

ANNUAL REPORT

2004 - 2005

ACT Disability, Aged and Carer Advocacy Service Inc

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ADACAS MISSION STATEMENT

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

(Amended and Adopted February 1999)

ADACAS' MANAGEMENT COMMITTEE

Chairperson:	Kym Duggan
Secretary:	Susan Robertson
Treasurer:	Phillip Gleeson
Public Officer:	Marguerite Castello (to November 2004) Kenneth Day (December 2004 to February 2005) Susan Robertson (from February 2005)
Other members:	Pat Daniels Melissa Johns Stephen Price Judith Sykes (to May 2005) Barbara Chevalier (to November 2004)

ADACAS' STAFF

Management and Administration

Manager	Colynne Gates (to November 2004) Andrea Simmons (from February 2005)
Office Manager	Linda Janssen

Advocacy for older people

Coordinator/Advocate	Michael Woodhead
Advocate	Kerry Holdsworth
Advocate	Judy Power
Advocate	Fiona Navilly (from June 2005)

Advocacy for people with disability

Coordinator/Advocate	Sandra Russet-Silk
Advocate	Jaymmie Midegs (leave without pay from October 2004)
Advocate	Belinda Barnard (to October 2004)
Advocate	Tom Allen (from October 2004)
Advocate	Dalane Drexler (from November 2004)

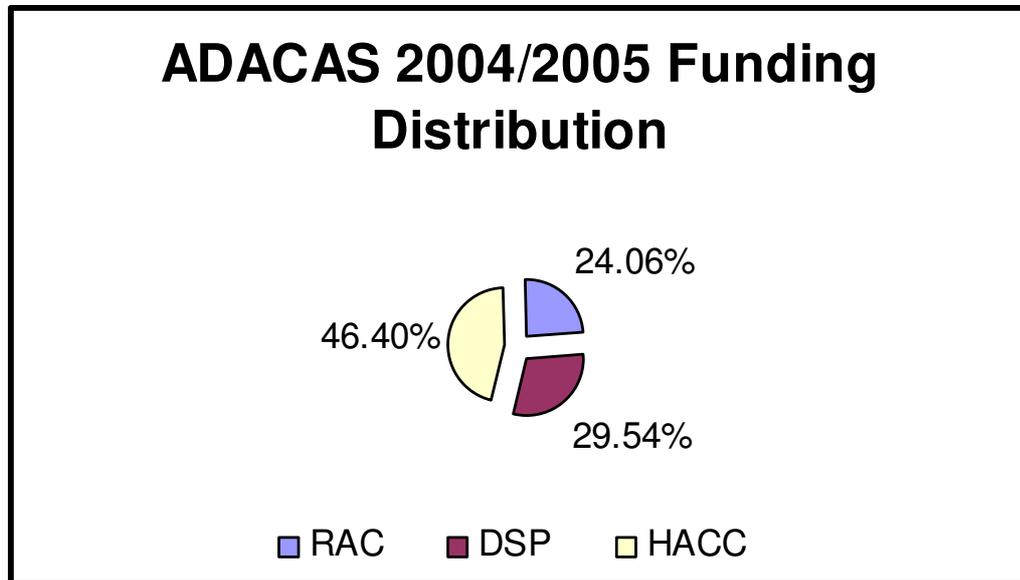
ADACAS FUNDING

ADACAS is funded by two levels of government, through three programs:

ACT Government:	Home and Community Care Program	(46.40%)
Commonwealth Government:	Department of Family and Community Services	(29.54%)
	Department of Health and Ageing	(24.06%)

NB: Funding proportions are “full year effect”, post HACC funding increase.

Table 1 Allocation of funds by program



CHAIRPERSON'S REPORT

The past year has been one of renewal and restructure for ADACAS both for the staff and for the Committee of Management. It is always difficult to lose the manager of any organisation especially when they have been with us for so long. Colynne Gates' departure has led us to rethink the way that we work and in some ways to return to a simpler flatter structure probably more akin to the original ADACAS structure that served so well.

