



ADACAS

A D V O C A C Y

ACT Disability, Aged and Carer Advocacy Service

Annual Report

2012-13

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ADACAS VISION

To assert, promote and protect the rights and responsibilities of people with disabilities, people who are older and people who are caregivers

ADACAS MISSION

We vigorously advocate for and with vulnerable people, who have a disability, are older, or their caregivers, so that they may exercise their rights as citizens, live valued and dignified lives in the community, and pursue their dreams.



Ivette Gonzales receiving the Hesta Healthy Workplace Award



Liza Venus receiving the 2012 Rookie of the Year in the Annual Disability Sector Awards

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ADACAS's People

ADACAS Board

Chairperson:	Stephen Still	continuing
Treasurer:	Gary Leckie	to October 2012
	Kym Stewart	from November 2012
Public Officer:	Pam Graudenz	to November 2012, continuing
	Coleen Box	continuing, from November 2012
Other members:	Dominic Cookman	continuing
	Sean Fitzgerald	from October 2012
	Penelope Davie	to November 2012
	Alana Fraser	from March 2013

ADACAS Staff

Fiona May		Advocacy Program
Sonia Di Mezza		CEO/ Secretary
Ben Davies		Coordinator
Ivette Gonzalez		NDAP/ HACC YP/ CMHP/ IDEAS
Jane Harriss		CMHP/ NDAP
Judy Power		NACAP/ HACC OP
Jillian Thompson		NACAP/ HACC OP/ IDEAS
Liza Venus		NDAP/ HACC YP
Malcolm Parker		NDAP/ HACC YP/ IDEAS
Gwendoline Davies	(from November 2012)	NDAP/ HACC YP/ IDEAS
Wendy Cory	(to February 2013)	NACAP/ HACC OP
Kate Brown	(Oct 12 to Nov 12)	NACAP/ HACC OP
Katrina Rea		NACAP/ HACC OP
Fiona Navilly	(Jan 13 to Feb 13)	Policy research
Rozanne Celica	(Jan 13 to Jun 13)	ADACAS NDIS Consultant
Deshawn Wattanatassi		ADACAS NDIS /research
Kirsten Wade	(to September 2012)	Business Manager
Kristy Capper		Admin Assistant
		Admin Assistant

Clinical Supervision Consultants

Elizabeth Done
Fiona Hall
Align Corp P/L
Wilma Davidson
Veritas Alliance Pty Ltd
Ilona Nichterlein
Janice Wickerson
Trish Walsh
Kandie Allen-Kelly

IT Consultant

Sennell Pty Ltd

Database Consultant

Rohan Mitchell (1024 Pty Ltd)

Pro Bono Legal Advisors

Ashurst

Chairperson's Report

Stephen Still

It is a great privilege to introduce the ADACAS Annual Report for the financial year 2012–13. ADACAS continues to go from strength to strength, and is well placed to productively engage with the excitement and challenges that will inevitably flow from the major reforms taking place in the sectors we cover.

Of greatest note in the Board's work this year has been the approval of the new ADACAS Constitution at the 2012 Annual General Meeting. As I mentioned in my last Chair's Report, the revised Constitution was the culmination of many months work. I am pleased to report that the revised arrangements have operated smoothly.

New initiatives over the course of the year have included the adoption of new governance policies for ADACAS to clarify the roles of Board members and the Chief Executive Officer, and the development and adoption of a strategic plan. As Fiona May describes, the strategic plan was collaboratively developed between staff, management and the Board of ADACAS and sets a clear direction for the organisation. Progress to date on implementing the report has been encouraging.

The new governance policies (available on our website at <http://www.adacas.org.au/corporate-information>) clearly articulate the roles of the Board, the Chair and the CEO and serve as a useful reminder of the significant responsibilities of each of these in management and strategic direction-setting for the organisation. The Board continues to work on capacity building, including through setting in place a process for regular self-assessment and targeted training for Board members in key areas such as financial management.

The Board has experienced significant renewal over the past year. Of particular significance is the decision of Gary Leckie to step down as Treasurer after six years. Gary's particular skill and diligence as a Treasurer was matched by his sound judgment on all of the governance matters coming before the Board and his good humour. He was held in high regard by his Board colleagues and the staff.

After a competitive process, the Board chose Kim Stewart as Gary's replacement. Kim has brought an enthusiastic approach and fresh perspective to ADACAS's finances, and has already made a strong contribution. Alana Fraser and Sean Fitzgerald also joined the Board this year, and have supplemented its knowledge and understanding of disability issues.

I would like to take the opportunity to thank Neil Muller and Michael Still, volunteers who participated in the Board Information Technology Sub-Committee. The deep knowledge of IT systems they have brought to bear on ADACAS's systems has seen a radical shift in ADACAS's approach and is bearing fruit in greater system reliability, security, value for money and user satisfaction.

Finally, it would be remiss of me not to mention the fine work performed by all the staff of ADACAS. Their commitment to aiding the most vulnerable members of our community, often in challenging or difficult circumstances, makes a positive difference every day. ADACAS could not achieve its goals without them, and I thank them for their hard work and dedication over the past year.

CEO Report

Fiona May

The 2012-13 financial year saw ADACAS continue to consolidate and advance the work that we undertake. You will see in this report that the amount of advocacy we provided has continued to increase and this is a testament to how hard the staff team have worked across the year.

Early in the financial year the staff and Board members spent a day developing a three to five year strategic plan for ADACAS. The time was right to begin a new plan. With a range of foundational documents renewed and a clear picture of the broader environment in which we operate, we had a clear framework for where ADACAS is and wishes to be in the longer term. The strategic plan confirmed the vision and mission of ADACAS and established the pillars of our organisation – those things which we continue to focus on doing well. It also identified a series of key strategies and a timeline to progress those over the coming years. The Board regularly reviewed progress against the plan as it guided our direction and priorities through the year.

The year also gave us opportunities to celebrate ADACAS and the great work that we do. In particular I would like to recognise two staff members who received awards during the year. Ivette Gonzales was nominated by a colleague for the Hesta Healthy Workplace Award and we were delighted that the sector chose to honour her for this work in making ADACAS a healthier place to work, at the ACTCOSS Community Sector Awards. She was joined by Liza Venus who was awarded Rookie of the Year in the annual Disability Sector Awards, recognising her achievements, hard work and commitment to her relatively new role as an advocate. All of the staff have continued to advocate vigorously and passionately for the rights of their clients as well as support myself and each other in the work that we do.

In January 2013 we underwent our first external audit under the National Disability Advocacy Standards. These new standards set the benchmark for advocacy services and it was a pleasure to have the opportunity to showcase the high standard of work ADACAS undertakes. Preparation for the audit was a considerable investment of time however it gave us the impetus to reflect more closely on some aspects of our work. The auditors were with us for two days, interviewing clients and staff, and reviewing policy and documentation. They concluded that we are fully compliant with all standards. This qualification enabled ADACAS to apply for and be awarded Prequalification by the Community Services Directorate which also recognises us as having the high quality core systems and processes required to undertake government contracts and tenders.

The audit provided an impetus for us to review and reflect on a range of policies and processes and many improvements were identified and acted upon. ADACAS has developed a strong culture of continuous improvement which supports both the core practices of the organisation and the advocacy work we do for clients.

During the year ADACAS opted into the *Human Rights Act 2004 (ACT)*. The Act provides organisations with the option of 'opting in' to it. Section 40D enables organisations to be declared subject to the public authorities obligations as delineated in Part 5A of the Act, pursuant to section 40D. On 10 December 2012 the Attorney General Simon Corbell made a declaration through a notifiable instrument which took effect on 1 January 2013.

Human rights lie at the very foundation of the work that ADACAS does on a daily basis. Ensuring that our clients' fundamental human rights are promoted, respected and upheld in our advocacy is crucial to ensuring that their voices are heard at every level. By opting in to the Act ADACAS has publically declared its serious commitment to abide by the provisions of the Act as well as to human rights in general.

As confirmation of how important such a step is to each and every staff member, ADACAS developed and implemented its Human Rights Policy, agreed upon by staff. This policy stipulates that human rights will play a pivotal role in forming the direction and shape of our advocacy work.

Changes to our Home and Community Care funding stream came into effect this year which gave us the opportunity to slightly restructure our service delivery. You will see that this report focuses on our disability work and our older persons work broadly rather than discussing each program in isolation. This enables us to highlight themes in our advocacy work without the artificial distinction of which funding program was used to undertake the work. Case data is still presented within programs which enables comparisons with previous years. In addition to our increased case work, ADACAS participated in some major systemic advocacy actions during the year. These are discussed within the older persons and disability sections of the report.

We have been able to continue and expand our Supported Decision Making work during the year and a separate section of the report describes the considerable work we have undertaken in this area.

This year has seen me strongly increase the focus on our relationships with external stakeholders. ADACAS continues to participate in a range of networks and forums that consider issues relevant to our client groups. While this can be a significant time commitment, it enables us to contribute to broader sector development issues and to stay abreast of changes that are occurring. I have established regular meetings with key stakeholders, including Disability ACT and Housing ACT Executive. These regular sessions provide an opportunity to raise and resolve a range of complex specific client issues as necessary and also to discuss policy and systemic issues that emerge. They have established greater levels of trust and communication between ADACAS and other organisations and contribute to our strong reputation in the Canberra community.

As my second year as Chief Executive Officer at ADACAS closes, I reflect on how far we have come in two years and what a pleasure it has been to work with the dedicated staff and Board members that we are so lucky to have.

ADACAS at a Glance

Individual Advocacy	
total number of advocacy hours	10,224
total number of people assisted	367
total cases	479
new cases	261
cases continuing from 2011-12	218
closed cases	236

Inquiries	
total number of inquiries	243

During 2012-13 ADACAS provided 367 clients with 10,224 hours of advocacy on 479 issues. This represents a continuation of the steady increase in advocacy that ADACAS has experienced over the past few years (Figure 1.0). The trend that we see is that while the number of clients climbs steadily, the number of issues is increasing more rapidly and the number of hours that we spend on advocacy is also increasing steeply (up 20 per cent on last year). This indicates that the work we are doing with clients is of increasing complexity, involving several distinct issues, and is taking more hours of advocacy to resolve. Once again accommodation and services are the two most frequent issues that we advocate about (Figure 1.1). As anticipated last year, there has been a significant growth in child protection work over the year. This is discussed in more detail on page 15.

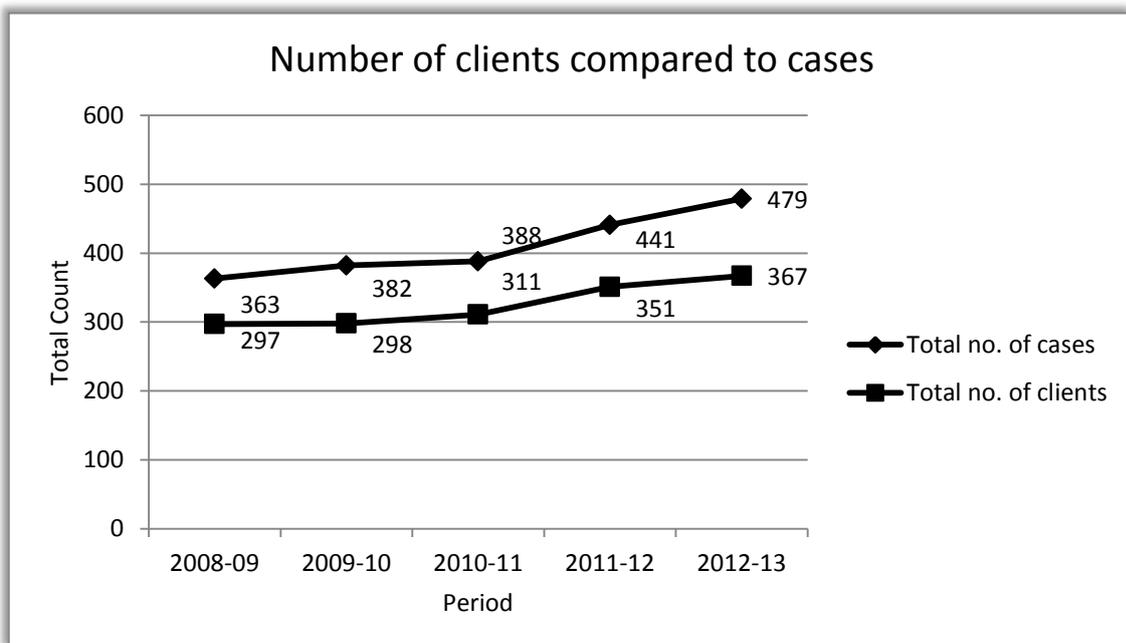


Figure 1.0

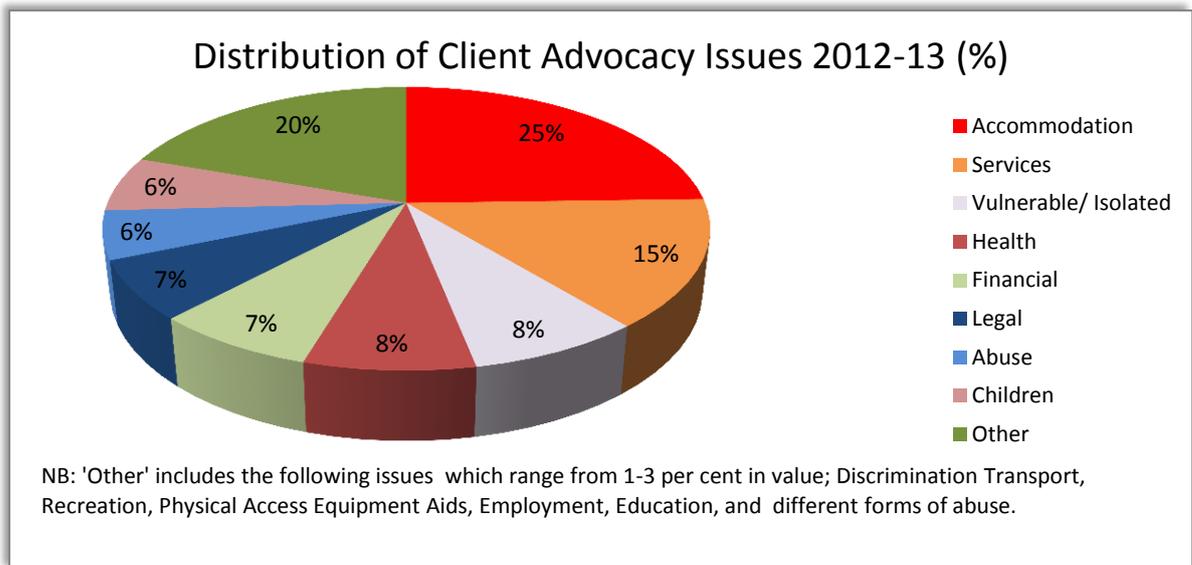


Figure 1.1

Funding Received

Home and Community Care Program for Younger People – provided with the assistance of the ACT Government

Home and Community Care Program for Older People – this service is supported by funding from the Australian Government under the Commonwealth HACC Program

ADACAS is part of the Australian network of disability advocacy services funded by the Australian Government.

