ADACAS

ANNUAL REPORT

1997

ACT Disability Aged and Carer Advocacy Service
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September 1997

ADACAS MISSION STATEMENT

ADACAS promotes and protects the rights and responsibilities of people with a disability, people who are ageing, and those who care for them.

ADACAS MANAGEMENT COMMITTEE

Community Representatives	Garry Dellar (Chairperson)
	Maurice Sexton (Treasurer)
	Gabriel Savas (Secretary)
Disability Representatives	Maree Wright
	Bonnie Brown
Aged Representatives	Oenone Edwards (Public Officer)
	Gerald Cornwell
Carer Representatives	Michael Fowler
	Lynn Russell (on leave)

ADACAS STAFF

Manager/Coordinator	Beryl Homes (to 31 January 1997)
	Colynne Gates (from 1 February 1997)
Advocate (Aged)	Judy Phillips
Advocate (Aged)	Joan Suckling (part-time)
Advocate (Disability)	Sandra Russet-Silk
Advocate (Psychiatric Disability)	Michael Woodhead
Advocate (Work Places clients)	Joanne Duffy
Office Administration	Linda Janssen (part-time)
	Beby Bros (part-time)

ADACAS FUNDING

ADACAS is funded by two governments through three programs:

ACT Government	Health and Community Care Program	28.98%
Commonwealth Government	Residential Aged Care Program, Department of Health and Family Services	30.11%
	Disability Services Program	40.91%

CHAIRPERSON'S REPORT

On behalf of the Committee and staff I welcome Colynne Gates to ADACAS. She was appointed as the new Coordinator in February 1997 having had extensive experience in Commonwealth Government, particularly in areas dealing with disability services. On taking up the position she was immediately met with a number of challenges, some of which are outlined in her report. ADACAS has always been fortunate in having dedicated and capable Coordinators and the tradition continues. The position is a demanding one, particularly in the current environment of difficult funding and some questioning of the value and relevance of advocacy itself.

The last year saw ADACAS undergo two reviews, one by the Commonwealth as part of a review of advocacy and the other by Michael Kendrick who delivered a helpful report on the future directions of ADACAS. Both reviews were positive about the past achievements and present effectiveness of ADACAS, particularly in carrying out its core function of individual advocacy.

The Kendrick report identified a need for a more coherent and effective approach to systemic advocacy. This advocacy is intended to bring about change to the broader systems as they impact on particular groups which share common problems or disadvantages rather than resolve the particular issues that relate to some individual client. ADACAS is not appropriately structured to carry out systemic advocacy other than in an incidental way. Firstly, we are not funded to do it, and our staff are fully occupied in dealing with individual clients. Secondly, systemic advocacy will often involve controversial and politically and socially sensitive issues which may be perceived as attacks on government policy or administration. As ADACAS is in one way or another almost wholly funded by government, it seems to me to be not well placed to engage in that activity without complicating its relations with its funding bodies.

There is a place for systemic advocacy. It is an important and necessary activity but it is best carried out by a body that is quite independent of government in its funding, and which does not have a substantial individual advocacy workload.

Yet another reason for focusing on individual advocacy is that this area has itself come in for questioning and criticism in some quarters. Certain groups, and some politicians, seem to see it as usurping the role of families or disturbing traditional arrangements for the care of, for example, people with disabilities. It is true that individual advocacy focuses on the wishes and needs of the individual, and ADACAS is often criticised for advocating outcomes which do not accord with the wishes of other members of the client's family. That is what individual advocacy is about – empowering the individual who might not otherwise have his or her needs or wishes taken into account when decisions are taken which affect their lives.

Also of course not all family environments are benign. ADACAS experience over the years has found many cases of mistreatment and financial exploitation of the client by one or more family members, sometimes accompanied by personal violence. Nevertheless the more usual position is that ADACAS works with families to get the outcome which the client wishes.

As to the future, ADACAS has been asked to provide administrative support through taking over the administration of the financial grant of Parent Advocacy, a small ACT advocacy agency which is not viably funded.

