Goulburn
	Supported Decision Making	Wollongong, Parramatta, Newcastle

2016

February	Conference - Harness the Possibilities: Enriching Lives in Changing Times	Coffs Harbour
March	Conference - Harness the Possibilities: Enriching Lives in Changing Times	Wagga Wagga
	Information session - Getting Prepared	Baulkham Hills
May	Conference - Harness the Possibilities: Enriching Lives in Changing Times	Dubbo
June	Information session - Getting Prepared - Families	Mudgee
	Information session - Getting Prepared - Professionals	Mudgee

Combined events 2015/2016

2015

August	Families Getting NDIS Ready	Penrith, Richmond, Lithgow, Springwood
October	Crafting the Good Life	Terrey Hills
November	Families Getting NDIS Ready	Moree, Tamworth, Muswellbrook, Wyong

2016

June	Families Getting NDIS Ready	Campbelltown, Bankstown
	Information session - Advocacy for people with developmental disability	West Ryde

Key focus areas

- 1 Advocacy on behalf of people with developmental disability
- 2 Personalised support
- 3 Solid foundations for children 0-6
- 4 Inclusive education
- 5 Welcoming, inclusive communities
- 6 Meaningful adult lives
- 7 Family Advocacy is an ethical, prudent, and sustainable independent advocacy organisation

1. Advocacy on behalf of people with developmental disability

People with developmental disability continue to be subject to discrimination, exploitation, oppression, segregation and rejection. Family Advocacy is proactive and reactive in systemic advocacy, leadership development and continued development of independent advocacy. Family Advocacy will act with minimum conflict of interest in order to promote, protect and defend the interests, rights and needs of people with developmental disability.

Strengthening Social Advocacy

Presented by John Armstrong and Bob Lee

John Armstrong (Social Role Valorisation senior trainer) and Bob Lee (Sunshine Coast Citizen Advocacy) conducted a three day *Strengthening Social Advocacy* workshop hosted by Family Advocacy. This workshop was for people sincerely interested in strengthening their advocacy and protection efforts on behalf of disadvantaged and vulnerable parties. The workshop covered the major components of advocacy including intrinsic issues facing people with cognitive impairment, how advocacy can contradict social policy and provided many strategies to be effective in our advocacy efforts.

Staff, Management Committee and five Family Leaders were sponsored from across the state to be part of this learning opportunity.

Participant feedback:

- > *Very empowering. Engaging & thought provoking. Challenged my thinking - energised me.*
- > *Bob & John are both incredible speakers. Fabulous presenters, wealth of knowledge.*



Families Getting NDIS Ready

The advocacy component of this workshop was to ensure that families were well equipped with strong advocacy skills in order to make the most of these emerging opportunities for people with developmental disability. As the NDIS rolls out across the state, Family Advocacy is well aware that strong advocacy skills are vital in making this new scheme work toward people with disability having good lives with real choices. The workshop clarified the need for advocacy with the aim to deepen the understanding of the barriers facing families



in accessing and getting the most out of the scheme and the importance of advocacy to address this. Over this financial year we have conducted ten of these workshops alongside the Resourcing Families team. Participant feedback:

- > *Great workshop with all the relevant information needed.*
- > *Well presented. Cleared up misconceptions.*
- > *It was great. I have been to a few information sessions. This has filled in a lot of gaps! Personal accounts were very useful and motivating*

Taking Action for a Good Life

We have, by invitation, conducted specific advocacy presentations to family groups on four occasions thereby extending our reach to families. This presentation has always aimed to strengthen the understanding of the need and purpose of advocacy on behalf of people with disability. Advocacy skills and a framework for effective advocacy form part of the content.

One of the presentations was to a culturally and linguistically diverse (CALD) Vietnamese parent group where documents were translated and an interpreter was available. A presentation was also delivered to a 3rd Year undergraduate class studying inclusion. Participants from these events received a resource which outlined the tools for being an effective advocate. Participants were encouraged to make contact with Family Advocacy to

discuss any specific issues and barriers they may be facing.

Participant feedback:

- > *Thanks for your presentation last week, our families really got a lot out of it. I appreciate your time and sharing.*

A 45 minute version of the *Taking Action for a Good Life* advocacy presentation was delivered at each of the three regional conferences held across NSW. There has been interest from some of the attendees of these sessions to have a full presentation delivered to families in their locations in the future.

Advocacy related advice and information enquiries

Throughout 2015/2016, an important part of the work of Family Advocacy continued to be the provision of advocacy related information and advice to the families, friends and allies of people with disability.

Family members and others have made contact to receive ideas and information to enable them to advocate around the rights and interests of the person with disability. People can receive advocacy related information and advice as often as they need to and this varies according to the nature and the level of complexity of the topic.

Communication is most frequently via telephone and email, while some people have visited the Family Advocacy office. There is a toll free 1800 telephone number available to ensure that people living outside the Sydney metropolitan area have access to information and advice offered by us.

There has been an extensive amount of topics that have been discussed throughout the year. Such discussions have exposed the challenges and topics of interest when speaking with families.

Education continues to form a large part of our contact with families with just over one third of all enquiries taken on educational matters.

Barriers families are facing in education continue to include:

- unwelcoming culture of schools impeding the student from being fully included
- suspending students without proper consideration of the impact of their disability and not putting better processes in place to counter this
- limited parental involvement to contribute to setting goals and strategies for the student
- coercing parents to consider segregated school settings
- discouraging enrolments of students with disability and continuing to cite funding as being a reason for not having a student at the school.

Family Advocacy continues to assist families to advocate in a positive way with their school to respond to the barriers listed above and to create a good learning environment for their family member with disability. The knowledge and understanding we receive from families then informs our systemic work to affect broader change.

With changes to the disability sector by way of the NDIS there were many enquiries from families seeking clarity around the scheme and its impact for their family member. A lot of miscommunication and conflicting information has been apparent which only creates anxiety and misunderstanding. Family Advocacy aims to assist families with up to date information, provide an understanding around the processes and raise the expectations of what this scheme can deliver for people through clearer information and advocacy tools. Calls around the NDIS have become the second largest area of enquiry in this financial year. Perhaps due to the changes in the sector there has been an increase in enquiries citing discrimination and gaps in service provision as the reason for their call to Family Advocacy.

There was also a noteworthy amount of enquiries from families who were contacting Family Advocacy around pursuing opportunities post school and planning for the future. These enquiries included information about making

the most of these opportunities and transition times, the expectations of a good life and a clearer understanding of the importance of advocating in making change on behalf of their family member.

Responses to each enquiry will depend on the individual circumstances but typically may include:

- considering strategies with the individual to formulate a course of action
- providing resources such as articles or documents to increase knowledge and assist people in coming to an informed decision
- advising contact details for other organisations when the request is outside the expertise of Family Advocacy (e.g. legal matters)
- linking the person seeking information to another family with insights to share
- gathering research around a specific topic to ensure that up to date information or new perspectives are supplied
- making contact with senior decision makers where an issue is of systemic significance.

Family Advocacy gathers this information to highlight statewide trends and enable responsive planning. It also informs the organisation of systemic issues that are able to be raised in appropriate forums and with appropriate decision makers.

CASE STUDY: Family Story One

A parent rang who was recommended to call by a friend. Her son was having difficulty at the Catholic primary school he was attending. Communication with the school had become very tense and the parents were being asked to sign documents that said they had requested their son to be partially enrolled. The parents did not sign and then rang Family Advocacy for assistance.

Family Advocacy was able to support the family in their discussions with the school in order to reconcile the relationship and move things forward. The family were also linked to another parent in the area who offered further support and shared her lived experience. The mother attended Family Advocacy's *One of the Kids* one day workshop on inclusive education to receive more understanding and knowledge around their expectations of the school and building effective communication and advocacy strategies.