This year we welcomed a new manager Andrea Simmons. Andrea will be no stranger to friends of ADACAS. She brings vast experience on a whole range of fronts to the organisation and her coming has seen a major re-think of how we are organised which at this time is still being finalised but has already received the enthusiastic agreement of the staff and the Committee. I am sure that Andrea's strength, vision and experience have all combined to bring us through a difficult period in the history of ADACAS with a renewed focus on the work we do best and that is individual advocacy on behalf of our many clients.

I wish again on behalf of the Committee to thank our staff for the good will they have shown to our new manager and their enthusiasm in tackling the structural issues we needed to address. I am very hopeful that we now have a structure for the future that will see all of our staff but particularly our more experienced tackle their tasks with renewed enthusiasm and commitment.

I would also like to thank a number of people who have contributed to ADACAS in the past but have left us during the year. Judy Sykes as a Committee member gave us a much needed insight into the aged care sector from a very hands on perspective, her experience is already missed. Ken Day joined us briefly on the Committee and left to take up the position of Executive Officer with Handy Help. Jaymie Midegs and Belinda Barnard decided not to continue as advocates with ADACAS and moved on to other organisations. I wish to thank them for their valuable work for us in the past and wish them well in their new roles. There were also a number of new people working with us this year, Tom Allen, Dalane Drexler and most recently Fiona Navilly and I welcome them on board.

I would also like to record the gratitude of ADACAS for the help, assistance and interest in the organisation shown for many years by the recently retired ACT Minister Bill Woods. Bill has taken a great interest in the work done by ADACAS during his time in the Assembly both in Government and during Opposition. Having a friend at court has certainly done us a lot of good on a number of occasions and we wish Bill all the best in his retirement and hope that his interest in the work that we do remains.

A matter that has caused us some difficulty this year has been recruiting new members for the Committee to replace those who have given so generously of their time in the past. I would like to urge anyone reading this report to give a thought to becoming involved in the work of ADACAS by becoming a member of the Committee. The example of our work that I discuss later is a clear indication of the value that ADACAS can bring to the most disadvantaged in our society. In addition the meetings are generally a lot fun and very informative.

One issue that continues to bedevil the community sector remains the impact of the SACS award and the effective reduction in the wages and allowances that can be made available to staff. What is fascinating is to compare these arrangements with those that apply to our

fund the ACT and Commonwealth Governments. It is very difficult to compete for good staff in this environment. We are aware of the efforts of ACTCOSS and others to address this problem but we again call upon Government to recognise the destabilising effect that this issue has had on the community sector in general.

I would like to return to a number of the themes that I have considered in my reports to you over the last couple of years because there has been renewed focus on these areas in recent days. These issues are retribution in nursing homes and young people in such homes.

Retribution and Young People in Nursing Homes

The primary focus of ADACAS has and always will be individual advocacy but there are times when the focus must shift temporarily to more systemic issues. The Gallop Inquiry in 2002 was one such time but 2004-05 provided us with another opportunity this time primarily in the aged care area.

During the past 12 months the Senate Standing Committee on Community Affairs conducted an inquiry into Aged Care in Australia. That Inquiry provided ADACAS with an opportunity to raise on a national stage these two burning issues. The work brought together as a team once more two of the biggest contributors to the protection of the rights of people living in nursing homes that have ever worked for us.

Michael Woodhead and Colynne Gates (working in her own time much as she did so generously in the Gallop Inquiry) worked together to draft and present a hard hitting submission highlighting these two significant issues. It became apparent early on in the Committee's deliberations that there would be a number of organisations able to strongly push the concerns about young people in nursing homes. So while our submission dealt with this issue ADACAS took a leadership role for the advocacy sector and took up the fight to get before the nation the very much hidden and often denied problem of retribution for complainants living in nursing homes.

ADACAS does not generally seek to deal with the issues of our clients through the media and in particular popular press but there came an opportunity that comes around so rarely that we believed we had to take advantage of the time. Michael Woodhead galvanised the media with his meticulously researched presentations on this issue. For a period of about a fortnight including during his appearance before the Senate Committee Michael managed to bring this issue squarely into the media spotlight much to the dismay of many service providers and governments. At his urging advocacy agencies in South Australia, Western Australia and Tasmania subsequently provided supporting information to the Committee.