The time has probably come for a review of the constitution of ADACAS, particularly the structure of the Committee of Management, to ensure that it properly represents our client base and our constituencies generally.

It remains only for me to express my appreciation to my fellow committee members for their contribution to ADACAS during the past year. I must also acknowledge yet again the dedication of the staff of ADACAS in dealing with a heavy and stressful workload and doing so much to make ADACAS the success it is. The Committee greatly appreciates your individual contributions.

Garry Dellar
Chairperson

COORDINATOR'S REPORT

This is my first report as Coordinator of ADACAS. I would like to take this opportunity to thank the Committee, staff, and Beryl Homes in particular, for their support as I come to grips with this very challenging position.

This is the seventh annual report of the ACT Disability Aged and Carer Advocacy Service, (ADACAS).

Overall results

Data and statistics are covered in Appendix A. In general, and as predicted in last year's report, this year has indeed been a challenging one for ADACAS. Client numbers are marginally down on last year, but the length of time on issues, and the complexity of issues has increased markedly.

The overall number of issues dealt with by ADACAS this year was 514 with a further 261 issues handled as enquiries. These figures appear to be significantly less than last year. However, the change is due largely to a change in the way data has been interpreted. (By way of comparison, the figure for 1996-97 is 1282 when the data is interpreted as in previous years.) Never-the-less there has been a decrease in client numbers and issues, and this can be mostly attributed to the loss of funding for an advocacy worker for people with acquired brain injury.

Client satisfaction rate was 95%, with an outcome achieved rate of 92%, a very positive result.

Funding

Financial statements for 1996-97 are at Appendix B.

ADACAS is funded by three government programs, and all funding levels were maintained for 1996-97. Funding contracts for 1997-98 have effectively been maintained at current levels. However some small grants have been received from the Commonwealth Government's Residential Aged Care Program, and the ACT Government's HACC program for data and computer equipment to assist in increased reporting requirements. This has enabled ADACAS to upgrade its computer facilities, including improving its data gathering, and analysis. ADACAS would like to express its appreciation to Mr Bill Barker of Kymcall Pty Ltd, for the generous assistance he has provided to ADACAS in respect of the development of the data base.

ADACAS has again applied for funding to re-instate the advocacy worker for people with acquired brain injury, without success. As part of its closer working relationship with other disability advocacy agencies in the ACT, we assisted in the development of an

application for a worker to provide advocacy support to clients of the Disability Program during its reforms. ADACAS also made an application in its own right in respect of the reforms in the Mental Health Branch residential services to provide advocacy support to residents of Hennessy House and Watson Hostel. To date, no positive response has been received to either of these applications.

Reviews

ADACAS has again undergone a review against the National Disability Services Standards. These are required by the Commonwealth Government and are undertaken every year by the agency, in consultation with clients. Agencies are also subject to an audit every five years. In the main, the review confirmed a high standard of service delivery. Similarly, ADACAS volunteered to pilot the HACC draft standards monitoring process, and an audit of our response again indicated high standards.

In addition to government sponsored assessments, ADACAS also underwent an independent review by Michael Kendrick. His final report was received in late January 1997. His report confirmed the high standing ADACAS has with its client group. The recommendations are under consideration by the ADACAS Committee, and include the development of other, independent funding sources, better ways to identify and follow through with systemic advocacy issues, and clarification of our respective roles between, and closer working arrangements with, other advocacy agencies in the ACT.

ADACAS will continue to discuss these issues over the next year, as they are matters that are fundamental to ADACAS and advocacy in general. Such decisions should not be made quickly, and will be made in consultation with key stakeholders.

Significant events

Three staff members attended workshops in Brisbane conducted by Wolf Wolfensberger. The workshops were very demanding of staff both physically and mentally. The subject matter included a close examination of the history of human service development, and some of the underlying assumptions which have guided this development. Arising from these assumptions and the process of human services development are significant issues for advocacy agencies. A second workshop focussed specifically on social advocacy, and provided a wealth of information for staff that was immediately useful, as well as other material which has provided us with “food for thought”.