CASE STUDY: Family Story Two

A parent who had received past assistance from Family Advocacy made contact to receive clarity around her son's post school funding. The parent was given current guidelines on use of the funding, expectations of the service provider and an understanding of the appeals process. The conversation also involved some ideas of how other families use this funding in creative ways to achieve more individual arrangements.

Breakdown of Enquiries

Education	33%
NDIS	11%
Future Planning	5.8%
Systems Issue	5.8%
Post School Support	5.4%
Services (gaps, access, policy)	5.4%
Discrimination	5.2%
Accommodation	4.8%
Recreational	4.2%
Individualised Funding	3.4%
Isolation	3.4%
Legal	3.4%
Employment	2%
Abuse/Neglect	<2%
Equipment (and aids)	<2%
Finances (including subsidies & entitlements)	<2%
Health	<2%
Independent Living Support	<2%
Transport	<2%

Leadership development and training

Leadership development and training at Family Advocacy involves the encouragement and nurturing of parents, other relatives and friends to take on leadership roles. In 2015/2016 there was a continued approach to engage younger families and siblings to further their participation in advocacy and their connections with Family Advocacy.

There have been many ways of supporting leadership development. Families have shared their knowledge on a broader level within workshops and information sessions as a guest speaker and as part of the workshop audience.

Family Advocacy has also supported family members to:

- attend events sponsored by Family Advocacy
- enhance their skills and knowledge by undergoing specific training
- provide values based training for deeper understanding and community building
- present and assist at Family Advocacy workshops
- contribute stories to be shared at events
- contribute articles to the Family Advocacy library and websites
- attend and participate in meetings with politicians or senior bureaucrats.

Developing advocacy skills

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

Family Advocacy recognises families are in the best position to be effective advocates for their family member/s with disability and believes in the importance of events that develop the connections, awareness and individual skills of families. Family Advocacy has provided many exciting opportunities for family members to increase their skills in the past year.

Families can take on leadership roles and influence change within their own family, in their community, assisting with the work of Family Advocacy and in broader arenas on behalf of people with disability.

Family Advocacy encouraged individuals who expressed an interest in becoming a Family Leader to gradually increase their skills, competence and confidence. Being a Family Leader involves presenting material and facilitating group work at workshops, information sessions and conferences across NSW. It is also a great way to meet a wide and diverse range of people to expand knowledge and share experiences.

Training for Family Leaders is ongoing for those who take on this role. Family Leaders increase their level of participation at a rate and in a way that suits them. To ensure that they are as confident, prepared and professional as possible, relevant workshop materials are supplied and discussed in advance.

Self-evaluation is encouraged and feedback offered. As well as contributing personal knowledge and experience at Family Advocacy workshops, Family Leaders gain skills and strategies that are useful when advocating for the rights and interests of their own family member with disability and when planning for his or her future

Attending Events

As part of our leadership development strategy Family Advocacy may provide sponsorship to families to attend events. These events may be run by other organisations as well as events run by Family Advocacy. This strengthens knowledge, allows for networking and encourages idea generation.



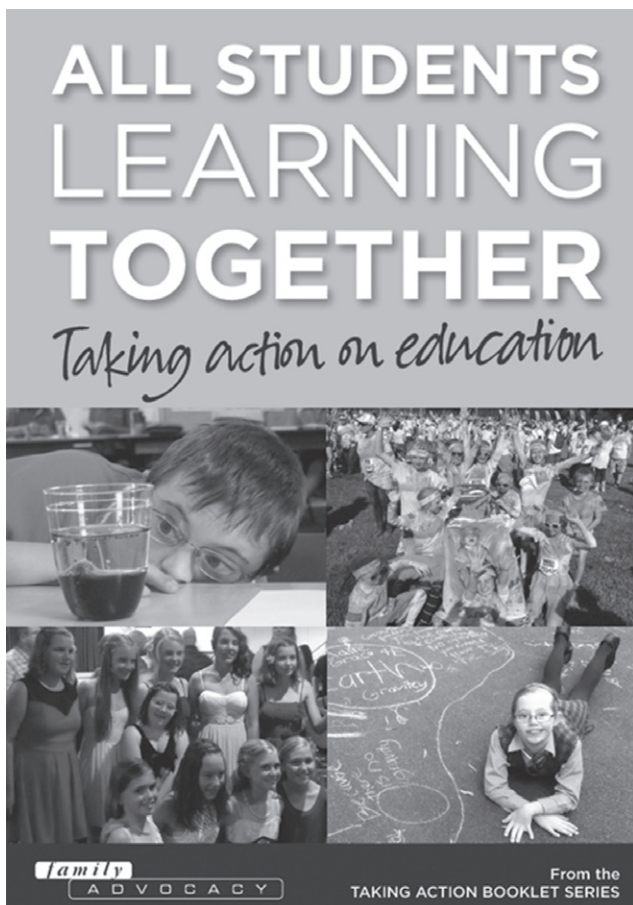
Some events families were supported to attend were:

- *Crafting the Good Life...with Darcy Elks*, Family Advocacy, Sydney
- *Belonging Matters Conference*, Belonging Matters, Melbourne
- *Towards a Better Life*, Social Role Valorisation two day training, Foundations Forum, Sydney
- *PASSING*, Social Role Valorisation 5 day practicum training, Foundations Forum, Sydney
- *Inclusive Education: Opening up university life*, Sydney University, Sydney
- *Inclusive Education Summit: Making sense of everyday practice*, Victoria Institute, Melbourne
- *Strengthening Social Advocacy* workshop, Family Advocacy, Sydney
- *Inclusive Education: One of the Kids*, Family Advocacy
- *Future Planning*, Family Advocacy
- *Harness the Possibilities* Regional conferences, Resourcing Families, Coffs Harbour, Wagga Wagga and Dubbo.

Resources

Family Advocacy aims to provide useful and practical information that will complement and extend the learnings from the various workshops and leadership development opportunities.

This year we have completed the development of a booklet on inclusive education – *All Students Learning Together: Taking Action on Education*. This booklet has been extremely well received and has been requested to be translated.



Systemic Advocacy: A snapshot of our work

Issue: National Disability Advocacy Program

The Federal Government released a discussion paper for the review of the National Disability Advocacy Program (NDAP).

What we did:

We responded to the discussion paper and review of the NDAP at length, in consultation with parents and experts. In particular we argued for family advocacy as a model to be spread nationally, in order to address government concerns about access to advocacy, and Family Advocacy's concerns about the continuation of the family advocacy model.

We met with Shadow Minister Jennie Macklin in the lead up to the federal election and gained her assurance that Labor would continue to fund advocacy organisations, not only peaks.

Family Advocacy continued to take an active role in the Disability Network Forum (DNF) and New South Wales Disability Advocacy Network (NDAN). Most notably this has led to collaboration on submissions and our Executive Officer is now taking a leadership role in NDAN.

Outcome:

The results of the NDAP review have not yet been released.

2. Personalised support¹

Having control over what, when, where and by whom supports are provided, increases the opportunities for people with developmental disability to lead full and meaningful lives included in their communities.

Family Advocacy will influence opportunities for people with developmental disability to have access to personalised supports and enhance people's capacity to take up those opportunities.



Throughout 2015/2016 Resourcing Families continued to work towards raising expectations of valued lives for people with disability as active members of their communities. Information, events and resources shared family stories and practical ideas for developing a positive vision, building support networks, creating meaningful community connections and self directing life and supports. As the NDIS continued to roll out there were increasing opportunities to share with families the advantages of a personalised approach to support with strategies for tailoring supports to an individual's genuine aspirations. Resourcing Families continued to make new resources available on the Resourcing Families website and support families with information and ideas via phone, email and face to face meetings when possible to assist people to self direct pathways towards real inclusion.