National Aged Care Advocacy Program—an Australian Government Initiative.

Mental Health Consumer Advocacy Program – ACT Health.

IDEAS Disability Advocacy Brokerage Program.

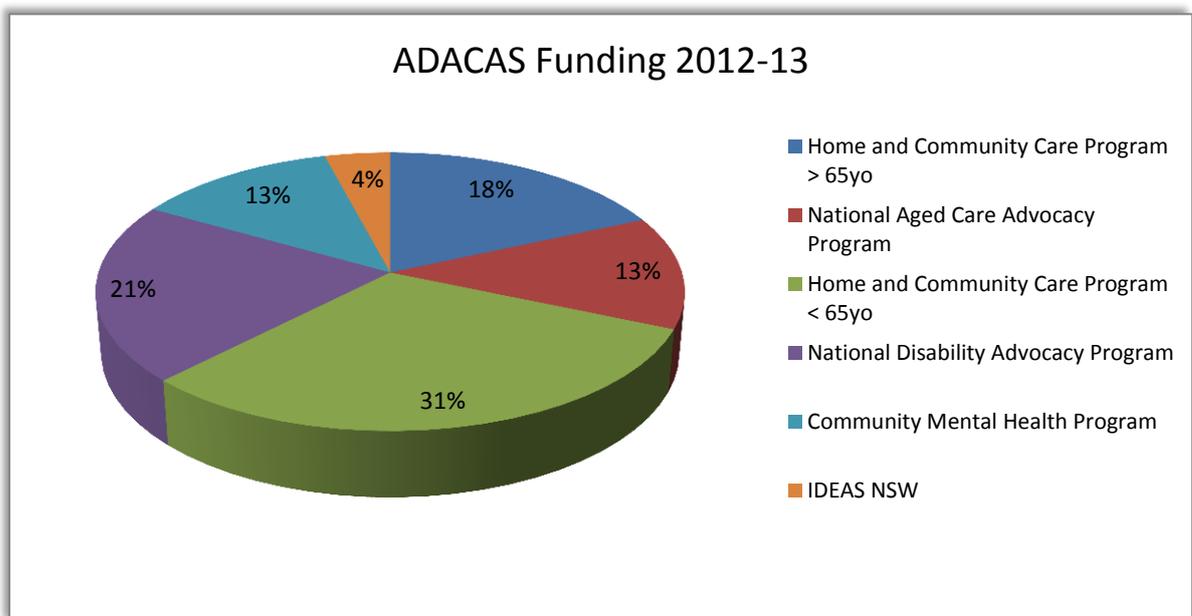


Figure 1.2

In addition to our advocacy work, this year we did significant additional project work representing \$148,200 of growth funding. These projects were:

Having Their Say – 12 NDIS stories funded by Disability ACT.

Supported Decision Making Research –this project was made possible with assistance from the ACT Government under the ACT Disability Grant Program

Supported Decision Making Website – Practical Design Fund project - an Australian Government initiative.

Advocacy for People with Disability

Total number of clients (HACC)	138
Total number of cases (HACC)	159
Total number of clients (NDAP)	48
Total number of cases (NDAP)	54

As a result of the split of the Home and Community Care Program into younger and older persons programs managed separately by the ACT Government (younger persons with disability) and the Commonwealth Government (older persons), ADACAS has restructured its advocacy team into two broad teams. All advocacy for people with disability is undertaken by our younger persons team. Advocates carry a mixed case load including clients funded under either the National Disability Advocacy Program or the HACC Younger Persons program. Advocates in this team also undertake work with people with psychosocial disability and mental health issues, some of which is funded by the Community Mental Health Program.

Accommodation Issues: These continue to be the most frequent issues which people seek help for. We have many clients who are seeking to access or change their social housing. During the year the ADACAS CEO met quarterly with the Executive of Housing ACT and these meetings have contributed significantly to a better relationship between the two organisations. Housing staff have a clearer understanding of the role of advocates and we have been able to provide feedback on policy matters which affect clients. Current housing application processes include the need to have letters of support from services that indicate that a person with disability will be accessing support during their tenancy. This process is flawed, as services will often not commit until a person has a place to live. With the introduction of the NDIS the process will have to change again, as the relationship between individuals and service providers may be dramatically different, particularly where the person with disability is self-managing their supports and not using an incorporated service provider. ADACAS has raised these issues with Housing ACT and looks forward to working with them to ensure that people with disability are able to access appropriate social housing as required. During the year ADACAS staff were invited to observe the processes of the Multi-Disciplinary Panel which meets weekly to make decisions about the priority housing list. This has enhanced our understanding of the processes and enables us to provide better advocacy for people seeking priority housing.

The long wait to access housing, even when on the priority list, continues to be a concern for many of our clients. We were pleased to have a number of clients who had endured lengthy waits offered appropriate homes during the year. Housing ACT now recognises that people with disability are unable to access the private rental market in the ACT regardless of their income, because there are no accessible properties available for rent.

While long term housing solutions can be difficult to arrive at, emergency accommodation is also in short supply in the ACT and virtually non-existent for people with disabilities.

Case Study – Michael

Michael was 16 years old with a mild intellectual disability, living in the ACT. One day his family refused to pick him up from respite. Michael could not be accommodated at an ACT homelessness refuge as they were all full. Care and Protection Services (CPS) were contacted and they took Michael to a refuge with 24-hour support located in NSW. The CPS worker provided Michael with a list of contacts, but advised him that they could not assist him further. As there was no transport to the ACT available from the refuge, Michael stopped attending school.

ADACAS was contacted and requested to provide advocacy support to Michael. An ADACAS advocate listened to him and attempted to arrange transport so that he would be able to attend school immediately. His family refused to support Michael, as did a representative from the Department of Education. Another organisation contacted by ADACAS advised that they were unable to assist Michael in any way as he was “currently residing in Queanbeyan” and not in the ACT.

After making numerous inquiries the advocate was eventually able to secure accommodation for Michael in a youth homelessness refuge in the ACT, located quite close to his school. The refuge provided some staff support during the day but not at night.

CPS continued to refuse to assist Michael, claiming that they were unable to support him as he was not at risk of harm, abuse or neglect. When the advocate sought assistance from Disability ACT they were advised that they could not offer a respite service as Michael was seeking long-term accommodation and Michael was too independent for the other models of support that they provide.

Although Michael is independent in some aspects it became clear that, as a main stream service, the refuge lacked the resources, training or knowledge to support Michael or people with his type of disability. The refuge tried to support him but Michael’s behaviours impacted significantly on the other residents and soon they stated that he would have to leave.

It was at this stage a case conference was called by the advocate with all relevant stakeholders requested to attend. At this meeting CPS committed to supporting Michael until he was 18 years old. They are now providing Michael with a home with 24-hour support in the ACT.

Michael’s case highlights the very real risk of people falling through the gaps between service systems. In this case his age ensured that CPS eventually undertook to support him, however if he had been 12 months older this solution would not have been available to him. People with mild to moderate disability are at risk of being ‘too disabled’ for mainstream services yet ‘not disabled enough’ for disability services. Advocacy is continuing to ensure that Michael’s voice is heard as plans for his future are developed.

We received many requests for advocacy during the year that relate to issues with neighbours. These cases are often difficult to resolve through advocacy as there are very few options for resolution that the affected person can access. Housing ACT has introduced the Improved Support Stronger Communities Team which seeks to address neighbourhood issues for social housing tenants, however they too are not always able to resolve matters. Where our experience tells us that advocacy will not be able to assist in a neighbourhood issue, we are not accepting these clients but often we are also unable to find an appropriate alternative referral for them.

Quality Service: The second most frequent issue that people require advocacy for continues to be access to and quality of services, including employment, health, in home support, community access, case management and recreation. Cases included people with disability who were seeking to access mainstream employment or services as well as disability specific services. In both cases the advocate worked with the client to ensure that their voice was heard and needs could be met. Many of our longer term clients experience ongoing issues with service provision essentially lurching from one crisis to the next as service is intermittent, quality varies or staff change. These are underpinned by a wide set of challenges which face the community sector, such as attracting and retaining quality staff, training and support and reforming a culture of service delivery which does not always put the person's needs at the centre of service design.

Case Study Tim

Tim is a middle aged man with an Acquired Brain Injury. He lives in a shared house with one other male who has an intellectual disability. The men are not happy living together and issues of concern arise frequently. These were sometimes managed well by a particular support worker who was willing to "go the extra mile" and develop a close working relationship with Tim and his housemate. However when this worker left, issues became more difficult to resolve.

The men chose to keep some pets in the house without first seeking approval from their service provider. The service provider eventually found out that the animals had been kept inside the house and had created a mess within the house. A decision was made to remove the pets and then have the house professionally cleaned. Support services were withdrawn until after the house was cleaned as it was considered a work, health and safety issue to have support workers working in the house while the house remained uncleaned.

The men were warned of the consequences of keeping animals in the house in the future, but the service provider failed to address a way to meet the underlying needs that the men were expressing through their behaviour. Given the level of support being provided, the service provider was well aware that they need support to manage their day to day living activities. Although ADACAS believes that the men had a right to own pets it was evident that they would require support to be able to keep the animals safely. Alternative ways to enable them to keep pets, such as maintaining a guinea pig run in the backyard, or supporting them to learn to care appropriately for their pets, were not explored.

When the two men bought more pets and again kept them in the house they began receiving threats of eviction. Instead of seeking to learn from the first experience and

provide them with some guidance in how they could safely look after their pets the service provider opted to threaten the men.

Tim had consistently sought the allocation of a flat of his own as he does not enjoy living with others. The incidents with the pets were used as a threat that if he did not behave “properly” this would serve to decrease his chances of securing his own place of residence.

The case served to highlight that some service providers only want to have clients who are compliant and prepared to “do what they are told”. The service provider needs to apply best practice in how they work with the client. It is evident that the Disability Service Standards – Standard Three “Decision Making and Choice” has not been met in this particular case.

As we move towards the launch of the NDIS the need to ensure that people with disability can build their capacity to both choose and control their services is paramount. Many of our clients have little experience of making decisions about their own care and need support to have their voice heard when care does not meet their needs. This is unlikely to change with the introduction of the NDIS and is likely to lead to an increased demand for advocacy. In addition, significant work needs to be done to prepare people for a new way of thinking about their services in the context of their hopes and dreams rather than in the context of a constrained suite of options which is insufficient to meet demand. Too often clients tell us that they do not want to complain about service because even poor service is better than no service at all. This culture of fear and dependency will not shift quickly and much will need to change before people genuinely feel in control of their lives.