I believe that ADACAS and our aged care clients owe a significant vote of thanks to Michael for an effort that certainly came at the cost of much personal criticism from a range of people. The report of the Senate Committee has now been handed down and it is worth reflecting on what this Committee in a bi-partisan manner said. The Committee commented upon the ADACAS submission:

"Some indication of the extent of retribution was provided during the inquiry. In the ACT, the Disability, Aged & Carer Advocacy Service (ADACAS) reported 55 instances of actual retribution in aged care facilities from 2001-2004. Of the 23 homes in the ACT retribution was reported in 13 homes – almost half of all homes in the ACT. In nine homes the retribution reportedly came from management; in six it came from staff and in two it came

from both management and staff. In five homes the number of reported cases of actual retribution was high, ranging from four to 10 cases. In the other nine homes, the number of cases ranged from one to three instances.^[250] In relation to the ACT, in 2003-04, the CRS dealt with four cases which raised the issue of real or potential retribution. All four of these complaints have been finalised. “

Later the Committee noted that ADACAS’s efforts at highlighting this issue have led to some results already:

“DoHA (the Department of Health and Ageing) advised the Committee that the Department and the Commissioner for Complaints have met with ADACAS to seek their views on options for addressing the issues of actual and perceived fear of retribution. Since then the Department has sought and received feedback from ACT-based homes. The Commissioner for Complaints has also undertaken a project to review available literature and evidence and identify strategies that could be considered; and in May 2005 the Aged Care Advisory Committee, the major forum for consultation with the aged care sector, considered these issues – industry groups have agreed to consider specific initiatives to address both any incidence and perceptions around this issue in aged care homes.^[266]”

In its conclusions the Committee noted

“Evidence to the Committee pointed to instances of retribution and intimidation of residents in aged care facilities and their families across many States. The Committee found this evidence particularly disturbing and reprehensible as these practices prey on particularly vulnerable people and cause obvious concern to the families of residents some of whom may themselves be victims of intimidation.”

The Committee made the following recommendations

Recommendation 17

That the Commonwealth examine the feasibility of introducing whistleblower legislation to provide protection for people, especially staff of aged care facilities, disclosing allegations of inadequate standards of care or other deficiencies in aged care facilities.

Recommendation 18

That the Commissioner for Complaints conduct an investigation into the nature and extent of retribution and intimidation of residents in aged care facilities and their families, including the need for a national strategy to address this issue.

There can be no doubt that if ADACAS had not pursued this issue at this time with the tenacity showed particularly by Michael these recommendations would not have been made.

In relation to young people in nursing homes others ably presented the evidence on these issues to the Committee. As a result the Committee made the following recommendation.

Recommendation 22

The Committee is strongly of the view that the accommodation of young people in aged care facilities is unacceptable in most instances. The Committee therefore recommends that all jurisdictions work cooperatively to:

- assess the suitability of the location of each young person currently living in aged care facilities;
- provide alternative accommodation for young people who are currently accommodated in aged care facilities; and

- ensure that no further young people are moved into aged care facilities in the future because of the lack of accommodation options.

We have yet to see how governments both State and Federal will react to these recommendations but you may be assured that ADACAS will be following developments very closely. It is not enough for recommendations to be made and then be left to gather dust somewhere it will be a matter of holding government to account in what they do with these recommendations.

I believe that this work again shows the value and worth of independent advocacy agencies like ours working to expose issues that the effect the most vulnerable in our society. This must always remain part of the core work of ADACAS

Kym Duggan
Chairperson

MANAGER'S REPORT

The past year has seen significant staff changes for ADACAS and a period of internal reflection. The organisation has continued with its primary focus on providing advocacy for individuals that delivers outcomes of their choosing while at the same time working to strengthen the organisational framework which supports advocates in their role. ADACAS has also been active on key systemic issues which affect the lives of vast numbers of people with a disability or who are ageing.

Individual Advocacy

In 2004 - 05 ADACAS provided advocacy to 266 people in relation to 684 issues. A further breakdown of these figures is available in the attached statistical summary (Attachment A) (Table1). These figures are lower than those for the previous year but similar to the figures for 2002-03. Our records show that the desired outcome was achieved in relation to 84% of the issues and that the clients were satisfied with ADACAS advocacy in relation to 90% of issues.