Capacity Building Project

Resourcing Families is funded by the NSW Department of Family and Community Services (FACS), Aging Disability and Home Care (ADHC) as one of nine organisations providing capacity building for people with disability and families in the Getting Prepared program. The focus is on assisting people to develop confidence and skills to self direct individualised supports in preparation for the NDIS.

1. Personalised support is optimised when:
 - a. the individual is at the centre of informed decision making
 - b. supported decision making is included
 - c. family members are partners in that informed decision making
 - d. planning is directed by the person and their family/ support network
 - e. there is a separation between planning and service provision
 - f. paid support complements rather than replaces informal support.

Families Getting NDIS Ready

Resourcing Families partnered with Advocacy and Leadership Development to create a workshop called *Families Getting NDIS Ready*. Jan Kruger and, in later workshops, Caroline Daley shared from a family perspective their journey to support their family member into the NDIS. Each shared how their vision of a meaningful and inclusive life in typical community gave them the confidence to set goals and shape an NDIS plan that facilitated skill development and connections with others. The workshop also included opportunities for families to explore strategies to raise expectations, think creatively and plan for an individual. There was a session to pose questions to a representative from the NDIA and another about effective advocacy in a changing support environment.

Participant feedback:

- > *Cleared the fog. Gave me clear guidelines for where to start and how the system should work.*
- > *The world is my son's oyster now. With the right planning his [son] dreams may happen with his hard work. I no longer have to tell him no, he can't but he can try. I can work towards his goals and what he wants out of life.*
- > *Excellent. Really valued Jan's personal experience with NDIS. Although very different situation to my own it was thought provoking. Appreciated being able to attend this in my local area instead of having to travel to Penrith or city. Thank you.*
- > *Very informative and an atmosphere where it felt safe to speak out.*

Ideas for Self Directing Supports

Ideas for Self Directing Supports presented by Meg Sweeney, was workshop five in the workshop series, *Keys to Developing Meaningful Lives*, which was presented in seven locations around NSW in 2014/2015. The interest in this workshop resulted in another five workshops being presented in October 2015 in Southern NSW. The workshop explored ways to self direct supports, including ideas for recruiting and employing your own staff and shaping staff roles to match the interests and roles that a person with disability wishes to pursue.

Participant feedback:

- > *Lots of great ideas about how to implement self-managed funding but particularly around strategies for employing appropriate staff.*
- > *I have learned many things – am very glad I took notes! The worksheets in the blue folder will be very helpful.*
- > *Great workshop – valid and ‘real’ information.*
- > *I have learned how to start the ball rolling. I am so glad I came – thank you!*
- > *The presentation made ‘a good life’ seem realistic and achievable. Love coming to workshops as they are very informative and get you thinking*



Supported Decision Making

Darcy Elks, educator and consultant from the United States presented a *Supported Decision Making* workshop to explore how families can support their loved one with disability to develop their own self determination and learn to make their own decisions. Supported decision making, as an alternative to substitute decision making, is an important means for people with disability and their families to develop the skills to have choice and control over their own lives.

Crafting the Good Life

Resourcing Families and Advocacy and Leadership Development joined together to host a family member weekend retreat facilitated by Darcy. The event was held in Sydney but participants were sponsored to attend from across NSW and came from Sydney, Albury, Nowra, Wagga Wagga, Broken Hill, Tweed Heads, Lismore and Wollongong. Couples were encouraged to attend and 19 family members participated. Resourcing Families had met a number of the people who attended the weekend event during the *Keys to Developing Meaningful Lives* workshop series of 2014/2015. These participants had attended a number of workshops in the series and were inspired to take action to move to individualised support for their family member. The weekend event was intended as a more intensive capacity building opportunity for these families and others to keep the momentum going for change with new inspiration, ideas and a supportive space to share and problem solve challenges or potential barriers.

Harness the Possibilities: Enriching Lives in Changing Times

In the first half of 2016, Resourcing Families presented three two-day regional conferences in Coffs Harbour, Wagga Wagga and Dubbo. This was a great opportunity to bring a large event to regional, rural and remote areas and provide information about the national reforms of the NDIS and showcase people tailoring supports to live lives of their own choosing. Conference speakers came from across Australia and included people with disability, family members, policy advisers, educators, researchers, international consultants, community mobilisers and advocates. Each speaker championed enriched lives that defy histories of low expectations and imposed limitations for people with disability through their lives, work and love of people dear to them. The majority of speakers had lived experience as family members of people with disability and shared how, with a positive vision of the future, they had shaped inclusive lives for their family member with genuine community connection.

The conferences included a question and answer panel about the NDIS, presentations on the nature and intent of the national reforms and NDIS participants talking about supporting real inclusion through the NDIS.

Sponsorship was available for people with disability and family members to attend and included conference fees, travel, accommodation and family support. Resourcing Families was able to sponsor 119 people to attend either the Coffs Harbour, Wagga Wagga or Dubbo conference.

Resourcing Families invited the Aboriginal Disability Network NSW (ADN NSW) to share their *Living My Way* teaching during breakout sessions at the conferences. A number of Aboriginal people known through ADN NSW were also sponsored to attend.



Participant feedback:

- > *The conference was one of the best, providing the right information at the right time and also relevant info. Very professional management of the event.*
- > *As a new carer to my granddaughter I have found this conference very empowering. I have plenty of new knowledge to take home and start planning with my granddaughter. I will be asking her about her dreams and future visions.*
- > *The Conference has been uplifting, positive, thought provoking, educational and resourceful. I am leaving in a different frame of mind to any other conference discussing issues around disabilities. Very professionally presented. THANK YOU!*
- > *I feel inspired after today... To make my brother's life [a] more inclusive lifestyle so he gains more friendships with peers his own age and has friends that look out for him and make him feel valued. I want him to feel a huge sense of belonging and happiness.*
- > *The sharing of personal insights/ journeys/ lived experience was powerful, informative and highly motivating. I think the part of the program brought 'reality' to phrases that are over used but under exemplified or enacted.*

Final Evaluation Report

The Final Evaluation Report of the Resourcing Families Capacity Building Project from Griffith University and Queensland University of Technology was presented in October 2015. The ADHC funded evaluation investigated the impact of the project on assisting families to have the information, confidence and skills to self direct supports, strengthen their networks and raise expectations for a better life for their family member with disability as valued members of the wider community. Research findings highlighted that families can make significant changes towards positive developments in the life of their family member when given the skills, opportunities and resources to do so.

Information sessions

Resourcing Families presented a number of information sessions for parent groups around the state upon request. Information sessions cover topics such as visioning better for valued lives for people, the opportunities to self direct through individualised funding, how to build up support networks through circles of support and ideas to kick-start personal planning for individualised supports. Parent groups have included early childhood groups, CALD groups, families whose family members have recently transitioned from large residential care facilities and groups wanting to prepare for the NDIS. Resourcing Families was also invited to present to groups of service workers to share how we are able to assist families they work with and the resources we have available for families to develop personalised supports.

Systemic Advocacy: A snapshot of our work

Issue: Self directed supports/personalised approaches

The Commonwealth Department of Social Services (DSS) conducted a review of employment services.

What we did:

Family Advocacy attended a consultation and provided extensive feedback to the DSS.

We commended the individualised approach that is similar to funding for other services under the NDIS and ends the block funding of sheltered workshops (Australian Disability Enterprises or ADEs), however, we also noted the risks of subsidised wage and tax incentives leading to potential abuse by employers or 'ghettos' of people with disability in particular employment.

Outcome:

The DSS has a new website outlining the various approaches to employment support. ADEs will now have to compete for funding with other services and will no longer be block funded.