ADACAS was approached by Work Places, a supported employment service for people with a disability, and asked if we would auspice Work Places’ Client Liaison Officer. After some discussion ADACAS agreed to this proposal. Ms Joanne Duffy, whilst employed by ADACAS, works solely with Work Places’ clients. Her role is to educate and support them to understand Work Places’ policies and procedures, to be involved in reviewing the policies and procedures and to participate in the annual reviews of Work Places against the Disability Services Standards. Joanne is also the first point of contact

for Work Places' clients in the event they have a complaint or dispute with Work Places. Outsourcing her to ADACAS will provide her with increased independence and reduce any conflict of interest she may have experienced. ADACAS is pleased to support this innovative concept, but will closely monitor the project to ensure ADACAS' independence is maintained.

Conclusion

In closing, I cannot say that the road ahead is clear and hazard free, but I am confident that the ADACAS staff have the skills, expertise and dedication to continue to deliver exemplary advocacy to our clients. I look forward to the challenges of the coming months in working with the newly appointed Committee of Management as we re-visit ADACAS' operations and look to establish a sound foundation for the future.

Colynne Gates
Manager/Coordinator

September 1997

Appendix A

Data Summary

Part 1 – Advocacy

In the year ending 30 June 1997, ADACAS provided advocacy support in respect of 514 client issues. The time spent was distributed as follows:

Information provision:	9%
Education/support:	49%
Representation:	42%

Of the 514 client issues:

176 were for people with a psychiatric disability
112 were for people with other disabilities
133 were for people who are ageing
48 were for carers of people with a disability
45 were for carers of someone who is ageing

In addition, the data indicates ADACAS clients were also in receipt of community based services as follows:

Services funded by:-

Commonwealth, Disability Services Program:	173
Commonwealth, Residential Aged Care Program:	94
ACT Government: HACC:	106
ACT Government, Disability:	15*

125 clients did not receive any community based services.

(* Some of these clients are also recipients of services provided directly by the ACT Government through Disability Programs.)

There were 77 client issues from people with a non-English speaking background, and another 13 issues from people with Aboriginal or Torres Strait Islander descent.

There were also 261 advocacy issues that were handled over the phone that concerned ADACAS client group.

Advocacy for people with a disability

ADACAS receives funding from the Commonwealth Government specifically to provide advocacy to people with a psychiatric disability. The remaining Commonwealth funds and a portion of the ACT Government's HACC grant enables the employment of another full-time worker for other people with a disability. Of the 288 client issues, and 175 telephone enquires, total 463,

94 were from people with an intellectual disability;
75 were from people with a physical disability;
8 were from people with a sensory disability; and
286 were from people with a psychiatric disability.

In addition, under the HACC program, ADACAS can provide advocacy support to carers of people with a disability. In the 1996-97 year, ADACAS has provided advocacy support to 62 carers of people with a disability comprising:

27 carers of someone with an intellectual disability;
15 carers of someone with a physical disability;
2 carers of someone with a sensory disability; and
18 carers of someone with a psychiatric disability.

ADACAS has provided 2145 hours of support to people with a disability and/or their carers in this financial year.

People who are ageing

ADACAS employs one full-time and one part-time worker to provide advocacy support to people who are ageing and their carers. Funding is provided by the Commonwealth government specifically for people in nursing homes and hostels, and their carers. The HACC program funds advocacy support to older people living in the community, and their carers.

Of the 250 client issues and enquiries in respect of older people and their carers:

22 were from carers of older people living in the community;
88 were from older people in the community;
19 were from carers of older people in a hostel;
19 were from carers of an older person in a nursing home;
66 were from older people living in a hostel; and
36 were from people living in a nursing home.

ADACAS has provided 739 hours if advocacy support to older people and their carers this financial year.

Issues raised

ADACAS maintains a comprehensive data base on the kinds of issues raised by clients. For people living in the community, the most common issue they faced was with rights in and/or standard of services received. This issue was followed closely by issues over community based accommodation, and thirdly, community options and choices. Health issues also rated highly, followed by legal issues and then abuse and violence.