Systemic Advocacy

While the majority of the work carried out by ADACAS relates to advocacy for individuals it is important that the knowledge derived from this work informs the policies and systems which are developed by services and governments. This year our systemic advocacy has been primarily concerned with the following issues:

Disability Reform

Recent policy and 'future directions' publications by Disability ACT have been largely positive in recognising that people with a disability are entitled to live their lives as full and active members of the community and to have an equivalent range of choices available in relation to how and with whom they live, work and associate. Unfortunately the service delivery arm of Disability ACT (ISS) appears to be unable to bring its practice into line with the broader Disability ACT policies and direction. The ISS still provides support through a congregate care model which houses people predominately on the basis of their care needs and appears to pay more attention to behaviour control than to supporting them to have a 'good life'.

ADACAS advocacy has largely been directed towards encouraging the ISS to lead the way in implementing the Disability ACT "Vision and Values" Statement and taking up the Challenge laid out in "Challenge 2014".

Human Rights Commission

The establishment of a new Human Rights Commission in the ACT which includes the appointment of a new Disability and Community Services Commissioner has the potential to provide significant benefits to people with a disability and those who are ageing. ADACAS advocacy to date has focused on ensuring that the new Commission has the necessary jurisdiction and powers to protect the rights and fundamental needs of our client group. Much now will depend on the way the enabling legislation is interpreted and the capacities and priorities of the new Commissioners and the President of the Commission.

Intensive Treatment and Support Service

Early this year the ACT Government announced that it would be replacing the existing house for people with a disability at Long Gully with a new facility. This facility will be designed to provide temporary secure accommodation for up to 6 people with a disability who are deemed to be in need of intensive treatment or support because of their challenging behaviours.

ADACAS has been arguing on the basis of a significant body of research that the people for whom the facility is intended will not be well served by being confined in such a place because they are unlikely to translate what they have learned there to any new environment. Rather the resources should be used to provide this group with more individually tailored support and housing in an environment appropriate to their needs and interests. In addition, it is clear that very few people in Canberra fit the criteria that have been suggested for use of the facility. This calls into question its ongoing viability as a transitional facility.

Retribution in Aged Care homes

For many years ADACAS has been identifying to government and industry its concerns about the way residents of some aged care homes are treated when they or their families complain or ask for things to be done differently.

Early in 2005 ADACAS took the opportunity presented by the Senate Community Affairs Committee Inquiry into Aged Care to make a submission describing retribution, what it looks like, how it affects residents and their family members and the fear that this generates across homes as a whole. The paper called for a multi-faceted “National Strategy for the elimination of retribution and fear of retribution in Aged Care” and made recommendations about the elements that should be included in such a strategy.

Our Chairperson has recorded in more detail the outcome of this submission but it is pleasing to note that the work undertaken earlier together with the Inquiry submission has yielded a range of results including:

- Two significant Senate Committee recommendations
- A Complaints Resolution Services (CRS) initiated project to review the available literature and evidence on retribution and identify strategies for consideration
- Agreement by the Aged Care Advisory Committee to consider specific initiatives and
- a memorandum of understanding between the CRS and the ACT Community and Health Services Complaints Commissioner for the referral and investigation of retribution complaints which come to the notice of the ACT Commissioner
- agreement by peak industry bodies that the issue is of concern and requires action.

Younger People in Nursing Homes

This too is an issue that ADACAS has campaigned hard about for many years arguing that younger people with high medical needs should not be required to live in aged care homes in order to have those needs met. Rather, they should be appropriately supported to live in the community in the ordinary way.

It is pleasing to note that the Senate Inquiry into Aged Care, following submissions from a range of organisations including ADACAS, made a large number of recommendations directed to the creation of more appropriate community based supports for younger people with a disability.

Organisation

In 2004-05, three advocates plus the Manager left the organisation and several took lengthy periods of Long Service or other leave. This created a range of operational challenges for the Organisation and has led to a detailed consideration of the organisational structure and framework within which advocates operate.