Issue: Self directed supports/personalised approaches

The transfer of ADHC services to the not for profit sector was ongoing, with lack of clarity about consumer and advocate input into this process.

What we did:

Family Advocacy formed a joint position statement with CID, PWDA and the Carer's Alliance. The joint position statement called on ADHC to tender in the smallest possible manner to ensure diversity. It also included a push for ADHC owned housing to remain separate to support services, ensure independent consumer input in the tender process and provide funding for decision supports and advocacy.

Outcome:

This strategy led to the two year lease arrangement with not for profits and a distinction to be made in service agreements between support provision and housing provision. In addition, the NDIA announced its view that housing and support should be provided separately and that the agency would not fund housing options with greater than five bedrooms.

3. Solid foundations for children 0-6

Getting off to a good start in life is vitally important for all children, particularly children with developmental disability. A good start means to start on a path that keeps the child embedded in their family and community.

The 'special and separate' path can leave children and families isolated, vulnerable and disconnected from the typical and ordinary environments other children and families enjoy.

Family Advocacy's aim is that all children are supported in age appropriate ways to be active members of their families and communities.

Let's Get Started

This two hour presentation is about the key transition point of moving into school. Family Advocacy was invited to speak with families from three early intervention childcare centres. These organisations have invited Family Advocacy to deliver these presentations as part of their program supporting families to transition to school.

This transition point is a time when families are making key choices on schooling for their child and often miss out on information around supports and benefits of being educated in the regular education class. Other families say they are often challenged around their decision to have their children educated in the regular class at school. The aim of the presentation was to assist families to have a clear vision, consider schooling choices from evidence base and whole of life thinking and apply strategies for communicating with schools.

This was an important presentation reaching families early on their journey with their children.

Participants particularly valued the insights and experiences shared by a Family Leader who was also able to answer questions.

4. Inclusive education

Family Advocacy recognises the many barriers faced by children with disability and their families in enabling students to be included in regular learning environments.

Family Advocacy's aim is that all children with developmental disability are welcomed and educated, with adequate support, in the same learning environment as their non-disabled peers. This includes early childhood education, school and post school education systems.

One of the Kids: Inclusive Education

Twelve workshops held throughout NSW, March to June 2016

These workshops were made possible through the Grant in Aid funding from DoE and is appropriate for families of preschool, primary and high school students looking to learn advocacy skills and strategies to assist in achieving an inclusive education for their children with disability.

One of the Kids covered topics such as how the school years can lead to a meaningful life, a brief history of disability education, what an inclusive education looks like, evidence and support for inclusive education, how inclusion can look in the classroom, education policies and supports that exist within schools as well as necessary advocacy tools and strategies for families.

The workshops provided an opportunity for good and often challenging discussions. Families made the most of networking with others and asking questions around their own specific issues. Evaluations indicated that people's expectations of the workshop were either met or exceeded. Over the year we have spoken to just under 100 people around NSW about inclusive education and will look to further these relationships and support of these families.

Many resources were provided on the day and also in a follow up email to continue the thinking and encourage families to further their knowledge and understanding. The new education booklet, *All Students Learning Together - Taking Action on Education*, was provided to all participants and extra copies were available for them to take to share with others. Evaluations have indicated that participants were pleased with the amount of information shared.

Participant feedback:

- > *The real family stories that were shared really brought to light not just challenges but also possibilities*
- > *Very good and helpful seminar, has given me the confidence and courage to keep advocating for my child's needs to be met*
- > *Also learned the importance of aide time being for the whole class and ways we can receive assistance/funding while using things that value his skills*
- > *It was more comprehensive than what I envisaged; the stories and videos were particularly inspiring*
- > *I really liked the information provided, it gave me a lot to think about and more confidence in knowledge and understanding to advocate for my children within school environment*



Resources

All Students Learning Together - Taking Action on Education

This booklet was provided to attendees at all of our education focussed events as well as at conferences held by both Family Advocacy and other organisations and departments including the Department of Education's Principals Conference. The booklet has been printed with funding received by FACS.

Since February this year we distributed 5000 booklets and reprinted the resource. The booklet continues to be widely distributed and we are taking many opportunities to have this broadly available in our communities, schools and early childhood centres.

A particular thankyou to the family members who have taken extra booklets to share in their local areas and it is through this support that Family Advocacy is able to have a better reach into communities throughout NSW.

Systemic Advocacy: A snapshot of our work

Issue: Education of children and young people with developmental disability in NSW schools

What we did:

During 2015/2016 we made representations to the federal Senate Inquiry into Education and Attainment for School Students with Disability and supported a number of families to respond. We also held a meeting with Melissa Clements, Director of Disability programs in DoE to discuss ongoing communication as the NDIS rolls out and another meeting with Melissa and Brian Smyth-King, Executive Director of Learning and Engagement, to raise the issues of concern including pressures parents face not to enrol their children in regular class.

We provided feedback on the DoE Inclusion Plan, which whilst stating it had an aim for more people with disability to access mainstream services, had no plan to increase numbers of children with disability in regular classes. We reached out to parents for their feedback and wrote a submission about this and other elements of the plan.

We participated in an audit conducted by the Audit Office of NSW that was assessing the performance of DoE in Supporting Students with Disability in NSW Public Schools. This participation also extended to relevant families from around NSW being linked into this performance audit through feedback opportunities.

We reconvened the Education Working Group, a group of members with school aged children wanting to make systemic change in the education system. This resulted in:

- a blog post on the FA website about the UN Draft General Comment on the Right to Inclusive Education
- a guide for family members on how to distribute the *All Children Learning Together - Taking Action on Education* booklet, produced by a family member and the Advocacy and Leadership Development team

- an invitation to the Executive Director of Learning and Engagement in NSW DoE, which he accepted.

We wrote to the Federal Minister in the lead up to the Federal election and met with his Adviser on Education, securing an ongoing relationship post-election.

We also contributed to the five-yearly review of the Disability Standards in Education and supported several families to respond.

Outcome:

The report from the Senate inquiry cited our submission and made many positive recommendations about improving access and attainment for children with disabilities.

Through meeting with DoE we secured a place for Family Advocacy Chairperson, Gina Wilson-Burns on the DoE's Stakeholder Advisory Group for Specialist Support Class Provisions.

The report on the review of the Disability Standards showed a number of recommendations in line with Family Advocacy's lobbying efforts, such as:

Recommendation 2: *That the Australian Government work with State and Territory Governments to ensure that accessible summaries of rights, obligations and complaints processes is provided to all prospective students as part of enrolment processes in every education setting.*

Recommendation 4: *That the Australian Government work with professional bodies for educators (and education administrators) to strengthen access to and uptake of substantive training in disability in pre-service and in-service training, to support the effective implementation of the Standards.*

Issue: Inclusive adult education

What we did:

Family Advocacy is a member of the Steering committee for inclusive education at University of Sydney run by Centre for Disability Studies, promoting the inclusion of people with disability in mainstream post-secondary education.

Outcome:

We continue to remain on this steering committee to work towards furthering this opportunity for people with disability across the state.

5. Welcoming, inclusive communities

Communities are places of great possibility for natural supports and opportunities for people with developmental disability.

Family Advocacy enhances the capacity of families to develop and contribute to welcoming, inclusive communities.

Systemic Advocacy: A snapshot of our work

Issue: Devolution

The Stockton Centre remains open despite long term bi-partisan support for closure.

What we did:

We sit on the Community Living Consultation group hosted by the Ombudsman and provided feedback on the Stockton devolution process. Through this process, as well as the Ombudsman's roundtable, we were able to speak up for the ongoing closure of Stockton, access to advocacy information for families, and individual housing.