Guardianship: ADACAS works with many people who are subject to guardianship and/or financial management by others. Those others are often family members or may be the Public Advocate or the Public Trustee. Frequently we are aware of guardians who work very hard to ensure that the protected person receives the best possible care and is enabled to have the best life chances that they can create. However, we unfortunately are also aware of a number of cases where guardians are not acting in accordance with the Guardianship Act and are overstepping their role. For example, Principles 4 (2)(d) of the Guardianship Act states that “the protected person’s life (including the person’s lifestyle) must be interfered with to the smallest extent necessary” and yet we are aware of guardians who determine what recreational activities a person can participate in and for how long, what social activities they have, and whether they can learn new skills, meet new people or try new things. This narrowing of a person’s life is often done with a concern for the person’s safety in mind. When this is combined with a service provision culture that assumes a duty of care approach which seeks to always minimise risk, a person quickly becomes trapped in a system which leads to increasing social isolation. Family guardians in the ACT are not required to undertake any training in the role and this may contribute to the overreach of guardianship. In addition, service providers tell us that they can find it difficult to manage the expectations of guardians on the one hand, with the wishes of the protected person on the other. Generally in these situations they choose to do as the guardian requests, which further marginalises people with disability from having agency in their own lives. This was evident in both our advocacy and supported decision making work. We have had the opportunity through our supported decision making work to engage with the ACT Civil and Administrative Tribunal (ACAT) on issues related to guardianship and have been able to work cooperatively with the ACAT to explore ways to reduce

the impact of guardianship on a person's life. During the year ADACAS had a number of opportunities to raise our concerns about guardianship with other stakeholders and to add our voice to the call for review of the Guardianship Act.

We brought to the attention of Disability ACT, a checklist provided to all families of students with disability by their schools as they prepare to leave school. It includes applying for guardianship as one more thing to be checked off during this process. This culture that when a young person with intellectual or complex disabilities reaches 18 the parents should automatically seek guardianship is strong in the ACT. It must change. Young people need to be supported to develop as much independence as possible so that they can retain to the greatest possible extent their right to make decisions. We recognise that for some people, retaining full autonomy may be unlikely, however to apply guardianship before a person has had the opportunity to learn to make decisions, take risks and experience any level of independence is to deny their basic human rights. Much needs to be done to change the general community assumption that a person must have a guardian, training for guardians should be developed to ensure that they do not overreach the role, and the Guardianship Act must be reviewed to establish a wider range of options, including supported decision making, which give effect to Article 12 of the United Nations Convention on the Rights of People with Disability.

National Disability Insurance Scheme: ADACAS continued to be heavily involved in the development of the NDIS during the year. This important initiative will change the face of disability services in Australia and high expectations rest on the detail of how it will be implemented. ADACAS has worked to raise issues of concern to our clients through submissions to the design process and in a range of forums, including directly with members of the ACT NDIS Taskforce.

We cooperated with Disability Advocacy Network Australia (DANA) on the national advocacy work they have undertaken in this area and are pleased that through this work we now have a clear indication from National Disability Insurance Agency staff that advocacy will not be 'rolled in' to the NDIS but will continue to be separately funded and freely available to those who need to access it. The role of advocacy under the NDIS as a safeguard for vulnerable people continues to be discussed. We are clear about the value that our clients place on their relationship with their advocate and the ways in which advocacy has and can safeguard clients.

Case Study - Gerald

Gerald is a 68 year old man living with late stage multiple sclerosis. Gerald got into an altercation with several of his neighbours, part of the fall out of which was a successful application for mutual protection orders for all parties signed by a Magistrate of the ACT courts. Because of cognitive issues associated with his condition, Gerald had some degree of difficulty in remembering the terms of the orders, what to do if a breach occurred and what to do to ensure that he himself did not breach the orders. ADACAS remained involved in Gerald's case after providing court support. ADACAS worked with other community organisations, the police and Gerald himself to ensure he understood what he could and could not do based on the terms of the order. Gerald was able to contact ADACAS advocates with queries about what he could or could not do and subsequently avoid several accidental breaches of the order. At the time of writing, Gerald had not breached the terms of his order, and has been supported to notify police when breaches

from other parties have occurred. Without the involvement of ADACAS, Gerald would likely have forgotten the terms of the order and its very existence. The ongoing involvement of an advocate is acting as a safeguard against him breaching court orders.

Case Study - Douglas

Douglas lives in supported accommodation where he receives high physical support because of an Acquired Brain Injury. Douglas has a great degree of difficulty communicating verbally and in writing because of the significant exertion required for even the smallest movements of his body. Douglas corresponds predominantly through email via a modified keyboard and computer. ADACAS worked with Douglas's service provider to establish a protocol whereby Douglas could email the management of his support service with any issues about how his support was being delivered. Douglas cc's his advocate into that email correspondence. ADACAS agreed to remain involved with Douglas and to advocate on his behalf if and when any issues arose with quality of service that Douglas felt he could not deal with on his own. When an incident occurred, the advocate was able to discuss Douglas's expressed wish for the outcome he was seeking and to meet with representatives of Douglas's service provider, advocating on his behalf from an informed position. This meant that issues and misunderstandings were quickly resolved. The ongoing involvement of an advocate is safeguarding Douglas with his service provision.

Our work on the NDIS focused on the needs of people who through their circumstances will not have the same opportunities as others to exercise choice and control. There are strong connections between this work and our supported decision making work, which is considered in more detail elsewhere in this report. We were also invited to participate in consultations for a number of NDIS Practical Design Fund projects, which were taking place nationally. We were able to raise the concerns that affect our client group and contribute to the development of important policy issues and valuable projects in this way. ADACAS also received funding for a Practical Design Fund project of our own. This is discussed in detail in the supported decision making report.

As the ACT prepares for the NDIS a number of other activities are underway. The ACT has launched a self-directed funding trial, seeking to learn what needs to be in place to support individuals to self-manage their funding. The My Choice ACT project began during the year and ADACAS participated on the reference group for this piece of work. My Choice ACT is only available to people with existing Individual Support Plans and has no impact on the amount of funding people are accessing. However the reference group has worked with the providers to guide the development of the resources people will need in order to self manage, including financial management systems, employer policies and practices, and the like. While the project involves only a small number of participants it is demonstrating the very significant preparation that is required for people to self manage and employ their own care workers. ADACAS's participation continues to focus on ensuring that the needs of the individual are not subsumed in the many administrative and legislative compliance issues that must be met.

ADACAS continues to raise the needs of the most marginalised and vulnerable as the policy development work for the NDIS continues. We hear often the assurance that anyone who

currently receives a service, including HACC services, will continue to be able to access that service when the NDIS is introduced (even if they are assessed as ineligible for an NDIS package). While this assurance is welcome we know that this is only part of the answer to ensuring that people with mild to moderate disability are able to access the supports they need, now and in the future, to be able to live ordinary lives in our community and have the best possible life chances.

Care and Protection: ADACAS has experienced a significant increase in the number of cases which involve child protection matters. Some cases relate to young people with a disability themselves who are entering out of home care, others involve working with families of children with disability who are engaged with Care and Protection Services(CPS), but the largest group involves parents with disability (either cognitive impairment or mental illness) whose ability to parent is being assessed by CPS staff. The data shows that over the past two years we have experienced a doubling of the number of care and protection matters that we are advocating about (Figure 1.3).

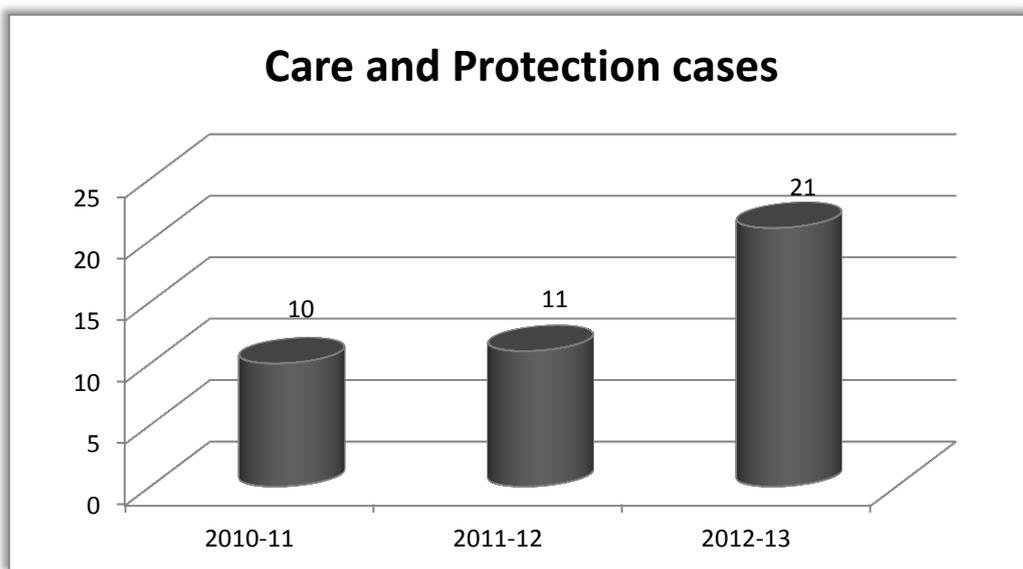


Figure 1.3

The right to family is enshrined in the United Nations Convention on the Rights of People with Disability (UNCRPD) yet it is quickly dismissed in a risk averse child protection environment. All the achievements which have been won regarding the forced sterilisation of women with disabilities will be lost if the culture and practice of CPS continues to be one that assumes that people with learning difficulties cannot parent effectively.

Advocacy relating to the needs of clients engaging with CPS has been one of the most significantly demanding areas for ADACAS advocates funded by HACC Young Persons, NDAP and Mental Health programs. Advocates consistently reported a high to crisis workload level while working with clients engaged with CPS. Advocates find the work intensive, and emotionally, physically and intellectually draining. Advocates often struggle to realise the wishes of their clients to the degree that should be possible based on the law, principles of natural justice and Office for Children, Youth and Family Support and Community Services Directorate (CSD) policy.

Generally CPS workers were friendly and professional when engaging with advocates, however they consistently demonstrated a poor understanding of how to effectively engage with people

living with mental health issues or intellectual disability. ADACAS believes that limitations in CPS's skillset in this area resulted in unfavourable, restrictive and litigious outcomes for parents living with intellectual disability and mental health issues.

CPS is required to respond to reports where a child, young person or pre-teen is at risk or potential risk of abuse and neglect. CPS has an important role in the community, responding to and appropriately preventing harm to vulnerable young people. There is no doubt that a significant and positive impact is made on the lives and quality of life of children and young people in the ACT community by CPS interventions.

The *Children and Young People's Act 2008* defines the role that the Director General, and subsequently her delegates in CPS take in receiving reports, assessing and investigating, supporting families to resolve issues and - where risk is too great - seeking orders to remove the child from the care of parents or otherwise intervene on the responsibilities of the birth parents.

When an assessment is made that there is a significant enough risk to a child or children, the child or children are removed from the care of the parents, the Director General takes over responsibility and the children are eventually placed either in out of home care or the family are required to work with CSD to achieve certain goals or responsibilities. Long term involvement comes in the form of voluntary orders, two year orders or orders for the care and protection of the child until he/she reaches the age of 18.

After the investigation of a report, most stages of the process require that an application is made and order granted by a magistrate of the ACT Children's court.

The following analysis breaks down the various stages and roles taken on as CPS moves from receiving a report along their pathway to a determination. Common issues birth parents and other family members living with mental illness and/or intellectual disability encounter are noted in brief case studies.

Responding to Mandatory Reporting:

While it is important to make a mandatory report when the situation warrants, there should be a more transparent process in determining when it is appropriate to follow up a report. It would appear that reports about parents living with intellectual disability and mental health issues are more likely to trigger an appraisal process than reports about the same or similar issues where the person does not fall into this category. There is little evidence supporting the need to target these groups or the likelihood of a child being at greater risk than the rest of the population when parents with disability are properly supported.

Reports relating to parents living with mental health issues and/or intellectual disability also appear to be made far more frequently than those that are made for issues relating to the standard population. There appears to be a degree of stigma associated with parents living with these issues that limits the pragmatism of reporters in responding to the issue in a supportive strengths based manner.

Case Study – Emma and Pete

Emma and Pete were eight months pregnant with their first child. Both were living with a diagnosis of an intellectual disability and Emma was also living with mental health issues. Knowing they would need significant support, Emma, Pete and Pete's family worked together to identify a place where they could all live together, so that Emma and Pete could be supported in their role as parents. Referrals were made to case management and support services in the community with the resources needed to supplement and sustain the family unit.

At eight months into the pregnancy the two families were making their final preparations before the birth. At this time an anonymous report was made and CPS investigated. This caused significant stress and strain on the family, both in the way in which CPS engaged and in the additional distraction and disruption of those crucial final preparations. Conversations with both families reflected the significant amount of information they had provided about how Emma and Pete were being supported to all stakeholders involved in the case. Either the mandated reporter did not provide all the information, triggering an appraisal, or CPS responded based on assumptions of concern that were clearly shown not to exist in circumstances where a couple with additional needs was well supported.

Appraisal

People with mental health issues and people living with intellectual disability appear to be overly targeted for assessment after a report is made. We believe that if the same risk factors are identified by a report for birth parents living with these health issues then CPS is more likely to make an assessment than if someone without these issues was reported for the same reason.

Reports are biased towards the outcome of removal, vary in level of detail and often provide extremely subjectively delivered evidence that omits or overlooks important considerations.

Many of our clients feel incredibly threatened by the involvement of Care and Protection services. Some of our client base have had multiple children removed from care and have significant grief, loss and trauma symptoms as a result of this. CPS engage in an investigatory, almost prosecution-like manner, and our clients often describe feeling as if they are being interrogated, constantly defending their actions, rather than being supported to remedy and build skills that allow them to better enact their parental responsibility.

Our clients often resent the interventions put in place by CPS. When they make their feelings known, have difficulty engaging or generally appear mistrustful, this is interpreted as being uncooperative, disinterested or disengaged from the process or as evidence of a lack of insight, skills or general willingness to maintain responsibility for the care and protection of their child.