As a result a new structure has been developed to:

- provide advocates with better opportunities for career advancement
- recognise the increasing skills and expertise of advocates over time
- provide greater flexibility in the roles of senior advocates
- provide mentoring for new advocates
- provide clinical supervision for all advocates

Work has also been progressing to modernise and streamline some of our practices, to better manage our information and resources and to improve the working environment for advocates. We are:

- installing a new MYOB accounting package and transferring all payroll and financial information onto the system
- culling historical records and organising for ready accessibility the printed resources which we retain
- investigating options for a new database and information management system

All advocates now have access to their own computer with appropriate computer software including power-point and have an ergonomically sound workstation. Air-conditioning, insulation and soundproofing is being installed and the staff room is now well equipped for meetings of 10-12 people.

Financial Matters

The full financial statements for ADACAS are contained in Attachment B to this report.

From the statements you will note that ADACAS recorded a surplus this year of \$25,857.98. This surplus arises from an unexpended insurance payout, interest received on term deposits and unexpended income arising from the sale of 2 ADACAS cars. It is important to note however that the totality of the grant monies received under the Disability and Residential Aged Care Programs was expended and all but \$2368.58 or 1.22% of the HACC dollars.

Information:

Another important aspect of ADACAS work is responding to enquiries from members of the public. This year ADACAS spent 303.25 hours responding to a total of 325 enquiries. Further details about the range of enquiries are contained in Table 4 of the attached Statistical Summary.

Community Education

The ADACAS education program is focused on improving knowledge and understanding within the community about the rights of people who are ageing or who have a disability and on letting people know about advocacy and the work that ADACAS does. The education program involves regular visits to Aged Care Homes, attendance at Aged Care Residents and Relatives Committee meetings and Aged Care Staff Meeting; 115 in total for 2004-05. It also involves sessions with training providers and the staff and/or members of other organisations; 28 in total for 2004-05. A further breakdown of the education sessions conducted can be found in Table 5 of the Attached Statistical Summary.

Community Networking

A key focus for ADACAS since the beginning of 2005 has been to develop lines of communication with those agencies in the ACT with whom we have a commonality of interest. This communication may be about:

- ensuring that we each know how the others policies and processes work so that mutual clients receive the right information, or
- key agencies being informed that particular trends are emerging, or
- joint or co-ordinated systemic advocacy opportunities

Communication for one or more of these purposes has begun with a range of agencies including the Community Advocate, the Disability Discrimination Legal Service, the Human Rights Office, Community Services and Health Complaints Commissioner, Advocacy for Inclusion People with Disabilities and the Client Guardian Forum.

Conclusion

Since beginning work as Manager of ADACAS in February of this year I have been sincerely impressed by the skill, knowledge and wisdom of the ADACAS staff. Their respect for and commitment to the well-being of the people for whom they work clearly drives their advocacy. Their willingness to continually question themselves as well as others gives me great confidence that the organisation will continue to grow in its capacity to provide effective advocacy for people with a disability and people who are ageing.

I would like to take this opportunity to thank all the staff for their assistance and guidance as I have come to terms with my role as a Manager, the intricacies of individual advocacy, and the place of ADACAS in the community. It can't have been easy to break in a new Manager and I truly appreciate the effort that has been involved and the grace with which it has been achieved.

My final thanks must go to the Committee for their ongoing oversight and guidance. Committee work can sometimes be challenging and at other times mundane but it is vital to the health and vitality of any community organisation. I look forward to our future work together.

Andrea Simmons
Manager

ADACAS STATISTICAL SUMMARY

ADVOCACY SUMMARY

The following figures give an indication of the work performance of ADACAS over the past year.

Table 1

Individual advocacy:	
advocacy hours	4372.75
total numbers of people assisted	266
total issues	684
new issues	461
issues closed	396
outcome achieved	333 (84.1%)
satisfied with ADACAS performance, per issue closed	356 (89.9%)
people unable to be assisted	82
Systemic advocacy:	
advocacy hours	255.25
total issues	50
issues closed	13
new issues	23
Enquiries:	
numbers of enquiries	325
time spent	303.25

Of the 266 people receiving advocacy this year:

- 105 were people with disability and their carers;
- 131 were older people and their carers who are clients of the Commonwealth's Residential Aged Care Program, including 3 people with disability and 6 people in receipt of Community based packages, (CACP and EACH); and
- 30 were older people living in the community and their carers.

ADACAS provided advocacy for 57 people from other cultures, and there were 3 people of Aboriginal background who received advocacy this year. In addition, 12 people with dementia, or carers of someone with dementia, were provided with advocacy.