Outcome:

Family Advocacy was able to present to families whose family members were moving out of larger residential centres, after persistent lobbying of ADHC.

The Labor Party Spokesperson for Disability Services reconfirmed their commitment to the closure of Stockton during the NSW state election.

6. Meaningful adult lives

Many people with developmental disability experience low expectations and limited opportunities that prevent the development of valued social roles.

Family Advocacy's aim is that all adults with developmental disability have lives that are rich with valued adult roles and have opportunities for personal growth and development, lifelong learning, employment, relationship building and supported living.

Future Planning for people with disability

Presented by Catherine Hogan (consultant and parent), Wendy Stroeve (parent), Matthew Dimmock (parent) and Georgina Perry (Ashurst Law Firm)

Family Advocacy held a Saturday event on future planning with the aim of the day to assist families to be thinking critically about the future of their family member. The planning and preparation went beyond the legal pathways and this event aimed to provide families with solid ideas such as the importance of a vision in planning, how important it is to open up the conversation and begin the process, as well as ideas on what families can start doing now.

Ashurst Law Firm presented a two hour session in the afternoon of this workshop around wills and trusts as well as the appointment of guardianship and power of attorney.

Participant feedback:

- > *Thank you, a very well-constructed workshop with lots of practical advice*

Future Planning for people with disability

Presented by Catherine Hogan (consultant and parent) and Anne Cregan (Gilbert & Tobin Law firm)

The *Future Planning* event was delivered in three regional locations; Coffs Harbour, Wagga Wagga and Dubbo. The format mirrored the event previously described with a family presenting in the morning and the legal session in the afternoon. This workshop was very well received with many bringing partners, siblings and others in their extended family along which we encouraged through our promotions.

Participant feedback:

- > *Speakers were very informative – very relatable examples of people's lives!*
- > *Most helpful, loved the stories shared and very interesting getting legal perspective instead of hearsay around attorney/tribunal/guardianship etc.*

Life after school – Expanding opportunities

A conversation with Darcy Elks

The presenter Darcy Elks, is a parent of three adult children, one of whom has a disability. Darcy has an indepth knowledge of working with people who are marginalised in society. Through positive encouragement of social value and inclusion for people with disability, Darcy addressed the issue of those who are devalued in society in a practical and proactive way.

This three hour conversation aimed to achieve a relaxing more informal evening which works well with Darcy's style.

Eleven families attended and two brought their family members with them and it was really encouraging to see their family member being actively involved in the planning of their adult life. Darcy and others were able to share stories and ideas from the lives of their own family members. The group had questions and comments that allowed us to consider the current system operating in NSW and the changing landscape. This inspired new thinking and ideas for the future. All attendees stayed on to chat further and also make connections with one another.

Participant feedback:

- > *Wonderful to hear sister's stories*
- > *Great to get ideas to maximise our vision for our child*

What Makes a Home?

Presented by Darcy Elks

This one day workshop aimed to assist families in thinking of the true meaning of home with an emphasis on the difference between a house and a home. It was valuable to have three family stories being shared on the day which highlighted the planning and preparation required. The families all shared their stories and perspectives through an interview style presentation facilitated by Darcy. This section was also filmed and will be available on our YouTube channel.

Participant feedback:

- > *Darcy was [is] a wonderful speaker & facilitator.*

> *Very educational and informative.*

> *Has given me the opportunity to follow some other options.*

Crafting the Good Life

Presented by Darcy Elks

This weekend event provided an opportunity for families who have had a connection with Family Advocacy either through workshops or through general enquiries. The intention of the weekend was to deepen their vision for their family member and strengthen the pathway to meaningful, authentic and inclusive lives for their family members.

Attendees received a substantial resource pack and many links and articles were also provided on a USB drive. Family leaders facilitated groups over the weekend which heightened people's understanding and provided opportunities to learn from the experiences of others.

Participant feedback:

- > *I will now view my family member as a very able, resilient, strong and gifted human being.*
- > *I feel more confident and empowered to allow [A] to develop a vision and start to put it into place.*
- > *It has opened up a new level of thinking outside 'the square'*
- > *Thank you for existing Family Advocacy, your depth of resources and practical help are invaluable*



Systemic Advocacy: A snapshot of our work

Issue: People with disability find access to housing on the private market inadequate and social housing waiting lists are long. Sometimes they are made more vulnerable by restrictive conditions in congregate care.

What we did:

We worked throughout the year to ensure that housing and support are separated in the ADHC transfer to the non-government sector due to the rollout of the NDIS.

We made submissions to the NDIS Specialist Disability Housing Framework and Policy review. We also established new relationships with NSW Disability Minister Ajaka's Senior Adviser on the transfer, Leonie King, the ADHC Executive Director of Service Delivery Programs and the Department of Premier and Cabinet transfer team. We met with these people regularly.

We co-hosted an event with the DNF for housing decision makers where people with disability and one family member, Meg Sweeney talked about regular housing options beyond the group home.

We joined with CID, and PWDA to release a position statement on the transfer.

Outcome:

The NDIS has recommended that separation of housing and support is regular practice where they fund supports.

Rather than transfer group home assets directly to service providers, ADHC has agreed to lease these assets, meaning there will be more possibility to renegotiate the leases and service provision when the lease ends.

We are now receiving regular briefings from ADHC about the transfer.

Family Advocacy is an ethical, prudent and sustainable independent advocacy organisation

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

Measures and systems are in place to ensure that Family Advocacy is in a position to continue to play its significant role in building the leadership and advocacy capacity of families of people with developmental disability. Effectiveness in the role grows as we believe in continuously improving the way we do this.



Quality Assurance

In 2015, Family Advocacy completed a three year quality audit cycle for the DSS. This year's recertification audit marked the start of another cycle. Accredited quality assurance auditors conducted the compliance assessment against the National Standards for Disability Services (NSDS).

The outcome of the audit is that Family Advocacy had an effective quality management system in place that complied with the national standards, resulting in an NSDS certification. The interviews conducted by the auditors with families and a review of the internal documentation and processes revealed to them an organisation that was clear and committed to its vision and mission, was under good governance and management and had established solid processes. They observed that Family Advocacy had a positive attitude towards the Continuous Improvement Process, providing transparency and consistency.

The Third Party Verification against the NSW Disability Services Standards received last year is still current.

Family interviews formed part of the process. Comments extracted from family interviews:

Regarding the organisation

- > *It is nice to be part of an organisation that has clarity of vision*
- > *Family Advocacy is fortunate to have the staff that they have because they come across as being very creative in their approach*
- > *I trust Family Advocacy because they have proved to me that they are the consummate professionals*
- > *To me, they are a great organisation because they have always been consistent in their values*

Regarding impact on families

- > *Being a part of Family Advocacy is all about being empowered to support our children*
- > *Through the knowledge that I have gained through Family Advocacy I am confident that I can speak with authority*
- > *I feel that since I have been associated with Family Advocacy I have come to appreciate a greater connection with my own family*
- > *I am a lucky person because I can advocate for my son with complete confidence since I became a Family [Advocacy] member*

Risk management

As part of good governance, the Management Committee (the Committee) of Family Advocacy takes risk management seriously and has measures in place to address and/or minimise risk. Risk can come from various fronts including the more evident areas such as financial, physical, security, legal and safety, to less evident ones such as reputation, privacy and confidentiality.

Business insurance, public liability (which includes personal accident insurance covering both staff and volunteers), motor vehicle insurance and workers compensation policies are renewed annually.

Family Advocacy has policies and practices that guide the actions of the organisation. This is reviewed bi-annually to ensure that it remains relevant to the vision and mission of the organisation and to the needs of the membership. Its operational practices manual outlines procedures for day to day activities, processes within human resources as well as financial areas of the organisation. This is also reviewed periodically so that it remains current, complies with regulatory requirements and supports best practice. Risk is addressed at all stages of the review. This is part of our commitment towards continuous improvement.