Case Study - Josie

Josie was already known to CPS when she became pregnant again. This client had remedied the issues that led to the removal of other children and had, of her own volition, sought the support of the services she needed to maintain the care and protection of her baby.

CPS still became involved, and after the birth undertook a number of unannounced assessment visits to Josie's home. Our client, living with a mental health condition and still experiencing grief and loss from the removal of other children was extremely upset and angry at these visits, often escalating over the period of a visit to the point where she was abusive towards CPS staff. ADACAS's advocate attempted to work with Josie and CPS to identify alternatives to the visits process that would allow Josie and her child to be appraised by CPS, and receive the support she and her child required. These recommendations were made based on the principles of effective engagement and behaviour management techniques developed from training from the Thomas Wright institute. However, CPS did not acknowledge or identify any alternatives to their conventional mode of assessment, even though the *Children and Young Peoples Act (2008)* identifies what *can* be done to make an assessment, not what *must* be done and thus options were legally available to them. After the first two visits it had become abundantly clear to CPS what the effect of the visits were. Josie was antagonised by the way in which workers engaged, and there appeared to be no or very little response to this behaviour even when the advocate analysed triggers for her behaviour, discussed methods for de-escalation and meaningful engagement with Josie, and communicated these in writing and verbally to CPS.

When CPS visited again, they largely ignored our recommendations, and triggers for behaviours occurred. We believe that Josie and her child were put in danger by CPS's actions. We believe that CPS had a duty of care to avoid engaging in this way particularly when they had been made aware of the risks caused by the method they employed to engage with Josie.

We assert that at the bare minimum, when CPS workers are engaging with people with disabilities or mental health issues they should be trained in effective engagement practices, behaviour support and management strategies, collaborative practice and how to utilise a strengths based approach.

Assessment and Family Support

Assessments of parenting capacity generally involve two stages - a range of parenting skill development courses and supported parenting options and, in the case of litigation by CPS, an assessment by an expert witness, generally a psychologist.

We have a number of cases where the parents involved were notified to CPS either prenatally or very shortly after the birth. In many cases the parents have not had the support and opportunity to take the baby home into their care, but instead are shunted from hospital to generalist care and assessment placements which in theory educate parents but which do not have any capacity to provide the tailored support which these parents need. Support and education options are delivered by services such as Karinya, Marymead, Barnardos and the Queen Elizabeth II family centre. ADACAS advocates have observed that the support offered, while perhaps comprehensive and effective for building parenting skills with members of the general population, are not in any way tailored, adjusted or modified to the learning support needs of a person with an intellectual disability. Instead parents are assessed in an unfamiliar setting while they are still adapting to the very big and new changes in their lives without the specialised support they need, and are found

wanting. In some cases parents are pressured into voluntarily relinquishing the baby into the care of others, or they have the baby removed. At no time have the parents we work with been offered appropriate skill development and support to become effective parents. The Healthy Start Initiative has developed resources that are being used nationally to enable people with learning difficulties to become parents, however parents in the ACT are not able to access such specialist services and they are therefore judged as being unable to parent and lose the opportunity before they have been given the chance to learn and demonstrate their actual capacity. In at least one case in the past year ADACAS advocates have read capacity assessments prepared for the courts that list indicators of learning difficulty in these learning environments as proof of insufficient capacity to parent. ADACAS believes that reasonable adjustments in line with the UNCRPD should be made to the learning environments for people living with disability and best practice literature indicates that there is significant chance of successful skill building if these adjustments are made.

Case Study - Francine and Sam

Francine and Sam are both living with an intellectual disability. A report is made while Francine is still pregnant and CPS make an assessment and begin to engage. Francine gives birth and spends the first weeks of her daughter's life in Karinya where she is supported to build parenting skills. Her progress is reported to CPS for assessment and case management purposes. Sam attends parenting courses as well and is supported to provide care to his daughter. Both parents are provided with the standard process and procedures around parenting education by the services hired by CPS to engage with them. Both parents experience difficulties understanding the concepts that are introduced to them. Both parents demonstrate a lack of flexibility in changing routines based on variations in the needs of their child. Neither parent was provided with skills development support in familiar environments or in the environment in which they would intend to parent. Both parents indicate to ADACAS that they have difficulty understanding all the concepts introduced to them, that they ideally would need more time and for concepts and skills to be broken down into simplified parts, allowing them to tackle problems progressively. They both are very willing to learn and make the necessary changes, but need a tailored approach which is not provided.

CPS reviews the case and determines that the parents do not have the capacity to be responsible for the care of their daughter because of their intellectual disability diagnoses. The child is removed to a foster parent and court proceedings begin in earnest. An assessment of the capacity of the parents is undertaken by an expert witness, the assessment uses the indicator of learning difficulties and cognitive impairment as evidence of insufficient capacity to parent.

Case Study - Rebecca

Rebecca was working with CPS to receive the support she needed to help manage the mental health and behavioural issues of her 10 year old daughter. Rebecca and her daughter formed a strong therapeutic relationship with her school counsellor and a psychologist who specialised in working with families with her and her daughter's needs. CPS refused to fund further sessions with these providers because they were not on their

list of approved providers. Individuals on the approved list stated that they had limited experiences with catering to the needs of families like Rebecca's.

Orders and Court Proceedings

Children's court matters are held in a closed court. As such, the magistrate and other parties to the matter have and regularly exercise their discretion around who is present when a matter goes to hearing. Typically, ADACAS advocates are required because of the complexities of the CPS process, particularly around supporting a person with intellectual disability to understand the Director General's application to the courts to the extent that they can make informed decisions about the instructions they give their legal representation. Additionally, with clients living with mental health issues and significant behavioural disorders advocates may assist a person to better emotionally regulate, along with the aforementioned support to understand.

ADACAS has observed a number of cases where advocates are allowed to provide support up to and including the directions stage of the hearing, however when the matter goes before a magistrate advocates are often not permitted to be present. The UNCRPD is clear that a person should have the support they need to exercise their human rights. When a magistrate refuses entry to an advocate, this could be construed as a breach of the CRPD and underlying human rights legislation.

Case Study – Geoff

Geoff was supported by ADACAS to decide that he did not wish to consent to the application for orders to 18 for his son made by CPS. Geoff's advocates were not permitted to enter the court room. Geoff became extremely agitated and was removed from the court room where he was supported by an ADACAS advocate to de-escalate and return to the proceedings. This happened on a number of occasions until eventually Geoff's legal representation ran out, and he was not able to exercise his legal rights. ADACAS advocates have considerable success in other hearing-like contexts in supporting a person to emotionally regulate and avoid escalation. If an advocate had been allowed to support Geoff in the hearing, he may well have been able to more effectively enact his legal rights and it may even have changed the outcome of the proceedings.

Orders to 18 and Care Plans

In all but one case encountered this year, when CPS engaged with birth parents they assessed and decided to remove the child from the care of the birth parents, applying to the courts for orders to 18. Very little consideration was made for orders that contained a care plan that would allow CPS to engage and support the parents to maintain some responsibility for the care of their own child. Contact provisions were similarly very limited, even in cases where the parent had not perpetrated any abuse or neglect or if the child's emotional wellbeing was affected in any way by the presence of the birth parents.

Section 8 (1) of the *Children and Young People's Act (2008)* clearly states that the best interests of the child should always be the paramount consideration when any delegate of the Director General acts and this section of the Act is commonly used in any and all justifications of the actions of CPS staff. In the context of CPS representatives deciding not to support a family to

either maintain the care and protection of their child or alternatively to work towards restoration through a two year order, there has been little to no dialogue as to why this decision was made. Review of the literature on the subject along with ADACAS's considerable expertise on the subject of supporting people with disability would indicate that there is considerable potential for care plans to be put in place that look towards restoration or support. Such plans are patently absent.

Case Study – Angela

Angela was living with a diagnosis of paranoid schizophrenia. At 22 she was beginning to build skills around managing symptoms along with receiving psychopharmacotherapy that significantly reduced symptoms. When Angela became pregnant, the developmental toxicity of her medications meant that she ceased taking her medications. Symptoms returned and over time Angela became unwell, and spent her last trimester in secure psychiatric facilities. CPS became involved and her daughter was removed to the care of a foster parent at birth. ADACAS staff observed that Angela rapidly struck out on a path to recovery with the resumption of her medication. She was soon discharged from hospital and continued to receive the mental health treatment she needed. CPS still determined that orders to 18 were appropriate despite the significant potential for Angela to recover to the point where she could eventually take on some or all responsibility for parenting her child.

Once caught up in the system, families where disability is present are then treated in the same way as families who enter the system with higher risk factors. These parents have not neglected or abused their children, yet they get orders that limit visits to four times a year, 'because that is what we do', and no consideration is given to alternative models of care, such as shared care. It is undeniable that providing intensive support to parents with learning difficulties would cost less than an out of home care placement with orders to 18. In an era of spiralling increased costs of care and protection, this should be welcomed.

Case Study – Sam

Sam and his partner were both living with an intellectual disability diagnosis and their son was removed from their care at birth by CPS. CPS determined in the care plan that contact provisions should be only four times a year despite no abuse or neglect occurring. CPS stated that this was to allow the child or young person to develop appropriate attachment to the foster parent. Sam and his partner experienced significant grief and loss with no referrals for ongoing support from CPS or other agencies to help them cope with the trauma of removal. There was no evidence to suggest that well managed, more frequent contact with his birth parents would have adversely affected the child's long term outcomes.

Alongside this intensive individual advocacy work we are continuing to develop our voice on Care and Protection systemic issues so that people with disabilities are enabled to become the best parents that they can be.

Community Mental Health Program

Total number of clients (CMHP)	61
Total number of cases (CMHP)	67

ADACAS continues to provide advocacy to people in the Canberra community who are living with mental health concerns. Our priority is to support people who are the subject of ACAT hearings with regard to their treatment and care. In addition we support people with mental health issues with a range of other advocacy issues relating to their accommodation, mental health care and services.

Again, the main issues facing clients with mental health issues are accommodation and access to services. We are hopeful that the forthcoming Partners In Recovery Program, spearheaded by the ACT Medicare Local will assist some of our clients with the long term management of these issues.

Case Study – Linda

Linda is a 50 year old woman who has been using advocacy services for many years. Linda is a victim of crime, suffers from Post-Traumatic Stress Disorder and has an intellectual disability. She has a history of having suffered assaults, abuse and robbery. Linda is frequently in crisis and will often ring numerous services if things are not addressed immediately. She often has trouble communicating with people over the phone due to her intellectual disability. Because she has found it difficult to communicate she finds it difficult to have her needs met, and without the support and assistance she needs Linda becomes quite vulnerable. She has trouble getting access to services on a long term basis due to her adverse reactions to the people around her and has problems keeping appointments. Many workers often find it difficult communicating with Linda due to a lack of understanding or training; her angry outbursts often put her in conflict with others, frequently resulting in the withdrawal of services.

ADACAS was initially contacted because Linda was having trouble accessing appropriate services - she needed medical assistance, had experienced trauma as a consequence of being assaulted, and was finding it difficult to talk to the police about her issues. Linda was at risk of homelessness. Her mental health issues made it difficult for Linda to allow people into her home to conduct routine maintenance or regular inspections.

During the time ADACAS has advocated for her, advocates have been able to liaise on her behalf with other services; manage her accommodation by speaking to the housing manager and therefore help her to sustain her tenancy; provide her with support to speak with police; and assist her in accessing trauma counselling as well as other necessary services. ADACAS has also helped her access and maintain a cleaning service, with the advocate engaging regularly with the cleaning service provider to resolve the many issues which may arise in relation to the service providers interactions with Linda.

While Linda has learned to be resourceful, access various services in the community and interact with other people, she needs ongoing help in managing medical appointments,

housing issues, and accessing financial and legal services. While ADACAS continues to help Linda to sustain her tenancy by liaising with Housing ACT on her behalf, she requires long term case management and successive attempts to establish an ongoing relationship with a case manager in this respect have failed. ADACAS is currently hopeful that the new Partners in Recovery Program may be able to support Linda, but the question still remains whether, with her complex needs, they will be able to effectively assist her in the long term.

During the year ADACAS continued to contribute to the development of the revised *ACT Mental Health (Treatment and Care) Act 1994*, providing comment on exposure drafts and input to the policy development process. The inclusion of supported decision making and the improved definitions of impaired capacity may significantly change the landscape for people with mental illness, enabling them to have more say in the treatment and care that they receive. Processes for implementing the new legislation will be crucial. Although the legislation enshrines new approaches to decision making and capacity, without investment in changing the approaches within clinical and community practice in the ACT the legislation will not achieve the change being sought.

We undertook an important piece of systemic work during the year which also focused on people with mental health issues. The ACT Civil and Administrative Tribunal was, on its own initiative, considering a matter of law and invited ADACAS, Advocacy for Inclusion and the ACT Human Rights Commission to participate as interested parties in the matter. The matter arose through a particular case of a person living with intellectual disability and mental health issues and whether the person was able to consent to mental health treatment. It raised matters of interpretation related to Tribunal powers in Psychiatric Treatment Orders (PTOs), guardianship legislation and the *Human Rights Act 2004 (ACT)*. It has been a lengthy process involving a number of submissions and hearings exploring these issues. We now await the ACAT's decision. Regardless of the outcome, the case highlighted the valuable place of supported decision making as a mechanism to ensure that people can retain as much self-determination as possible. It also highlighted the need to review the Guardianship Act in the ACT. This is a commitment which the incoming ACT Government made during the election and one which needs to get underway. We call on the ACT Government to urgently begin the process of reviewing the Guardianship Act.