For older people living in residential settings the most common issue was health care, followed closely by fees. Other issues of importance to people living in institutions were social independence, freedom of choice, financial matters, homelike environment, privacy and dignity and guardianship.

ADACAS has found that people living in the community are more likely to follow through with complaints or to seek ADACAS assistance in resolving issues for them. Younger people with a disability also seem to be more aware of their rights, and strategies and ways of having their rights and other issues dealt with.

It has been our experience this year that, although many people residing in institutions have raised issues with us, sometimes quite serious ones, they are unwilling to follow through with formal action to have the issue resolved. Their reasons for this were usually because they did not want to make a fuss, and also because they had concerns about possible repercussions of making a complaint. Whilst the first reason may be a "generational" factor, the second is of concern to ADACAS, and will need closer examination, especially in light of the reforms in the aged care industry, including standards monitoring.

In analysing the issues raised by clients, and the advocacy process adopted by ADACAS there are a number of systemic issues that require resolution. ADACAS seeks to have systemic issues resolved through referral where possible to appropriate authorities or other community agencies with a mandate in the area of concern.

In 1996-97, the following issues have been identified:

ACT Housing;	Inconsistent decision making in respect of priority transfer in situations where clients are at risk of violence, being harassed by neighbours or where clients have rental arrears.
	Frequent change-over in staff and some gaps in training, thus incorrect information is being given to clients resulting in financial losses by clients and other disadvantages.
	Creating ghettos through its allocation process. IE Housing people with psychiatric disability in high density accommodation along with people with drug and alcohol related problems and other marginalised people.

	Financial hardship caused as clients break a private lease when ACT housing is made available.
	People being denied accommodation because of rental arrears and debts which were incurred largely as a result of the impact of their disability several years ago.
	People being required to continue with rental payments when living in emergency housing as a result of violence and waiting for priority transfer.
	Tenants not being given options on repairs, and being billed inappropriately for painting and repairs.
ACT Police	Not giving credibility to people with a psychiatric disability generally, and especially when reporting abuse.
Health	Revealing confidential information to carers, but not legal guardians, of people with a disability.
	Not giving full information to person with a disability or older person and not encouraging their participation in health related decisions. (Prefer to deal with family.)
	Premature discharge from hospital.
	Discharge planning not conducted well, especially for people with acquired brain injury.
	People with psychiatric disability seeking emergency admission to hospital, being refused because of a lack of available beds.
	GPs not visiting patients in nursing homes promptly. One client, having fallen and in considerable pain, waited five days after notification, before the doctor called and diagnosed broken ribs.
Community Service Delivery	Services not providing support as specified in contract with ACT government.
	Consumer representatives on management committees not given full information about their role and responsibilities, and support to fulfil their obligations as committee members.
	Lack of grievance procedures, and where they exist, lack of publication and education of service users in their use.

	Ineligibility or lower priority of access for people whose diagnosis is on the cusp between health and disability, even though, (and possibly because,) their support needs may be enormous. Inappropriate referrals to other agencies, perhaps to clear their books or to transfer responsibility for people with high support needs elsewhere.
Funding	Lack of support services for families of people with a psychiatric disability. People being denied Legal Aid because of cut backs, but granted after appeal with advocacy support. What happens to those people who do not access advocacy or who may be unaware of, or unable to access the appeal process? Gaps and inefficiencies in service provision due to congregate model of support. Funding, and therefore staffing and support for many community based and government provided services for people with a disability is tied to a location and/or group situation. That is, the house where people are living, or a group employment situation eg sheltered workshop or work crew, has a fixed amount of staffing allocated to it, based on the needs of the current clients. When one decides to leave, the next eligible individual may "lose their turn" because their support needs are higher than is available. Alternatively, if a person with lower support needs than is provided at the site is moved in, they will be "over-supported", resulting in loss of skills and competencies, creation of dependency, and inefficient use of resources. Increases in grants have not kept pace with increases in real costs. In some cases, grants have been reduced, eg "efficiency" dividends. Support needs of individuals, and operating costs may not have reduced, and in some cases (eg movement to awards, and where clients have degenerative disability) they have increased.
Transport	Eligibility for taxi vouchers generally and for people with psychiatric disability in particular. People may not be able to use public transport because of their psychiatric disability. There have also been occasions when people with a psychiatric disability have not been allowed onto a bus, or have been asked to leave it. The cost of transport even with a taxi voucher, does not enable people with disability to access the community in ways that are comparable to people without a disability. For example, maximum