The membership can trust that the organisation has systems in place that are consciously and proactively addressing risk.

Work Health and Safety (WHS)

WHS is an area that impacts the employees, volunteers and visitors directly and we endeavour to maintain high standards.

Family Advocacy recognises the importance of having a safe workplace for employees and visitors. Establishing a safe environment and healthy staff is addressed through processes and equipment as well staff awareness and knowledge around safety and wellness.

Family Advocacy has two first aiders and two emergency office wardens with the latter as part of the Emergency Evacuation Team of the building. The wardens participate in emergency training organised by the Building Superintendent twice a year. Staff have been trained in the use of the evacuation chair, which the organisation has deemed important to retain within our office premises. This equipment enables people with mobility issues to evacuate the building if required.

During the year, a height adjustable table was purchased to enable staff to work in a standing position in order to provide posture change and with the aim of providing better health outcomes.

Family Advocacy has established procedures and checklists to minimise the risks within the work environment of its staff and to ensure the safety of its visitors. Two staff conduct a WHS assessment on the office environment annually to address any potential risks within the physical environment. The assessment is in addition to each staff members' responsibility to work safely and remove potential risks as they may arise.

Health issues are also addressed through a workstation assessment. This is generally conducted at the start of employment but is also available at other times when relevant. This enables staff to access more suitable equipment if needed.

An incident and injury process exists to monitor any incidents that may occur in the process of staff carrying out their work, within or outside of the office.

Positive practices have been encouraged through health campaigns and training in the proper use of equipment. Management is constantly looking at strategies to reduce stress in the workplace.

WHS remains a permanent discussion item for staff meetings which serves as a forum for raising any concerns in this area.

Financial Management

Financial sustainability is always at the forefront of concern for Family Advocacy.

Family Advocacy takes a proactive stance in safeguarding the organisation's sound financial position and is looking for ways to ensure that it will have sufficient means to continue to fulfil its vision.

Every year, a qualified independent auditor conducts the financial audit of the organisation to ensure that all accounting transactions have been entered and presented accurately in financial reports in accordance with Australian Accounting Standards.

The Treasurer's Report provides more details on the state of our finances.

Management Committee

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 governed by 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 in advocating 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, Treasurer, Secretary and up to a maximum of 15 ordinary members, is elected each year at the time of the Annual General Meeting (AGM).

In fulfilling its primary role, the Committee meet at least six 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
- 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 reports to members at the AGM where the Annual Report and the audited financial report for the year ended is presented to members.

Annual General Meeting

The AGM of Family Advocacy was held on Friday 30 October 2015 at Checkers Resort in Terrey Hills. Gina Wilson-Burns, as the incumbent Chairperson of the Committee, presided over the AGM. Family Advocacy appreciated the presence of Darcy Elks who presented *Crafting the Good Life* over the following weekend.

Gina presented the Chairperson's Report and Alex Purvis the Treasurer's Report, as laid out in the 2014/2015 Annual Report. All nominations for membership onto the Committee were accepted and election of the new committee members followed. Andrew Brak was reappointed as Public Officer and Harley, Russell and Day chartered accountants was reappointed as the Auditor for the year 2015/2016.



Committee Members



Gina Wilson-Burns
Chairperson

Gina is an unapologetic advocate for her son. She promotes the life changing experience of parenting a child with multiple severe disabilities not as a 'traumatic or crushing experience' but one of hope, possibilities, love and laughter. Gina acknowledges we need to remove much of the redtape and perceived limitations to empower families to do what families do best; live, love and grow. She is the author of the inclusive education blog Inky Ed! (<http://inkyed.wordpress.com>).



Meg Sweeney
Secretary

Meg is the mother of three young adults. Her eldest daughter has a significant intellectual disability which led Meg to be involved in advocacy to enable a more just and inclusive society. Meg was a Community Visitor, a member of the Disability Council of NSW and is a life member of Family Advocacy. Meg currently facilitates workshops on the NDIS and self management, and is involved in personal planning. She is passionate about people developing and maintaining their own unique identity in the community through valued roles and inclusive practice.



Alex Purvis
Treasurer

Alex is a father of four adult children and for many years he has been involved in promoting the rights of his son and developing individualised self managed support to give his son a meaningful and enriched life. His knowledge of advocacy, legal and persuasive techniques were honed through his experiences in encouraging the education system to include all children.



Matthew Dimmock
Committee Member (until February 2016)

Matthew has two children and is a passionate advocate guided by a firm belief in the potential of all people to live valued, contributing and connected lives embedded in their local community. He believes in the transformative power of inclusive education on the lives of all children and is excited about the possibilities presented by the expanding self directed opportunities in NSW.



Amanda Fletcher
Committee Member (until March 2016)

Amanda is the mother of two children, her eldest child having an intellectual disability. Amanda has been a passionate advocate for people with disability with a firm belief in the inclusion of everyone in community. She has shared her passion and commitment at a number of Family Advocacy events.



Linda Hughes
Committee Member

Linda is dedicated to working towards a socially just and inclusive society where people with disability are included as active and valued citizens. Linda and her son self direct his NDIS supports and together they are able to find creative solutions that ensure he enjoys a good and typical life in the community. Linda has recently been involved in establishing a user led disability support organisation in the Hunter and works with people with disability and families to get them on the road to self direction.



Lesley Light
Committee Member

Lesley has a strong belief in the power of advocacy for her son and for others to be treated fairly in their pursuit of a rich life, full of opportunities and experiences. Lesley, through her role on the Committee is committed to improve the lives of people living with developmental disability.



Alison Wilson
Committee Member

Alison has two children and her interest in disability advocacy started when volunteering as a General Practitioner for the Sydney Paralympic Games in 2000. She holds a firm belief about the inherent value and uniqueness of all people and strives to encourage others to look beyond any diagnosis to the person. Since the birth of her daughter, she has been a strong advocate for full inclusion in school and community organisations such as church groups.



Sharon Williams
Committee Member

Sharon is a mother of three children one of whom has an intellectual disability. Sharon is committed to the 'good life' for her son which entails his inclusion in regular experiences that boys his age enjoy at home, school and community. Sharon and her family hold a strong vision for him living his own life, his way, whatever it takes.

Staff and Allies

Staff and Allies



Cecile Sullivan Elder
Executive Officer

Cecile is responsible for the leadership of the organisation in its vigorous and independent advocacy efforts. This includes the overall day to day operational management as well as the strategic direction of Family Advocacy in line with its mission, vision, policies and practices.



Advocacy and Leadership Development Team

Karen Tippett
Advocacy and Leadership Development Coordinator

Karen is the Advocacy and Leadership Development Coordinator, providing advocacy related advice and information to family members of people with disability. Karen can also be contacted about workshops and upcoming events, as well as volunteering with the organisation.



Monica Sweeney
Advocacy and Leadership Facilitator

Monica's role provides advocacy related advice and information to family members of people with disability. Monica can be contacted about upcoming events.



Systemic Advocacy

Meg Clement-Couzner
Systemic Advocate

Meg works in the area of systems advocacy, representing the voices of families by negotiating with government on the rights, interests and inclusion of people with disability.



Resourcing Families

Emma Baxter
Resourcing Families Coordinator

Emma's role as the Resourcing Families Coordinator is to provide information, ideas and resources for families who want to develop strategies for creating inclusive lives for their family member with disability. This includes developing valued social roles, building support networks, making community connections and self directing supports.



Jessica Buhne
Capacity Development Officer

Jessica's role is to provide information, ideas and resources for families who want to develop strategies for creating inclusive lives through developing valued social roles, building support networks, making community connections and self directing supports.