IDEAS

Total number of clients (IDEAS)	17
Total number of cases (IDEAS)	21

ADACAS continues its long and effective partnership with the Information on Disability and Education Awareness Service (IDEAS) in NSW. During the year we supported 17 clients in the region of NSW around Canberra. Through their access to individual advocacy these clients were supported to overcome significant issues in their lives.

As with our ACT work, services and accommodation issues are also the most common concerns of our IDEAS clients, with cases relating to children coming in third. ADACAS again noted the increased difficulty which people living in smaller regional centres face in accessing the supports and services they need. It can be difficult for clients to resolve service issues when the service's head office is located a significant distance away.

Case Study – Betty

Betty is in her 50s and has an intellectual difficulty. For most of her life she lived with her mother who sheltered her and protected her from the world. Betty, however, developed few skills in coping with life and when her mother died became very vulnerable. A target for all sorts of undesirable influences and ridicule she eventually came to the attention of support services, including IDEAS in NSW.

When IDEAS contacted ADACAS they were very worried about Betty's situation. An ADACAS worker agreed to visit Betty and work with her. When we first met her she was living in a self-contained unit in a caravan park on the south coast of NSW. She received assistance with transport and other daily needs from local groups and was supported to work three days a week in a special program for people with a disability. Since her mother's death, the NSW Public Trustee managed Betty's finances. Betty owned her little unit, having been able to buy it with the money her mother had left her. Sociable and outspoken, Betty soon became the target for gossip and hostility among the other residents in this closed ageing community. Betty loved animals and shared her life with two budgies, some fish and her beloved little dog Scruffy. Walking Scruffy and chatting to visitors and other residents was something Betty loved to do. However, residents were soon complaining about her behaviour to the park management and claimed that her dog was dangerous (Scruffy had never bitten anyone,) that she was drunk and generally a nuisance. Betty does not drink but she is quite unsteady on her feet.

Management began to monitor Betty, training their surveillance camera on her movements; they forced Scruffy to wear a muzzle, and refused to let Betty take Scruffy outside unless she had a carer with her. Betty was devastated and miserable; she stopped going to work, was fearful for herself and her dog, and cried frequently. Park management complained about Betty's service providers and raised these concerns with the NSW

Ombudsman. This then triggered questions about whether the decision to place Betty in the caravan park was a suitable choice.

An attempt to negotiate with the park management was unsuccessful as by then they just wanted Betty to leave. Betty's rights were being ignored and trampled on, a wall of disapproval and prejudice surrounded her.

Containing the discrimination Betty was experiencing was the first step. With the assistance of the advocate, having made it clear that her rights would be defended, it was necessary to assist Betty to develop skills in making choices and decisions for herself and supporting her to identify how her future might look.

It turned out that Betty had once lived in a rented house with a garden and that she had managed it well with the supports she had in place. After many discussions between the advocate and Betty, Betty decided that she wanted to leave the park and move to a house where Scruffy would have a garden and where Betty would not be the subject of gossip and ridicule.

The advocate negotiated with the Public Trustee and submitted a number of proposals to them to find alternative accommodation. Meetings were held with support services to ensure that stakeholders were working toward Betty's goals, and tasks were identified and actioned. Betty was encouraged and supported to return to work and her primary service, House with No Steps, did some really wonderful work with Betty to support her through the change.

Betty has now moved to a house with a garden and the Public Trustee will sell her property in the park and use the funds for her benefit and comfort. Scruffy has a garden and is free of the muzzle – he remains the friendly little dog he always was. The Ombudsman concluded its investigation in favour of the service provider and Betty has now returned to being a respected and welcome member of her community.

ADACAS participates in the NSW Disability Advocacy Network, which meets bi-monthly in Sydney. During the year the network moved to a more formal structure with the development of a constitution and an executive committee structure as it hopes to work more collaboratively and have a stronger voice on issues affecting people with disability in NSW. ADACAS contributed key comments on the draft constitution, including ensuring that membership of NDAN is open to any advocacy service that provides advocacy to the people of NSW (as opposed to those based in NSW) and it can therefore be a voice for vulnerable people across the State and draw on the experience of all advocacy services working in the region. Participation in NDAN has also enabled us to both learn from and contribute to understanding of the NDIS development in the two jurisdictions.

Advocacy for Older Persons

Total number of clients (NACAP)	54
Total number of cases (NACAP)	76
Total number of clients (HACC)	72
Total number of cases (HACC)	102

ADACAS created the older persons advocacy team during the year. The team provides advocacy under both our HACC Older Persons funding and our National Aged Care Advocacy Program funding. The team advocated for 126 people involving 178 issues during the year. Combining this work into a single team has strengthened our ability to provide advocacy to older people and to draw on this individual work to contribute to systemic issues. In renegotiating our HACC contracts with the split of this program, ADACAS obtained agreement that some systemic advocacy would be funded under the HACC program. While this gives us only a small amount of time to spend on broader systemic issues it recognises the valuable contribution that individual advocacy services can make to the broader reform process.

In our individual advocacy work we again noticed a number of themes emerging. Where appropriate we addressed these themes on both an individual basis, responding to the specific issues for a client, as well as through more systemic action.

Social Isolation Issues: As many older people progressively age many find themselves isolated. Such a situation may be exacerbated by a variety of diverse circumstances such as when children grow up, move away and create their own families; where spouses die; where an older person may develop a cognitive impairment or disability, impeding their ability to move easily out of the house; or where there may be language difficulties. Advocacy can be a method whereby people in the community are assisted and enabled to reach out and create new or strengthen existing networks for the older person.

Cognitive Impairment: An issue that frequently affects older people relates to their ability to have their wishes expressed, acted upon and respected by those around them who are caring for them, whether it be in a carer capacity or as a family member. ADACAS advocates continue to work hard to ensure that the wishes of all of their clients are the fulcrum point, guiding and directing the advocacy work that is implemented on their behalf. Even if a client has cognitive impairment advocates always listen to what their clients want and act upon these instructions.

On 30 April 2013 ADACAS made a written submission to the 'Senate Inquiry- Case and Management of Younger and Older Australians Living with Dementia and Behavioural and Psychiatric Symptoms of Dementia'. The gist of the submission to the inquiry was the importance of ensuring that the rights of people living with dementia were respected rather than ignored. An excerpt from the submission stated the following:

ADACAS has a policy approach of following the expressed wishes of our clients, whether or not they have dementia. It is our observation that rather than listening carefully to the person with dementia the commonly adopted approach is one whereby the staff and

management of aged care facilities, as well as the person's families and guardians, are increasingly resorting to imposing a 'best interest' approach to the resident, even quite early in the progress of the condition. This is where the person's wishes are not considered or taken into account; rather it is decided by someone else what that person's best interests are. It is our strongly held belief that although a person may suffer from dementia and although that dementia may make communication increasingly difficult, the person with dementia retains fundamental human rights that include *inter alia* the right to family, freedom of movement, to information, and freedom of expression. Although communication may often be difficult and problematic it is imperative that all concerned take the time and care to adopt a person centred approach whereby they listen and communicate with the person with dementia, in an effort to understand what their wants and needs are and, where possible, to act upon them.

Duty of Care versus Dignity of Risk: ADACAS often deals with issues where the desire of residential aged care facilities to keep residents 'safe' rubs up against the desire of residents to continue to lead a normal life, with all its inherent risks. The invocation of 'duty of care' to prevent people from undertaking activities once considered 'normal' but largely because of age now considered 'risky' can lead, however unintentionally, to people being denied their fundamental freedoms and basic human rights.

Case Study – Brian

ADACAS was contacted by a gentleman in his 90s who used a motorised scooter to enable him to engage in the social activities he liked outside of the facility. The facility manager, however, was concerned about resident's safety and when the scooter was sent for repairs, advised the repairer not to return it to the resident despite his having paid for those repairs. ADACAS's client became increasingly frustrated and angry which, in turn, was considered by the facility to be 'challenging behaviour'.

At this stage, Brian had not been assessed as having significant cognitive impairment, was not the subject of a guardianship order, understood the road rules as they applied to motorised scooters and understood the risks he was taking when driving his scooter. He chose to accept those risks just as we accept the risks every time we get in our cars.

After ADACAS became involved, the facility manager agreed to the return of the scooter but within two months had removed and hidden the battery, again citing safety concerns. No formal assessment of Brian's physical or cognitive capacity was undertaken before the facility took its action.

According to the Department of Health and Ageing's *Decision-Making Tool: Supporting a Restraint Free Environment in Residential Aged Care*:

'The intentional restriction of a resident's voluntary movement or behaviour by the use of a device, or removal of mobility aids, or physical force for behavioural purposes is physical restraint.' ... And... 'Any decision to restrain a resident carries significant ethical and legal responsibilities...its use should only be considered after exhausting all

reasonable alternative options and be informed by a comprehensive assessment of a resident and her/his interactions.'

The facility was breaching both Brian's human rights and clear government guidelines, and once again Brian was angry at this 'restraint'. This led to an escalation of his perceived 'challenging behaviours', the facility's response to which was to consider moving him to a secure dementia wing. Again, there was no comprehensive diagnosis of significant dementia to warrant this.

The facility eventually applied to the ACT Civil and Administrative Tribunal for a guardianship order, and a temporary order was put in place until a comprehensive assessment of Brian's cognitive capacity could be undertaken. ADACAS supported Brian throughout this process.

Without an advocate, Brian would have been physically restrained – not only through the removal of his motorised scooter, but also through being locked in a secure dementia ward – without any appropriate and thorough assessments having been done. His consumer, legal and human rights were being breached in the name of safety and duty of care.

Culturally and Linguistic Diversity (CALD) Clients: ADACAS is often approached by clients from a culturally and linguistically diverse (CALD) background seeking advocacy support. Clients within this beneficiary category face the increased risk of having their vulnerabilities exacerbated due to their inability to communicate in English, further compounded by misunderstandings faced by clients deriving from diverse cultural backgrounds. ADACAS has attempted to address this issue and reach out effectively to clients from CALD backgrounds by ensuring that staff participate in cross-cultural training (including specific CALD and dementia focused training). Staff participated in various CALD focused training including Dimensions of Culture (by the Mental Health Community Coalition); Cross Cultural Training (Migrant and Refugee Settlement Services of the ACT); and Speaking My Language (Partners in Cultural and Appropriate Aged Care). Where possible, ADACAS strives to assign clients to work with advocates who speak the client's native language. ADACAS staff are able to offer clients from CALD backgrounds assistance in the following languages: Thai, Spanish, Italian, French and Arabic. In instances where a person's language is not spoken by an advocate, assistance is available via a telephone interpreter. The ADACAS brochure is in the process of being translated into the most widely spoken community languages in order to create a wider outreach to the CALD community.

ADACAS has furthermore become active in the Partners in Culturally Appropriate Aged Care Network as well as the National CALD Ageing Network. This has entailed engaging; communicating; meeting and sharing ideas for how the CALD ageing population can be greater assisted.

In June 2013 ADACAS collaborated with The Aged-Care Rights Service (TARS) to provide input into a presentation on the rights of older people and how advocacy can assist them, during the CALDWAYS First Biannual Regional Forum which took place in Parramatta on 5 June 2013.

As the number of older people in Australia increases so too are we witnessing a corresponding increase in the number of older people from CALD backgrounds. During the year, ADACAS also saw an increase in the number of older clients from CALD backgrounds seeking advocacy support. ADACAS is witnessing an increase in cultural challenges between older people and their interactions with either the aged care facility or community organisations providing HACC services. In many cultures it is normal or even expected that the younger generation will step in and support the older person in the person's home. For many in Australia this can be a difficult objective to achieve, with many having to face the reality of admitting parents into an aged care facility, creating feelings of shame for not being able to support the parent in the home. Many service providers in the aged care sector often experience difficulties with communication where the older person does not speak English well or cultural misunderstandings; for example, understanding food preferences or dietary restrictions generated by religious or cultural beliefs or particular behaviour patterns deriving from cultural practices. This is where the intervention of an advocate can greatly assist the resident.

Case Study – Gina

Gina has been living in an aged care facility for the past seven years. She was born in Italy, and has lived in Canberra for many years. She is widowed, does not have any family members in Canberra to visit her, and is thus socially isolated. Gina also has dementia, causing her to become disorientated and confused at times. Gina likes to go to the local club to enjoy a meal. It is one of her remaining forms of entertainment. She also enjoys smoking every now and then. Every Wednesday and Friday she walks down the road to the local club and enjoys her time there.

Gina receives a pension but does not have any other form of income or any assets. She doesn't fully understand her financial situation and frequently overdraws her account, spending more than she has within her financial means. Over the course of a year a debt with the aged care facility built up and remains unpaid.