ADVOCACY ISSUES

Information is recorded on each advocacy issue and enquiry dealt with by ADACAS. The following table provides information on the number and types of issues responded to this year.

Table 2

Issue Types	All people	Carers of, and people with disability	Carers of, and people in aged care homes	Carers of, and older people living in the community
1. Administration and fair trading eg personnel or staffing issues, fees and charges	37	3	32	2
2. Level of care eg access to specialised services, continence issues etc	170	37	116	17
3. Consumer rights eg abuse by a service provider staff, lack of choice and decision making	169	60	105	4
4. Environment eg catering, theft, security of tenure	53	6	39	8
6. Alternate decision making eg Guardianship, Financial management, Powers of Attorney	27	14	11	2
7. Care Options eg access to appropriate care	16	7	7	2
8. Financial issues	33	16	12	5
9. Health system interaction	14	9	2	3
10. Regulation eg consumer protection	2	2	0	0
11. Significant others eg abuse	28	22	5	1
12. Legal	48	41	4	3
13. Education	5	5	0	0
14. Transport	7	3	3	1
15. Employment	7	7	0	0
16. Accommodation	62	52	4	6
17. Other	6	3	3	0
TOTAL	684	287	343	54

ADVOCACY OUTCOMES

Table 3

	People with disability	Older people living in the community	People living in aged care institutions	Total
Total issues closed	128	18	250	396
Outcome achieved	125	17	191	333
%	97.7%	94.4%	76.4%	84.09%
Satisfied with ADACAS	103	17	236	356
%	80.5%	94.4%	94.4%	89.9%

INFORMATION

Of the 325 enquiries ADACAS responded to this year:

- 95 were from, or on behalf of, people in aged care institutions;
- 76 were from, or on behalf of, older people in the community; and
- 154 were from, or on behalf of people with a disability.

The total time spent in responding to the enquiries was 303.25 hours.

More detail about the nature of the enquiries is provided in the table below.

Table 4

	re people with disabilities	re people who are ageing in the community	re people living in aged care homes
Abuse by significant others	8	6	7
Legal issues	16		
Employment	8		
Accommodation	17		
Consumer rights	9	15	18
Financial	13	3	
Health System	9		
Level of Care			16
Administration / Fair trading			
Disability Issues	13		
Residential Aged Care			18
Other	42	32	13

COMMUNITY EDUCATION ACTIVITIES
July 2004 to June 2005

Table 5

ORGANISATION	NUMBER OF ACTIVITIES
Residential Aged Care Program:	
Amity at Aranda	8
Brindabella Gardens Hostel	3
Brindabella Gardens Nursing Home	4
Brindabella Gardens Hostel Resident's meeting	1
Brindabella Gardens Nursing Home & Hostel (Staff)	1
Carey Gardens	6
Croatian Village	4
Eabrai Lodge	4
Ginninderra Gardens Hostel	4
Ginninderra Gardens Hostel Resident's Committee	1
Ginninderra Gardens Nursing Home	6
Ginninderra Gardens NH Resident's Committee	1
Goodwin Ainslie	4
Goodwin Farrer	3
Goodwin Monash	3
Jindalee	9
Kalparrin	4
Kankinya	2
Kankinya Resident's meeting	1
Mirinjani Hostel	4
Mirinjani Nursing Home	5
Morling Lodge	6
Morling Lodge Carers Meeting	1
Morshead	4
Mountain View	4
Ozanam	4
St Andrew's	5
St Andrew's Resident's Committee	2
St Andrew's Relatives Support Group	2
St Nicholas	4
Villaggio	5
	115
Other Aged Care Activities:	
Aged Care Services Australia	1
Cantonese Speaking Community	1
Chinese Carers PICAC,HACC	1
Italian Carers PICAC, HACC	1
Italian Community PICAC, HACC	1
Mandarin Speaking Community	1
Spanish Speaking Community	1

	7
ORGANISATION Continued:	NUMBER OF ACTIVITIES
Other activity:	
CIT	10
TRAHCS	7
ACT MHCN AGM	1
Handyhelp	1
PWD	2
Total all Activities	143

ATTACHMENT B

FINANCIAL STATEMENTS