Claire Northrop
Project Officer
(until February 2016)

Claire provides technical, administrative, promotional and communications support for the Resourcing Families team, especially for events, webinars and the website.



Communications

Rhiannon Brodie
Communications Coordinator

Rhiannon's responsibilities are to coordinate Family Advocacy's corporate communication, websites, inclusion library and resource development in order to keep families and allies up to date with the latest information.



Human Resources, Accounts and Administration

Marybelle Ignacio
Office Administrator

Marybelle is responsible for the overall management of the office. This includes compliance with statutory and administrative requirements, as well as quality standards. Marybelle oversees the organisations finances, human resources, assets and WHS.



Philippa FitzPatrick
Administrative and Events Officer (until July 2015)

Philippa's role provides office administration support through reception, event coordination and database management. In July of 2015 Philippa retired after 13 years of service. Family Advocacy greatly appreciates her contribution to the successful running of the organisation.



Paul Barrett
Accounts, Administration and Events Coordinator

Paul manages the organisation's regular accounting tasks as well as payroll, financial reporting, budget and audit preparation. In July 2015 Paul took on the role of Administration and Events Coordinator.

Volunteers and Family Leaders

A warm thank you to all our Family Leaders and volunteers who give extra time, commitment and dedication by volunteering to assist and thus support the work of the organisation. Some who live close to our Epping office help with tasks to keep the office running smoothly. Others contribute to resource and workshop development and share stories for articles and the website.

When travelling throughout NSW conducting workshops and connecting with families, we value the contribution of Family Leaders. They help present at events and share their stories. The insights and additional knowledge from their lived experience is an extremely valuable component of these events.

Thank you for your generosity of time and personal effort to provide this valued role. Families who attend our events continue to let us know how important hearing from other families is to them. We also understand that it would not be possible for our Family Leaders to take this time to assist without the support of your family, so we extend our thanks to your families as well.

Thank you for your contributions in 2015/2016.

Alex Purvis	Jo Basha
Alison Wilson	Karen Schwartz
Andrew Brak	Linda Hughes
Annette Bush	Liza Baker
Bettina Ignacio	Lyn Legge
Di Samuels	Margaret Hardman
Gina Wilson-Burns	Penny Graham
Jacob Hughes	Sally Stewart
Jan Kruger	Shari Raymond
Jennie Fenton	Sharon Williams

Volunteer guest speakers

Many Family Advocacy events and presentations are enhanced through the expertise of guest speakers. A warm thankyou to each speaker for being involved in these events and offering such an enriching opportunity for the participants.

Volunteer guest speakers for 2015/2016

Anne Cregan

Bob Lee

**Margaret Ward and acknowledging
Griffith University**

Membership

Family Advocacy is an incorporated association with 151 members from NSW. Membership is open to individuals only and not organisations or individuals representing organisations. The individuals that make up the membership of Family Advocacy believe in and support the vision and mission of the organisation and are committed to its goals of creating a genuinely inclusive society. Eleven members have been awarded life membership for their significant contribution and support to the organisation over many years.

Family Advocacy highly values its members and all the contributions they make to the organisation. Members can actively participate in the work of Family Advocacy by presenting at events, providing input into policy, systems advocacy, strategic planning and by becoming a member of the Committee.

Family Advocacy acknowledges the important role of its members and thanks them for their continued help and support throughout the 2015/2016 year.

Communications

Communications

Resources

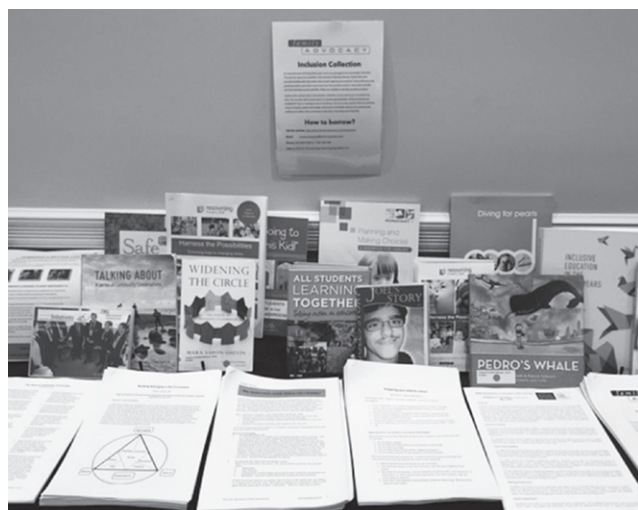
Providing information and resources to families and professionals is a fundamental role of Family Advocacy. Our resource collection provides practical and inspiring examples of what is being achieved by people with disability not only in Australia but all over the world.

Different types of resources including video content, webinars, articles, weblinks, blogs, factsheets, booklets and learning tools continue to be developed and made available.

Resources can be accessed through:

- our websites
- post
- email
- events
- e-newsletters
- Facebook
- YouTube
- visiting the Family Advocacy office.

Family Advocacy held a number of workshops and events throughout the year where a resource table was made available. Resources displayed were free to take or borrow from Family Advocacy and included books, booklets, reports and articles.



E-newsletters

Family Advocacy's e-newsletter, *Communiqué* was delivered four times throughout the year to 3,467 families in New South Wales. The purpose of *Communiqué* is to provide up to date information about the issues that affect people with disability and the quest for inclusive lives. It highlights developments in Family Advocacy's systemic advocacy efforts, changes to policy or the system, new resources and upcoming events.

Resourcing Families distributes an *E-news* to both families and professionals. The *E-news* consists of useful links to new resources and other information and ideas that are helping to build capacity in people understanding and taking up self directed opportunities in NSW.

Websites

Family Advocacy has three websites:

www.family-advocacy.com

www.resourcingfamilies.org.au

www.supportedliving.org.au

These websites are managed internally and Family Advocacy aims to ensure that we provide easy access to information that meets the needs of the families we support. This includes easy-to-find and register event pages, an extensive and sophisticated resource library and more interactive opportunities to connect with us through our websites.

Over the last twelve months new resources and content have been added to the websites, including more information in regards to the rollout of the NDIS in NSW and the importance of advocacy in a changing disability sector. Stories and examples of people with disability who are living an ordinary and good life continue to be added to the websites so families can continue to be inspired.

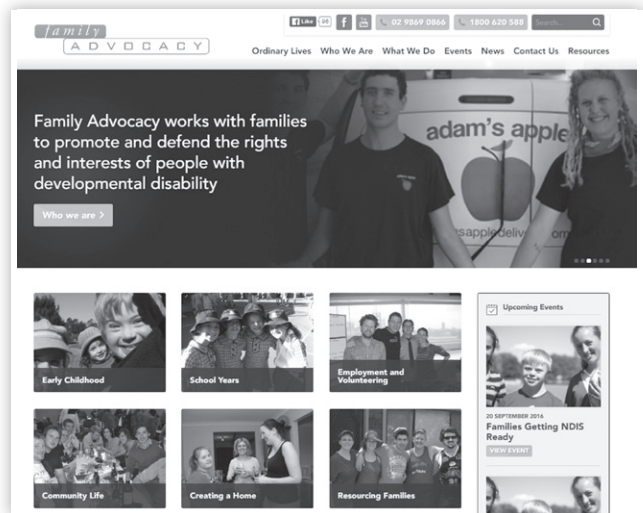
Significant time and work has been put towards Family Advocacy's online resource library. Known as the Inclusion Collection, it is a unique library designed to provide practical and inspiring examples as well as evidence based research of what is being achieved not only in Australia but throughout the world. The Inclusion Collection is an extensive combination of books, articles, reports, online videos and selected writings by both families and professionals. With 1,720 resources currently available, it is fully searchable by key topics such as education, moving out of home, relationships, advocacy, future planning, early intervention and much more.