ADACAS was requested to provide advocacy support to Gina. The advocate assigned to support Gina speaks Italian and is able to speak with Gina in her native language. Although Gina can communicate quite well in English it is easier for her to understand what is happening when it is explained to her in Italian. ADACAS contacted another organisation which provided the financial assistance that Gina needed to be able enter a debt repayment agreement with the facility management.

As time progressed, Gina's capacity to manage her own affairs deteriorated. As she has no family to support her, the aged care facility determined that Gina needed the support of the Public Advocate and the Public Trustee to manage Gina's affairs and applied to the ACT Civil and Administrative Tribunal for the Public Advocate and Public Trustee to have guardianship over Gina's affairs. The Public Advocate requested the ADACAS advocate to meet her at the aged care facility so that the Public Advocate could meet Gina and get to know more about her and her circumstances before the hearing. The advocate introduced Gina to the Public Advocate and, in Italian, explained their role.

On the day of the tribunal hearing Gina refused to attend and so the ADACAS advocate attended the hearing on her behalf. During the hearing, the Tribunal Member attempted to talk to Gina through a teleconference to understand Gina's wants and needs; however she was confused and unable to express herself. The member asked Gina's ADACAS advocate to provide some relevant background and information about her. The advocate explained Gina's cultural background, her wish to visit her local club, the fact that she liked to smoke and other information to help the Tribunal gain some understanding of Gina.

The Tribunal held that guardianship would be given to the Public Advocate and the Public Trustee. The Public Advocate stated during the hearing that she would ensure that Gina would be supported to continue the activities that she enjoys. The assistance of the ADACAS advocate ensured that Gina's voice was heard and understood throughout the process.

Elder Abuse: A concerning aspect of our work that continued during the year related to high incidents of elder abuse, including financial abuse. In many instances older people acquire vulnerabilities that encompass physical disabilities or cognitive impairment that develop as a person grows older. As such vulnerabilities develop people close to the older person may take advantage of the situation by using the older persons assets for their own personal use or by depriving the older person of receiving the standard of care and support which is their right. ADACAS advocates strive to eliminate such risks by empathetically listening to clients, understanding where the problem lies and taking instructions and directions from the clients with regards to the action which they seek to take in order to eliminate or prevent such abuse from occurring. During June 2013 the Aged Rights Advocacy Service Inc. (ARAS) hosted the 2nd National World Elder Abuse Awareness Day Conference at the Adelaide Convention Centre. An ADACAS advocate attended this conference, to increase our knowledge about this very important and concerning issue.

It is the experience of the advocates that sometimes family members, or even officially appointed guardians of older people, presume that as they are in some way related to the older person this imbues them with the right to use the older person's assets for their own personal use. Advocates have worked to ensure that the older persons' assets are protected and not subjected to misuse by relatives and family members. An officially appointed guardian is compelled by legislation to ensure that the management of the older person's assets is always conducted with a view to advancing the best interests of the older person and not the guardian's own personal interest. Confusion regarding what the definition of an inheritance is a common occurrence. However, it is imperative for all family members to understand that an older person's assets can only become an inheritance once the older person dies and either bequeaths their assets to family members or where it passes on to the family law via relevant provisions of testamentary law. It is not an inheritance while the older person is still alive and thus cannot be used for a guardian or family member's personal use.

Case Study - Lily

Ten years ago Lily was diagnosed with various health problems. Although Lily continued to live in her own home and went to work each day, she suffered from some mental health issues, eventually resulting in Lily being admitted to hospital. Her good friend Mary

ensured that she was cared for and was able to access the appropriate medical support that she needed.

Over the years Lily's mental health continued to deteriorate until she was eventually diagnosed with early onset dementia. One day she suffered from an episode that resulted in her admittance, once again, to hospital. The situation was so critical that her doctors did not expect Lily to make it through the night. The staff at the hospital contacted Mary as Lily did not have any other family who could support her. They requested that Lily sign an Enduring Power of Attorney (EPOA) so that Mary could be empowered to make all decisions on Lily's behalf while she was in hospital.

Once Lily was discharged from hospital the hospital staff encouraged her to move into an aged care facility so that Lily could receive the support that she needed. Around the time of Lily's admittance into the aged care facility a work friend advised Lily to appoint her son Clive as her EPOA, so that she could ensure that her welfare and finances were being taken care of when she moved into the aged care facility. Lily signed the EPOA without anyone realising that the EPOA appointing Mary was still active.

Initially Clive visited Lily regularly, often bringing clothes and toiletries that he had purchased for Lily. These visits eventually ceased altogether. As the years went by Lily's dementia grew worse. When her pharmaceutical bills went unpaid the management of the aged care facility attempted to contact Clive, without success.

The staff of the nursing home telephoned Mary, who was a frequent visitor, explaining that they were unable to contact Clive and that Lily's pharmaceutical bills were not being paid. They further advised Mary to contact ADACAS for advocacy support.

An advocate visited Mary and Lily, to understand the problem. The advocate subsequently telephoned the bank which held Lily's bank account and was able to confirm that money was regularly being withdrawn, although no money was being spent on meeting Lily's needs. It was furthermore confirmed that the pharmaceutical bill was in arrears and that no effort was being made by Clive to ensure that this bill was paid.

It was evident that the current EPOA held by Clive needed to be revoked. The advocate supported an application being made to the ACT Civil and Administrative Tribunal (ACAT) to revoke the EPOA held by Clive and to ensure that Mary was able to support Lily to manage her affairs.

The advocate prepared the supporting documents for the hearing, including statements from Lily's doctor advising that Lily had already been diagnosed with dementia before signing the EPOA appointing Clive. Considering these circumstances, it was clear that the EPOA appointing Clive was invalid.

The advocate attended the Tribunal hearing with Lily, who felt very nervous. Clive did not attend the hearing but was interviewed by the Tribunal member by teleconference call. Clive admitted that for the past six years he had been spending Lily's money for his own personal use and that he had even given some of her money to his housemate. A few days

before the hearing he had written a cheque from his mother's account to pay for his car registration.

On the basis of the evidence before her the member revoked the EPOA held by Clive, stating that the case constituted a clear case of financial abuse of an elderly person. As it was a civil matter the member clarified that she was unable to proceed with considering the criminal ramifications of Clive's actions.

Mary was once again granted EPOA of the management of Lily's financial affairs. Upon further investigation it was discovered that Lily had no money left in her bank account as Clive had spent it all.

Indigenous Issues: Over the past two years, ADACAS has assisted a number of older indigenous people with complaints about their service provider. The service provider has been funded specifically to meet the needs of indigenous people needing community aged care support.

The complaints have centred largely around consistency of care, lack of communication, non-provision of care, and most seriously withdrawal of care without notice. Concerns have also been raised over the independence, adequacy and transparency of the service provider's complaints mechanisms and processes.

The issues have been canvassed through a variety of forums, including the service provider (in the first instance), the ACT Human Rights Commission, the Commonwealth Government's Aged Care Complaints Scheme and direct approaches to responsible Ministers.

The outcomes of these complaints have been variable – in one instance care services have been reinstated while in other instances indigenous elders remain without care (one has not had a carer for more than two years); directions have been made to improve complaints mechanisms; and communication between the service provider and their clients has, to some extent, improved. Some complaints are still being progressed.

Throughout these processes, ADACAS's indigenous clients have expressed a concern that they are suffering a 'double disadvantage'. They believe that not only are they disadvantaged by the significant gap that remains in the health status of indigenous and non-indigenous Australians, but also that in this instance, the agency set up specifically to assist them with care in their later years is not being held to the same standard as other agencies.

Systemic Advocacy in an Aged Care Facility: During the year ADACAS received over a prolonged period of time a number of complaints from residents and their family members regarding a particular aged care facility located in the ACT. The complaints related to a wide spectrum of issues including the residents' fear of retribution if they lodged a complaint against the facility; the staff's attempts to dissuade residents from seeking assistance from an advocate; the paucity of carers working in the facility able to address the residents' collective ongoing needs; the lack of training provided or skills held by some of the staff; the unhygienic conditions that some of the residents were living in; a lack of pain management; experiencing a low standard with regards to the quality of food and often cold food being served to the residents; inadequate continence management; a lack of privacy and dignity with staff entering rooms without first knocking; miscalculations with regards to fees charged to the resident by the facility; a lack of security with

regards to objects being stolen and not being properly investigated; and abusive verbal treatment by staff. At the request of the residents ADACAS wrote a submission about the facility detailing the nature of the complaints and sent it to the Aged Care Complaints Scheme.

It was ADACAS' experience that the response by the Aged Care Complaints Scheme with regards to addressing the complaints was insufficient to address the needs of the residents in any meaningful way. The Scheme took an inordinately long time to investigate the complaint with the facility in question; stated that they were unable to investigate properly with regards to anonymous complaints, even though it was explained that the residents feared retribution; and did not properly take the facility management or staff to task with regards to any of the complaints raised.

The complaint has now been closed, albeit unsatisfactorily in our opinion. We will be pursuing our concerns about the capacity of the Complaints Scheme with the Aged Care Commissioner in the coming months.

This case highlighted the importance of having a complaints scheme that is able to properly and effectively respond to the needs of residents in aged care facilities who, in ADACAS' experience, often face many attacks on their human rights. The Scheme needs to be able to develop a mechanism whereby complaints that are lodged anonymously can still be pursued and investigated, thereby respecting the chosen privacy and confidentiality of the residents. The Scheme furthermore needs to ensure that any investigations are taken in a timely manner as prolonged finalisation of a complaint in this instance served to place the clients at great risk of retribution by the staff of the facility. Lastly, where a complaint is found to be verified by the Scheme more resilient and effective action must be taken against the facility to ensure that the facility takes action to rectify the problems that have occurred. In this way the Scheme can act as a tool which will ensure that residents are protected and are able to fully enjoy their rights during their time of residence in an aged care facility.

National Collaboration: As one of the services funded under NACAP, ADACAS continued to cooperate with other NACAP funded services across Australia. During the year the services had the opportunity to come together in Canberra to talk about issues which affect the program with each other, with other stakeholders and with the Department of Health and Ageing. During this meeting we agreed that we need to become a more effective voice at the national level to represent the issues and concerns of the people for whom we advocate. We resolved to become the Older Persons Advocacy Network (OPAN) so that we could speak with one voice about shared issues of concern. OPAN has begun to establish the networks with other national stakeholders including COTA and the National Aged Care Alliance (NACA) and to begin to provide input to the policy reform work that is underway. At this time OPAN is unfunded, however to become an effective voice at the national level it will require investment.

Aged Care Reform: A major focus of our systemic work during the year was participation in the *Living Longer Living Better* aged care reform process. The package of reforms was launched by the Government on 20 April 2012, encompassing a 10 year plan to reshape aged care. It is evident that as Australia's aged population is increasing major changes are required to properly support and accommodate these changes. During the year the Aged Care Team has worked hard and continuously to provide input into various consultations that have been organised by the government in an effort to formulate the most effective program possible. ADACAS attended the

Briefings on Proposed Changes to the *Aged Care Act 1997* (the Act), in an effort to obtain insight into how the Act will change in the future and its impact on our clients. The proposed changes were to form the foundations for the Living Longer Living Better aged care reform package. ADACAS also participated in a range of other consultations and provided submissions on various aspects of the reform. On each occasion we sought to ensure that the perspective of our clients was brought to the attention of policy makers, particularly vulnerable older Australians who do not necessarily have access to usual information channels (such as the internet) and the need to ensure that frail and vulnerable older people, including those from CALD backgrounds and other special groups, are able to access aged care services that are specific to their needs, taking into account their circumstances and diverse backgrounds. We provided:

- Input into the Culturally and Linguistically Diverse (CALD) Aged Care Strategy
- Input into the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy
- Submission to the Consultation Paper “Dementia and Veteran Supplements in Aged Care”
- Input into the Workforce Supplement Guidelines
- Feedback on the Home and Community Care Packages Program Guidelines
- Input into the national consultation for the Linking Service for the Aged Care Gateway
- Input into the Pre Costing Progress Report on the Specified Care and Services Review
- Input into the HACC Service Group Two consultations.

Raising Awareness of Advocacy: During the year ADACAS networked with a number of organisations and agencies, striving to ensure that we can respond to the needs of our older clients on both a systemic and individual basis. ADACAS was an active participant in the ACT Agency Liaison Group Meeting, facilitated by the Aged Care Standards and Accreditation Agency Ltd, attending meetings and providing input into the various challenges and issues that affect our clients.

ADACAS continued to provide information about the role and availability of advocacy through a range of opportunities, including print media and information sessions for aged care providers, residents and families. ADACAS participated in the Seniors Expo which took place on 21 March 2013. The Expo was an opportunity for ADACAS to provide outreach to older people in the ACT community who are in need of advocacy support. Many people approached the ADACAS stall to inquire about the organisation’s services and how ADACAS is able to assist older people both living in the community and in residential aged care facilities.

Training Course for Aged Care: Advocates continued to visit all aged care facilities located in the ACT, to provide outreach to residents living in the facilities as well as education, training and information for both staff and residents, focusing on the rights of older people, the work of ADACAS, how ADACAS can assist older people and explaining what advocacy is about. To support the continued implementation of the training program, the Aged Care Team began working on a comprehensive training manual about ADACAS, advocacy and the rights of older people. A volunteer assisted with the project and it is anticipated that a training manual will be completed in the upcoming year.