	co-payment for someone with a disability should be no more than the equivalent bus fare. The expense of the taxi voucher system does not enable people to have any kind of quality of life.
	People living in nursing homes and hostels are not eligible to use HACC transport services, and cannot access public transport. As they also have little money left after nursing home or hostel costs have been deducted, many people are unable to pay for taxis to attend important appointments eg doctors and specialist appointments.
Education	Access for children with autism to education, even to the extent of being excluded from special schools.
Other	Some non-mainstream religious organisations are aggressively recruiting people with psychiatric disability.
	Local television not verifying facts on a story before going to air.

Referrals

ADACAS can receive a referral from anyone, anywhere in the ACT. In the 1996-97 year, the majority of referrals to ADACAS were self referrals, (350). Referrals from government service providers totalled 109, whilst community service providers accounted for 100 referrals. The remainder was from family and friends.

In some cases the issue raised by a client is not an advocacy one and can be resolved more appropriately by service providers of one sort or another. In these cases ADACAS refers clients onto the most suitable agency, and may assist the client to gain access. The most common single point of referral made by ADACAS was to the Welfare Rights and Legal Centre. Other referrals were made to mental health services both government and community based as well as other health related providers; other legal and similar agencies, eg Guardianship Tribunal etc, as well as numerous referrals to accommodation, employment and community access support agencies.

Gaps in service system

ADACAS has identified 74 situations which revealed a gap in the service system. There were 18 situations where there was no service at all; 4 where the service was full; 39 where the model of available service delivery was inappropriate, and 13 where eligibility criteria was an issue.

Advocacy networks

ADACAS is a member of two networks of advocacy agencies; the ACT Disability Advocacy Network, and the National Advocacy Network, for the Residential Aged Program. ADACAS also attends the ACT HACC/DSG Network meetings, and represented this group on the Coordinated Care Trial Consumer/Provider Reference Group. As part of these networks, and in its own right, ADACAS has provided comments and submission on numerous discussion papers and reviews where these had capacity to impact on the lives of ADACAS' client group. These include:

Disability: ACT Disability Programs reforms and strategic plan;

The Commonwealth's discussion paper on the National Disability Advocacy Program and review of same;

ACT Mental Health Services;

Commonwealth's review of the Mental Health Strategy;

ACT Legislative Assembly Social Policy Committee on mental health services and on housing.

NITAB, Competency standards for Aged Care, Disability and Mental Health workers

Attorney General's Department, Review of Mental Health Legislation

Mental Health and Drug Strategy Unit, HACC, Review of ACT Mental Health Legislation

Mental Health National Peak Body Task Force

ACT Legal Aid, Review of service, Domestic Violence and Restraining Order Section

Older persons: Aged Care Reforms, including being invited to attend the Senate Hearings.

Development of an independent, national complaints handling mechanism for residents in nursing homes and hostels;

Part 2 – Community Education

ADACAS conducts a range of community education programs in order to increase the knowledge and awareness of ADACAS, advocacy and the needs of ADACAS' client group. Specifically, as part of its funding under the Commonwealth Aged Care Program, ADACAS conducts extensive education programs to key stakeholders in aged care about ADACAS, advocacy in general, and on aged care issues, for example the Charter of Rights For Residents of Nursing Homes and Hostels. ADACAS also conducts education programs for other community and government agencies on request, and pro-actively offers education programs to a wide range of groups of people in order to promote the concept of advocacy and to raise the profile of the needs of disadvantaged people.