Social Media

The Family Advocacy Facebook page is another way for us to connect with families. The Facebook page includes all upcoming events for Family Advocacy as well as updates on systemic issues, links to news stories, blog posts and our responses to current affairs.

Earlier this year Family Advocacy moved its online video library from Vimeo to the more accessible online video platform YouTube. This has seen an increase in viewing and sharing of the online video collection. There are 159 videos that can be easily accessed with topics ranging from inclusive education, advocacy, self direction, supported living, circles of support and many other topics.

It is the intention of Family Advocacy to keep families informed and to ensure that information is easily available through a number of different means.



Internal Management and Administration

Internal Management and Administration

As the backbone of the organisation, the Administration and Accounts team provide support to the Executive Officer and work area staff who undertake the core work of Family Advocacy. When required, the team also provide logistical and administrative support that enable the Committee to carry out their governance responsibility.

The work of the team covers broad internal areas of the organisation, including support for events, financial management and managing the human, physical, and technological resources. This work is carried out with an emphasis of monitoring and improving the quality of work through processes and procedures, measured against high standards.

Personnel and Operations

Family Advocacy bid farewell to long standing staff member, Philippa FitzPatrick. Being the Administration and Events Officer, she was a focal point in the administration of the office, a role she carried for close to 13 years. For those who knew her, her familiar face, voice and presence will be missed and we wish her well in the next phase of her life and thank her for her work all these years. Resourcing Families Project Officer, Claire Northrop finished her contract and is pursuing studies in her area of interest. We wish her success in this endeavour.

Our Executive Officer, Cecile Sullivan Elder brought in positive changes in the Human Resource area, replacing the appraisal process with performance management and staff mentoring. As such there is a new focus on the individual strengths of Family Advocacy staff.

A new set of eyes provided by Paul Barrett, our very capable Accounts, Administration and Events Coordinator triggered more improvement in the area of accounts reporting, as well as changes in the event support processes. This has provided more relevant and useful information on which to base future decisions.

Family Advocacy acknowledges the importance of continuous professional development, providing opportunities for staff to attend relevant events, forums, and conferences (both nationally and internationally). This has benefits on many levels including:

- increased connections with likeminded organisations and families
- contributions to a grass roots information bank that can be drawn upon when advising and informing other families
- forming a solid foundation in providing leadership in the industry and helping families develop leadership in this area
- informing the organisation of improvements in systemic advocacy approach of providing policy input to government.

Equally important is the sense of personal wellbeing of each staff member. Family Advocacy strives to develop a positive culture in the workplace and where it can, maintains flexibility in work conditions to allow staff to address the challenges of balancing work and home life.

Technology

Family Advocacy has endeavoured to keep pace with the continual changes in technology. Over the past five years, we have moved from an internal server based mode to 'cloud' mode beginning with our database. This may be followed by emails and websites. We have reached more families and enabled easier access to more resources by increasing our online presence, through our websites and social media. We will continue to explore relevant interactive technologies.

Database and Data Collection

Increased capacity in this area has provided improved management and thinking around the use of the database. Partial clean-up of data, jointly undertaken by staff and volunteers, has contributed to the integrity of reports and mailouts. There is still a lot of work to be done in this area and we are constantly looking at new ways of using the database to improve our reach to families in an effective way.

Environmental Consciousness

Expansion in the use of technology and improved use of the database are strategies over the years that have all contributed in our efforts to reduce our environmental impact.

As global citizens, Family Advocacy aims to ensure:

- the use of double sided printing, thus reducing the volume of paper used
- internal documents are printed on recycled paper
- the ongoing maintenance of photocopiers in order to reduce paper wastage
- the use of environmentally friendly products for cleaning
- recycling of plastics, glass, tin and paper products
- those on our distribution lists provide an email address where possible as a way for us to keep in contact
- the use of the database is to send only relevant hardcopy information to recipients
- the use of written communications are sent through email or digital means.

Five years ago, we had a heavy paper base for disseminating information. Now, we are improving our websites and developing a social media presence through Facebook and YouTube. We will continue to look for ways to reduce paper wastage and more broadly, reduce any adverse impacts on the environment through internal processes as well as by moving with current technology.

Treasurer's Report



Treasurer's Report

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

We are grateful for the funding provided by Government, both on a Federal and State level for this financial year 2015/2016.

The Department of Social Services continued to support the organisation through recurrent funding.

NSW Department of Family and Community Services also provided support through four streams of funding:

1. Recurrent funding for the ongoing advocacy and information function and ongoing operations of Family Advocacy through the Ageing, Disability and Home Care Department.
2. Funding for Resourcing Families.

3. A one off injection of project money of \$650,000 provided on 27 June 2013 to be spent over three years for the Resourcing Families Capacity Building Project. This was fully expended during this year.

4. A one off grant of \$200,000 received on 24 June 2015 to fund three, two-day conferences, in regional NSW was expended during the year.

A one off grant of \$32,000 received on 26 May 2015 from the Department of Education.

The organisation's liabilities can be fully funded from its accumulated provisions and the organisation continues in a sound financial position. A budget for 2016/2017 has been ratified by the Committee.

Recurrent Funding and One Off Grants		
	2015/2016	2014/2015
Revenue from Commonwealth Government	264,091	266,529
Revenue from State Government	280,538	267,780
Revenue funding from ADHC for Resourcing Families	205,750	200,000
Revenue from ADHC for the Capacity Building Project of Resourcing Families	152,842	273,978
Revenue from ADHC to hold three regional two-day conferences	200,000	-
One off grant from National Disability Services	-	7,739
One off grant from DoE	32,000	26,667
Total	\$1,135,221	\$1,042,693

Donations

We would like to thank those who have provided financial support throughout the year through their donations to the organisation. A total of \$8,788 was received from the following generous givers:

Adil Foundation
Cathy Naing
Christine Dawson
Dianne Ward
Jeanette Milne
Jeongmin Park
Joseph & Mary Naim
Kate McNamara
M & N Chowdhury
Margaret Stead
Mark Williams
Sharon Williams
Stanley Po
Wilma Reibel
Undisclosed recipient

We would also like to acknowledge those organisations who have donated in kind:

- Salesforce Foundation: ten free licences of Salesforce Enterprise Edition, available for not for profit organisations.
- Connecting Up: discounted software and training for not for profit organisations.
- Microsoft: discounted software.

Disclosure of Interests

Payments were made to the following committee members:

Alison Wilson, Matthew Dimmock, Linda Hughes, Gina Wilson-Burns and Sharon Williams received honoraria during the year at the standard rate set out in the Volunteer Session Leaders Policy, for their contribution towards the work of the organisation as a Family Leader.

Meg Sweeney received consulting fees for her contribution towards the work of the organisation as an Event Consultant for Resourcing Families workshops at her own set rate.

In accordance with the requirements of the Rules of the Association, I advise members that no other 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.

Alex Purvis
Treasurer

Acronyms and Abbreviations

ADEs	Australian Disability Enterprises
ADHC	Ageing Disability and Homecare
ADN NSW	Aboriginal Disability Network New South Wales
AGM	Annual General Meeting
CALD	Culturally and Linguistically Diverse
CID	Council for Intellectual Disability
DNF	Disability Network Forum
DoE	Department of Education
DSS	Department of Social Services
FACS	Family and Community Services
NDAN	New South Wales Disability Advocacy Network
NDAP	National Disability Advocacy Program
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSDS	National Standard for Disability Services
NSW	New South Wales
PWDA	People with Disability Australia
WHS	Workplace Health and Safety

family

A D V O C A C Y

Family Advocacy Annual Report 2015 | 2016

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