ADACAS has identified the training program for staff and residents as a greatly needed tool to increase understanding of residents’ rights and how they can be respected. It was evident in some

of the training sessions that some aged care staff do not have a strong understanding of what a rights based approach to aged care really means. A commonly adopted approach in the aged care industry is to follow a “best interest model” of care whereby the aged care worker decides what is in the best interests of the aged care recipient and works accordingly to that belief, without taking into consideration or even inquiring into what the older person wants to occur in their life. ADACAS follows an “express wish” model, whereby our advocacy support is informed by what our clients instruct us that they want to happen in their particular situations. Such a model follows a rights based approach and ensures that the older person’s human rights are respected as are their wishes with regards to their lives. The training strove to engender a greater understanding of the express wish model in the aged care industry with the objective of encouraging staff to work more closely with older people in having their rights realised.

ADACAS Projects Report

During the year ADACAS undertook a number of projects which complement or extend our advocacy work. The capacity to take on work of this sort is a new development for ADACAS and one that we are excited about. This work led to a 16 per cent increase in our total funding for the year. More importantly it enabled us to undertake significant additional projects which improve the lives of our clients and increase the capacity of the organisation to undertake both our individual and systemic advocacy work.

The introduction of the National Disability Advocacy Standards has led to a significant new quality assurance process which is now required of NDAP funded services. Recognising this, the Department of Families, Housing, Community Services and Indigenous Affairs, provided services with some one-off capacity building funding (\$15,000) to enable them to undertake activities that assist them to prepare for the audit against the new standards. ADACAS invested these funds in quality improvement activities including the development of a three year Strategic Plan for the organisation.

The plan confirmed the intent of the existing vision and mission of ADACAS and identifies our pillars. The process of identifying the pillars of the organisation ensures that the key strategies do not need to capture the 'business as usual' elements of our work and can instead be truly strategic and growth oriented.

The ADACAS pillars are:

- Maintain our high quality advocacy service
- Protect and build ADACAS's reputation
- Best practice governance
- Ensure ongoing staff support
- Match resources, facilities and systems (IT, Finance, HR etc.) with future needs

In addition we identified nine key strategies to advance the organisation over the next three years. Framing the strategic plan in this way has established a strong and clear direction for the organisation while maintaining a focus on our core business.

Having Their Say Project

In addition to our ongoing policy work around the National Disability Insurance Scheme, ADACAS undertook a specific project at the time of the introduction of the NDIS legislation into Parliament. ADACAS commends the ACT NDIS Taskforce for recognising that an important group of people with disability were not being heard in the development process for the NDIS and for being prepared to provide funding to change this. People living with multiple and complex disabilities, intellectual disability, other cognitive impairments, or communication barriers leading to significant social isolation often have little or no voice in the decisions that are made affecting

their own lives and are even less likely therefore to have a voice in matters of public policy. The introduction of the NDIS is the largest policy change for people with disability in a generation and yet this key population is excluded from its development. ADACAS was pleased to be able to design and deliver a project which enabled 12 of our clients to be heard regarding what they want from the NDIS.

With funding support from the NDIS taskforce we undertook a process of in-depth interviewing of 12 clients who would otherwise never have the opportunity to be heard about the NDIS and included these interviews in our substantial submission to the Senate Inquiry into the NDIS Bill. Our submission was well received and we were also asked to attend hearings when they were held in Canberra. We welcomed the opportunity to discuss our concerns about the Bill directly with members of the Committee and also gave one of our interview participants the opportunity to speak directly to them. Ms Leanne Annette lived in an aged care facility despite her young age and for many years has had very little say over decisions about her own life, let alone major policy changes such as the NDIS. She was delighted to have the opportunity to put her views about the NDIS and this experience has ignited her ongoing engagement in the development of the NDIS in the ACT. She is now participating in policy development within the ACT in other ways and acknowledges that this would never have happened before participating in the Having Their Say project.

Through this project the voices of 12 people were heard directly by the Parliament. They were able to state exactly what they want out of the NDIS and their concerns about how it should operate. The 12 stories are available on the ADACAS website (www.adacas.org.au) under the Disability Advocacy tab. They include:

Allison (31) has multiple sclerosis. She is the sole parent of a daughter (5) with developmental delays who is beginning school this year. Allison's condition is relapsing as well as degenerative.

Leanne (46) and Janice (47) both have cerebral palsy and require 24 hour care. Due to the unique nature of their condition, care and support services need to be tailored to each individual's circumstances.

Rocky (28) has had brain surgery to recover from a seven year involuntary movement disability acquired from prescribed anti-psychotic drugs.

Kreesen (57) also has an acquired disability. A stroke in 2004 left him significantly restricted in speech and all movement. He now uses a motorised wheelchair and a microphone and speaker to communicate.

Pedro (52) has been in a wheelchair since he was 11. He wears hearing aids and has a motorised scooter.

Stephanie (44) has sciatica and Achilles tendonitis in both legs, as well as arthritis and dermatitis. She experiences constant and universal pain.

Genice (42) has deteriorating tunnel vision and learning problems.

Leigh Anne (49) and Jenny both have diagnoses of schizophrenia, which is episodic in nature.

Sarah (23) has multiple, but not definitive, diagnoses of psychiatric conditions.

Stephen (29) has a diagnosis of obsessive compulsive disorder, anxiety, depression and tuberous sclerosis.

(Note: Some of these names may have been changed in order to protect their anonymity)

A result of our, and others, strong work in this area is the inclusion of a number of changes to the Bill, which reflect the value and importance of advocacy. We continue to work to ensure that advocacy will continue to be independent and freely available to all who need it, both in regard to the NDIS and regarding any other area in their lives where their rights are being ignored or their voice is not heard.



Ms Annette at Parliament House for the Senate Hearings on the NDIS legislation

Supported Decision Making

Supported decision making (SDM) is an emerging, global movement growing from the UNCRPD. It recognises that decision making is central in the delivery of equality and full citizenship and calls on the States to provide as much support as is needed for people with disability to approach decision making with the same rights and responsibilities as those that do not have a disability. The NDIS, and its imperative to deliver choice and control to people with disability, will bring Australia a step closer to fulfilling its responsibility to the convention, but also raises the question as to how people whose decision making capacity is impaired, or simply not recognised, can be supported to be engaged in the scheme.

Exactly what decision support may look like is the focus of a number of projects, nationally and internationally. ADACAS gained funding for two separate projects in the 2012-13 financial year that enabled the organisation to advance our experience and understanding of the practise. These two projects, one web, the other relationship based, were undertaken simultaneously, informed each other and provided the opportunity to think about the practise of SDM in a broad context.

ADADCAS applied for and received a grant of \$90 200 under the NDIS Practical Design Fund to develop a supported decision making web site. The purpose of the site is to build the capacity, experience and expectation of people with disability as decision makers. Now complete, this has three distinct branches, each with its own purpose in developing capacity and experience in decision making. The site was conceived and written by Kate Rea and Ben Davies, with technical development and graphic design by Ingenious, and can be seen at www.support-my-decision.org.au.

The learn-to-be-a-decision-maker section describes decision making, including the right to decide, in easy English. This is a resource for people with little experience of, or expectation to be involved in decision making, to learn about their right to decide and build skills to make a decision. There are more than 60 explanations of complex concepts including what a decision is, options, trust, vested interest, guardianship, risk and what to look for in a decision supporter. Many pages include tips, such as conversation starters, for exploring ideas and developing a deeper understanding of each topic with supporters.

The site contains a tool that can support a person to make a decision. This breaks down decisions into stages, providing space to think about and record what is important in each stage. There are pages to explore change, record options, weigh consequences, and think about skills. The tool organises complex information into simple visuals, enabling people to see, for example, what they think about multiple options, simultaneously. It includes a secure log so that information can be saved, enabling users to make their decision at their own pace, or use it for multiple decisions. Decision makers can also use the tool to confirm their decision making capacity to others, with a printable page that shows the story of how a particular decision was made.

Decision support, like decision making, is a skill that you learn and develop with practise. The third branch of the site is a resource for decision supporters to develop their skills. It describes the attributes and behaviours of decisions supports, as well as principals for decision supporters to work within.

As part of the development of the site Kate Rea and Fiona May undertook a course on writing in easy English at Scope in Victoria. This has in turn improved our capacity to communicate with ADACAS clients in general. It has also drawn ADACAS's attention to a community wide deficit in accessible information for the substantial numbers of Australians who live with low literacy levels.

The second SDM project was an exploration of formal relationship based supported decision making. The project, funded for \$25,000 by Disability ACT enabled ADACAS to support six people with an intellectual impairment to make more of the decisions that were important to them. They were supported using the formal, relationship based, SDM model, developed and trialled by the South Australian Office of the Public Advocate with support from the Julia Farr Foundation. In this model, a decision maker is given as much support as is needed by a decision supporter, in a freely given relationship. Together they develop a supported decision making agreement, which details the decision, supports needed and the roles and responsibilities of each. The relationship, and the agreement, is overseen by a paid monitor, who also has a role in developing the capacity of the decision maker and supporter.

Recognising that access to and experience of decision making is often shaped by the values and behaviours of those who share the lives of people with disability, the project was framed within the broader socio-cultural context in which decisions are made. Along with the six decision makers, who collectively represented a very diverse range of support needs and decision making experience, ADACAS engaged families and service providers to explore their responses to the right to decide and the concept of supported decision making.

The project set out to explore one particular model of supported decision making, set against the socio-cultural context in which decisions are made. While the efficacy of this model was confirmed, the project outcomes also recognised the extent to which support for decision making needs to exist on a spectrum, from formal to informal, and encompassing people with disabilities along with those who share their lives. Some people may need only a little support to access information or weigh up a decision. Others, however, will need to access more comprehensive support, including support to understand decision making, build expectations that they will be involved in the decisions that are important to them, or consider the possibilities for decision support, even before they identify a decision and work towards its fulfilment.

Many of those engaged in the project enjoyed very limited opportunity for self-determination, with lives largely lived within the service sector and governed by the values and decisions of others, including families and care workers. The project illustrated that, for this group, support for decision making is also about creating cultural change that normalises active participation by people with disability in decision making, and by extension access to decision support, and builds the capacity of people who share their lives to enable participation in decision making on a day to day basis.

Overwhelmingly the project revealed that each person's capacity for self-determination was limited not by their ability to make a decision, but by the individualised support they received, be it formal or informal, to exercise their right to decide and the capacity to have control in their lives. Recommendations emerging from the project promote recognition for a spectrum of decision support responses that need to become as mainstream as ramps, automatic doors, and braille on ATM machines. For people with decision making impairment, decision support is a

fundamental access tool. Decision support responses must, therefore, be freely available to all people on the basis of need, rather than meted, rationed or only available to those lucky enough have decision support included in their support package.

ADACAS presented our SDM work in a number of forums over the 2012-13 financial year. This has included

- ACT Expert Panel on the NDIS
- [www.support-my-decision](http://www.support-my-decision.com.au) at the NDIS Practical Design Fund Conference
- National Supported Decision Making Network, including contributions to on-line discussions and presenting a paper
- Queensland Advocacy Inc. Supported Decision Making Conference

Fiona May and Kate Rea also attended the 2nd International Guardianship conference held in Melbourne in 2012. In Queensland we were accompanied by one of the project participants. Mr Rhys Hill made a supported decision making agreement and gave a presentation in Queensland about how much difference participation in the project made to his life.



Fiona May, Rhys Hill and David Hill at the Supported Decision Making Conference in Brisbane

ADACAS Financial Report 2012-13

Board Report

Statement of Comprehensive Income

Change in Equity Statement

Statement of Financial Position

Cash Flow Statement

Notes to and forming part of the Financial Statements

Board's Declaration

Audit Report to Members

Committee Members

ACT Disability, Aged and Carer Advocacy Service Incorporated

Your committee members submit the financial accounts of the ACT Disability, Aged and Carer Advocacy Service Inc. (ADACAS) for the financial year ended 30 June 2013.

Committee Members

The name of each person who has been a committee member during the year ended 30 June 2013 and to the date of this report are:

Stephen Still	Chairperson
Kym Stewart	Treasurer-App't October 2012
Gary Leckie	Treasurer- Resigned October 2012
Dominic Cookman	Committee member
Pamela Graudenz	Committee member
Sean Fitzgerald	Committee member - App't November 2012
Alana Fraser	Committee member - App't March 2013
Penelope Davie	Committee member - Resigned November 2012
Colleen Box	Public officer-App't November 2012

Principal Activities

The principal activities of the association during the financial year were: promoting and protecting the rights of people with disabilities, of people who are ageing, and of those who care for them.

Significant Changes

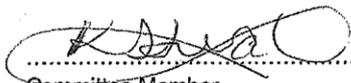
No significant change in the nature of these activities occurred during the year.

Operating Result

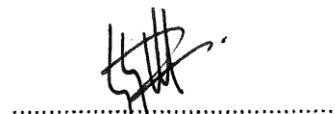
The surplus (deficit) amounted to:

Year ended 30-Jun-12	Year ended 30-Jun-13
\$ 39,527	\$ 25,475

Signed in accordance with a resolution of the Members of the Committee:


.....
Committee Member

Date.....17.10.13.....


.....
Committee Member

Date.....18/10/13.....