The total number of educational programs delivered this year was 271, and 4561 people have attended. The Commonwealth's Residential Aged Care Program has a specific requirement for educational programs to be delivered to residents and staff in nursing homes and hostels, and to staff and key workers in other related agencies. ADACAS has provided over 800 hours of such training, and people attending these aged care focused educational programs have included:

14 younger people with a disability living in nursing homes;
130 older people living in the community;
2958 residents of nursing homes and/or hostels;
653 staff in nursing homes and/or hostels,
36 staff of other community and government provided services,
226 carers, and
25 other people, eg legal or medical professionals, public servants etc.

As part of its contractual arrangements with the Commonwealth Residential Aged Care Program, ADACAS visits every nursing home in the ACT every month and every hostel every second month to meet with residents and to provide information, and advocacy support. These visits are important as they enable the residents and staff to become acquainted with ADACAS. When issues do arise they are more confident in approaching us to seek our assistance.

In addition, ADACAS also provides support to Residents Committees in nursing homes and hostels. In November 1996, ADACAS received additional funding and organised a forum of Residents Committee members, held at Old Parliament House. This enabled the committee members from the majority of the nursing homes and hostels in Canberra to meet members from other committees and to discuss issues of common concern. The forum was very successful, but as resources have not been made available to repeat the event, it is unlikely it will be held in 1997-98.

Similarly, ADACAS and the Carers' Association of the ACT organised a Carers' Forum which was held in March. The forum provided carers with a wide range of information relevant to older people living in the community and about to consider residential care. The opportunity was also taken to provide introductory information about the aged care reforms. Again, because no additional funding has been made available, this event may not be repeated in 1997-98.

In addition to all the nursing homes and hostels, ADACAS has also provided educational programs to the following organisations in 1996-97:

ACT Human Rights Group
CDS Group House Staff
CIT – Woden Campus Welfare Students
Disability Program, ACT
Ezi-Iron
Living with Hearing Loss
Pack & Post
PRS – Young Ones
St Ninians Church
Tuggeranong Health Centre
Mental Health Foundation Respite House staff
Aged Care Assessment Team
CIT Students – Disability Studies
Deakin Rotary
All Seasons
Koomari Printery
Migrant Health Unit
Phillip College
RAC Office
TRACHS
Tuggeranong Seniors Group
Workways

Part 3 – Research

ADACAS research has been limited this year due to other priorities.

ADACAS has secured the placement of Health Sciences student who is developing a training manual for advocates working with people with a psychiatric disability.

Part 4 - Administration

Staff

Coordinator/Manager, Ms Beryl Homes retired in January 1997, to be replaced with Ms Colynne Gates.

Part-time Advocacy worker, Aged Care, Ms Joan Suckling replaced Ms Annelise Beckmann, effective November 1996.

Part-time Administrative assistant, Ms Beby Bros, commenced in August 1996.

ADACAS monitors its advocacy work through regular meetings with each staff member.

ADACAS reviews and plans its work through regular staff meetings which are attended by all staff.

Staff training and development

Staff have attended the following training and development events:

HACC inaugural conference (registration fees funded by ACT government)
ANAMH Mental Health Forum/Planning day
Senate Community Affairs Committee of Enquiry into Aged Care Reforms
Disability Programs reform public meetings
International Association of Jurists
Management Assessment Panel Information and Mock Panel Workshops
Risks and Restraint Conference
NESB consumer, carer and community forum
Managing Conflict Anger and Emotion
Social Role Valorisation workshop
Empowerment for people From Non-English speaking backgrounds, Transcultural Mental Health Centre, NSW
Medication Awareness, Mental Health Services
ACT Shelter Forum, Falling Through the Gaps
1997 Biennial National Autism Conference
"They Said We'd Never Make It" – Ageing and Disability Conference

Committee

There have been some changes in the Management Committee following the AGM in September. Ms Lynn Russell was granted leave to go overseas, and Mr Gerald Cornwell joined the Committee as an aged representative.

Management Committee meetings during the year were:

1996	1997
30 July 1996	24 January 1997 (Executive)
20 August 1996 (Executive)	18 February 1997
19 September 1996 (Executive)	15 April 1997
24 September 1996 (AGM)	17 June 1997
31 October 1996	
17 December 1996	

APPENDIX B

FINANCIAL STATEMENTS

FOR

1996-1997