**ACT DISABILITY, AGED AND CARER
ADVOCACY SERVICE INCORPORATED**

STATEMENT OF COMPREHENSIVE INCOME

2012	For the year ended 30 June 2013	2013
\$		\$
	Income	
173,707	National Disability Advocacy Program	198,998
-	Disability ACT (SDM Grant)	25,000
529,211	Home & Community Care (net of c/f amount)	434,002
126,926	National Aged Care Advocacy Program	122,301
108,483	Mental Health Consumer Advocacy	111,626
2,285	Disability ACT Grant	18,000
-	National Disability Insurance Scheme	90,200
-	DANA Administration	300
8,505	Interest received	10,058
297	Membership income/donations	86
30,694	IDEAS Inc brokerage	36,132
17,127	Contribution for motor vehicles	20,640
25	Other Income	3,697
<u>997,260</u>	Total Income	<u>1,071,040</u>
	Expenses	
5,930	Advertising and promotion	3,432
10,082	AGM, meetings & conferences	11,838
1,950	Audit fees	1,800
27,880	Depreciation	28,319
20,640	Equipment purchases & maintenance	12,891
13,277	Insurance	7,488
29,352	Motor Vehicle, travel & mileage	38,719
20,080	Moving Cost	-
10,782	Office supplies/stationary & general expenses	11,519
3,470	Prof fees/governance/memberships	3,008
32,306	Rent	40,647
658,405	Salaries & staff benefits	733,521
25,493	Staff development/support supervision	25,017
8,960	Staff leave provisions	(10,927)
51,030	Superannuation	58,935
27,873	System monitoring & development	56,091
10,223	Telephone/computer and internet	10,493
-	Planning Day	12,774
<u>957,733</u>	Total Expenses	<u>1,045,565</u>
<u>39,527</u>	Net Surplus/Deficit for the Year	<u>25,475</u>

**ACT DISABILITY, AGED AND CARERS
ADVOCACY SERVICE INCORPORATED**

**CHANGE IN EQUITY STATEMENT
For the year ended 30 June 2013**

	Note	
Balance as at 30 June 2011		120,370
Surplus (loss) for year 2012		39,527
Prior year adjustment	9	<u>(9,841)</u>
Balance as at 30 June 2012		150,056
Surplus (loss) for year 2013		25,475
Prior year adjustment		1,442
Balance as at 30 June 2013		<u><u>176,973</u></u>

**ACT DISABILITY, AGED AND CARERS
ADVOCACY SERVICE INCORPORATED**

STATEMENT OF FINANCIAL POSITION

As at the 30 June 2013

2012		Note	2013
	Current Assets		
176,338	Cash and cash equivalents	2	189,419
<u>17,464</u>	Trade and other receivables	3	<u>47,210</u>
<u>193,803</u>	Total current assets		<u>236,629</u>
	Non-Current Assets		
<u>93,747</u>	Property, plant and equipment	4	<u>103,262</u>
<u>93,747</u>	Total non-current assets		<u>103,262</u>
<u>287,550</u>	Total assets		<u>339,891</u>
	Current Liabilities		
57,554	Trade and other payables	5	68,906
44,992	Provisions	6	44,091
<u>15,000</u>	Unexpended Grants c/f	7	<u>40,000</u>
<u>117,546</u>	Total current liabilities		<u>152,997</u>
	Non-Current Liabilities		
<u>19,947</u>	Provisions	6	<u>9,921</u>
<u>19,947</u>	Total non-current liabilities		<u>9,921</u>
<u>137,493</u>	Total liabilities		<u>162,918</u>
<u>150,056</u>	Net Assets		<u>176,973</u>
	Members' Funds		
150,056	Accumulated surplus		176,973
<u>150,056</u>	Total Members Funds		<u>176,973</u>

**ACT DISABILITY, AGED AND CARERS
ADVOCACY SERVICE INCORPORATED**

**CASH FLOW STATEMENT
For the year ended 30 June 2013**

2012		Note	2013
\$			\$
	Cash Flow from Operating Activities		
988,755	Operating Income		1,163,340
8,505	Interest Income		10,058
<u>(1,002,056)</u>	Payments to suppliers and employees		<u>(1,124,499)</u>
<u>(4,796)</u>	Net cash provided by Operating Activities	8	<u>48,899</u>
	Cash flow from Investing Activities		
2,531	Receipt from sale of asset		7,600
<u>(29,002)</u>	Acquisition of equipment & vehicle		<u>(43,418)</u>
<u>(26,471)</u>	Net cash provided by (used in) investing activities		<u>(35,818)</u>
<u>(31,267)</u>	Net decrease in cash held		<u>13,081</u>
<u>207,605</u>	Cash at beginning of financial year		<u>176,338</u>
<u>176,338</u>	Cash at end of financial year	2	<u>189,419</u>

**ACT DISABILITY, AGED AND CARERS
ADVOCACY SERVICE INCORPORATED**

**NOTES TO AND FORMING PART OF THE FINANCIAL STATEMENTS
For the year ended 30 June 2013**

2012		2013
\$		\$
	Note 2- Cash	
176,138	Cash at bank	189,219
<u>200</u>	Petty cash	<u>200</u>
<u>176,338</u>		<u>189,419</u>
	Note 3- Trade and Other Receivables	
11,487	Prepaid expense	24,349
5,977	Sundry receivable	9,097
-	Accrued revenue	10,192
-	Bond	<u>3,572</u>
<u>17,464</u>		<u>47,210</u>
	Note 4- Property, Plant and Equipment	
	Equipment & Fittings	
57,396	At cost	51,956
<u>(22,610)</u>	Less: Accumulated depreciation	<u>(25,626)</u>
<u>34,786</u>		<u>26,330</u>
	Motor vehicles	
114,855	At cost	136,116
<u>(55,894)</u>	Less: Accumulated depreciation	<u>(59,184)</u>
<u>58,961</u>		<u>76,932</u>
<u>93,747</u>	Total Property, Plant and Equipment	<u>103,262</u>
	Note 5- Trade and other payables	
2,780	Business Credit Cards (CBA)	-
37,097	Trade payables and Accruals	48,793
14,921	GST and PAYG payables	20,113
2,715	Provision for Grant repayment	-
<u>41</u>	Other payables	<u>-</u>
<u>57,554</u>		<u>68,906</u>
	Note 6- Provisions	
	Current	
44,992	Employee entitlements – annual leave	44,091
<u>44,992</u>		<u>44,091</u>
	Non Current	
19,947	Employee entitlements – long service leave	9,921
<u>19,947</u>		<u>9,921</u>

**ACT DISABILITY, AGED AND CARERS
ADVOCACY SERVICE INCORPORATED**

**NOTES TO AND FORMING PART OF THE FINANCIAL STATEMENTS
For the year ended 30 June 2013**

2012		2013
\$		\$
	Note 7- Unexpended grants	
15,000	- Department of Families, Housing, Community Services and Indigenous Affairs- NDAP	-
-	- ACT Health- HACC	40,000
<u>15,000</u>		<u>40,000</u>
	Note 8- Cash flow information	
	Reconciliation of Operating Surplus (Loss) with Cash Flow from Operations	
39,527	Operating surplus (loss)	25,475
-	Prior Year adjustment	1,442
	Add/subtract Non Cash Items	
27,880	Depreciation	28,319
8,960	Provision for staff leave entitlements	(10,927)
(1,266)	Loss on sale of assets	1,676
-	Profit on sale of assets	(3,691)
<u>75,101</u>	Operating Surplus adjusted for non-cash items	<u>42,294</u>
	Movement in Current Assets and Liabilities	
(3,581)	Decrease/(increase) in Sundry debtors	(3,120)
(11,487)	Decrease/(increase) in Accrued revenue and bond	(13,765)
-	Decrease/(increase) in Prepaid expense	(12,862)
33,380	(Decrease)/increase in Creditors	11,352
<u>(98,209)</u>	(Decrease)/increase in Unexpended grants	<u>25,000</u>
<u>(4,796)</u>	Net Cash from Operations	<u>48,899</u>
	Note 9- Prior year adjustment	

During 2012, a review of ACT Disability, Aged and Carer Advocacy Service Inc's fixed asset register was completed. This review highlighted some anomalies in depreciation calculations which have been rectified and disclosed as prior year adjustments in these financial statements.

ACT DISABILITY, AGED AND CARERS ADVOCACY SERVICE INCORPORATED

Notes to and forming part of the Financial Statements For the year ended 30 June 2013

Note 1 - Statement of Accounting Policies

These financial statements are a special purpose financial report prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Act. The Committee has determined that the association is not a reporting identity and therefore there is no requirement to apply Accounting Standards and other mandatory professional requirements in the preparation and presentation of these statements.

The statements have been prepared in accordance with the requirements of the Associations Incorporation Act, and the following accounting principles.

Incorporation

ACT Disability, Aged and Carer Advocacy Service Inc is an association incorporated under the *Association's Incorporation Act 1991*.

Income Tax

The Association is a non-profit organisation and is exempt from paying income tax in accordance with Section 50-5 of the *Income Tax Assessment Act 1997*.

Historical Cost Accounting

The accounts have been prepared on an accruals basis and are based on historical costs and do not take into account changing money values nor current values of non current assets. The accounting policies are consistent with the previous period unless otherwise stated.

Depreciation

The depreciable amount of all fixed assets are depreciated on a diminishing value basis over the useful lives of the assets to the association commencing from the time the asset is held ready for use.

The depreciation rates used for each class of depreciable assets are:

Computers	40%
Phone System	20%
Motor Vehicles	22.5%
Air conditioning	20%

Goods and Services Tax

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Taxation Office. In these circumstances the GST is recognised as part of the cost of acquisition of the asset or as part of an item of expense.

Employee Benefits

Provision is made for the liability for employee entitlements arising from services rendered by employees to balance date. Employee entitlements expected to be settled within one year, together with any entitlements arising from wages and salaries, annual leave and long service leave that will be settled after one year, have been measured at their nominal amount.

**ACT DISABILITY, AGED AND CARERS
ADVOCACY SERVICE INCORPORATED**

**Committee's Declaration
For the year ended 30 June 2013**

The Committee have determined that the association is not a reporting entity.

The Committee have determined that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the accounts.

In the opinion of the Committee the accompanying accounts:

1. present fairly the financial position of ADACAS as at 30 June, 2013 and the results and cash flow for the year ended on that date.
2. at the date of this Report there are reasonable grounds to believe that the association will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Committee and is signed for and on behalf of the Committee by:


.....
Committee Member


.....
Committee Member



**INDEPENDENT AUDITOR'S REPORT
TO THE MEMBERS OF ACT Disability,
Aged and Carer Advocacy
Service Incorporated
ABN: 15 750 251 576**

PRINCIPAL : Phillip W Miller CA

Level 1, "David Temple House",
Unit 2 / 2 Napier Close,
Deakin ACT 2600
PO Box 105
Deakin West ACT 2600

Ph : (02) 6260 3588
F : (02) 6281 7708
E : pwm@mcsaccounting.com.au
W: www.mcsaudit.com.au

Report on the Financial Report

I have audited the accompanying financial report, being a special purpose financial report, ACT Disability, Aged and Carer Advocacy Service Incorporated of, which comprises the balance sheet as at 30 June 2013, and the income statement, a summary of the significant accounting policies, other explanatory notes and the statement by members of the committee.

Committee's Responsibility for the Financial Report

The committee of the association is responsible for the preparation and fair presentation of the financial report and have determined that the accounting policies described in Note 1 to the financial statements, which form part of the financial report, are consistent with the financial reporting requirements of the Associations Incorporation Act 1991 and are appropriate to meet the needs of the members. The committee's responsibility also includes designing, implementing and maintaining internal control relevant to the preparation and fair presentation of the financial report that is free from material misstatement, whether due to fraud or error; selecting and applying appropriate accounting policies; and making accounting estimates that are reasonable in the circumstances.

Auditor's Responsibility

My responsibility is to express an opinion on the financial report based on my audit. No opinion is expressed as to whether the accounting policies used, as described in Note 1, are appropriate to meet the needs of the members. I conducted my audit in accordance with Australian Auditing Standards. These Auditing Standards require that I comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial report in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the

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ABN: 67 089 734 761

reasonableness of accounting estimates made by the committee, as well as evaluating the overall presentation of the financial report.

The financial report has been prepared for distribution to members for the purpose of fulfilling the committee's financial reporting obligations under the Associations Incorporation Act 1991. I disclaim and assumption of responsibility for any reliance on this report or on the financial report to which it relates to any person other than the members, or for any purpose other than that for which it was prepared.

I believe that the audit evidence I have obtained is sufficient and appropriate to provide a basis for my audit opinion.

Independence

In conducting my audit, I have complied with the independence requirements of Australian professional ethical pronouncements.

Auditors Opinion

In my opinion, the financial report of ACT Disability, Aged and Carer Advocacy Service Incorporated presents fairly, in all material respects the financial position of ACT Disability, Aged and Carer Advocacy Service Incorporated as of 30 June 2013 and of its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements, and the Associations Incorporation Act 1991.

Name of Firm: MCS Audit Pty Ltd
Chartered Accountants

Name of director:



Phillip W Miller CA

Address: Unit 2 / 2 Napier Close, Deakin ACT 2600

Dated: 15 October 2013

