

ADACAS

ANNUAL REPORT

1998

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Table of Contents

ADACAS Mission statement	3
ADACAS Management Committee	4
ADACAS staff	4
ADACAS funding	5
Chairperson's report	6
Manager's Report	8
Overall results	8
COOOL	8
Deinstitutionalisation of Hennessy House And Watson Hostel	10
Funding	11
Evaluation and review	12
Conclusion	12
Staff reports	13
Advocacy for people who are ageing	13
Advocacy for people with a disability	14
Work Places Project	16
Advocacy ACTION	17
Appendix A: Data summary	19
Part I – Advocacy	19
Advocacy	
- for people with a disability	20
- for people who are ageing	21
Issues raised	23
Results	25
Part II – Community Education	26
Part III – Staff Training and Development	27
Part IV – Networks	28

Index to Tables

Table 1:	Funding allocation	5
Table 2:	1996/7 and 1997/8 Advocacy Issues	19
Table 3:	1996/7 and 1997/8 Enquiries	20
Table 4:	ADACAS gender distribution; clients	22
Table 5:	ADACAS gender distribution; carers	22
Table 6:	Regional distribution	22
Table 7:	Age distribution	23

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 to May 1998) Helen Watchirs (Chairperson from June 1998) Ann Procter (Treasurer) Gabriel Savas AM (Secretary and Public Officer)
Disability Representatives	Maree Wright Bonnie Brown
Aged Representatives	Maurice Sexton Jack Jones
Carer Representatives	Michael Fowler Karen Connaughton

ADACAS STAFF

Manager	Colynne Gates
Advocate (Aged)	Judy Phillips
Advocate (Aged)	Joan Suckling (part-time)
Advocate (Disability)	Sandra Russet-Silk
Advocate (Psychiatric Disability)	Michael Woodhead
Work Places' Project staff	Joanne Milton (Consumer Training and Support Officer) Ann Macduff (Advocate)
Office Administration	Linda Janssen (part-time) Beatrix Bros (part-time)

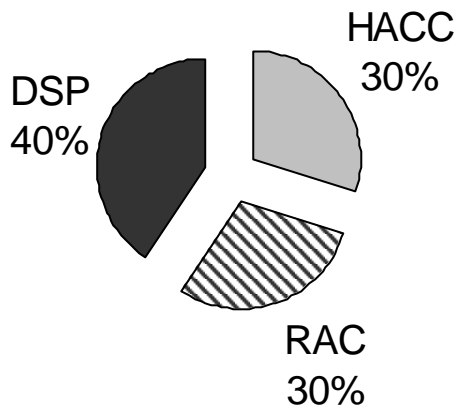
ADACAS FUNDING

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

ACT Government	Health and Community Care Program	29.65%
Commonwealth Government	Department of Health and Family Services	
	Residential Aged Care Program	29.91%
	Disability Services Program	40.44%

Table 1 Allocation of funds by Program

ADACAS 1997/98 Funding Distribution



CHAIRPERSON'S REPORT

On behalf of fellow Committee members and staff I would like to thank Garry Dellar, outgoing Chairperson, for his meaningful contribution over the years to ADACAS, particularly during stressful times. We appreciate all his hard work and wish him well in his future endeavours. Since accepting the position of Chairperson of ADACAS on 24 June 1998 I have been most impressed by the professionalism, vision, commitment and energy of ADACAS staff and management committee members and look forward to working together in the future to achieve common objectives.

In the last year there have been several developments which have impacted on ADACAS' work. One I feel strongly about, given my background as a human rights lawyer, is the reduction in Commonwealth funds to the Human Rights and Equal Opportunity Commission (HREOC). It has been slashed, according to HREOC figures, by 40% - the Government maintains that this is actually 27% in real terms.

Although HREOC's figures are more substantial, even if one accepts the Government figure, there has been a large downsizing of an essential service to protect the rights of vulnerable people. This waning commitment is being felt in all States and here in the ACT.

What is particularly worrying about this trend is that Australia is continuing its involvement in UN and bi-lateral development assistance activities, replicating our "best practice model" in other countries, while HREOC is being white-anted at home. Draft legislation restructuring HREOC which will jeopardise its independence is currently being considered by the Senate. If adopted, it will further dilute Australia's implementation of the 1992 Paris Principles Relating to the Status of National Human Rights Institutions.

Another possible target in this winding-back of human rights protection is the review of the specialist legal advocacy centres set up under the *Disability Discrimination Act 1992*. In Canberra this service is provided by the Welfare Rights and Legal Centre. A Consultative Committee is to be established with representatives from the Attorney-General's Department, state managers of Commonwealth Community Legal Services Program (Legal Aid Commissions), the DDA legal services and the National Association of Community Legal Centres.

ADACAS was unsuccessful in seeking to have consumer representation on this Committee, despite a partnership approach with real community involvement in reviews being taken in most other fields of government policy, projects and programs. Of further concern was the apparent inability of the Office of Disability, located within the Department of Health and Family Services, to influence the Legal Aid and Family Services Division of the Attorney-General's Department in their decision not to include representatives of people with a disability on the Consultative Committee.

The Office of Disability was initially established to report to Government on how its policies were affecting the lives of people with a disability, and to maximise the opportunity for their voice to "be heard" by Government.

It is disheartening to learn that the Office itself is not involved in the review. Neither does it see it as sufficient a priority, given its other responsibilities, to advocate for its involvement.

The review is to evaluate the effectiveness and appropriateness of strategies and arrangements employed by the DDA legal services to meet the needs of people with disabilities (and their associates, such as family and carers) experiencing discrimination. A consultancy to conduct the review was advertised on 2 May 1998, but no public decision has yet been given on who is the successful tenderer. The project will involve research, client surveys and assessment visits, and consultations with a wide range of stakeholders, including clients and potential clients, carers, parents and advocates such as ADACAS. It is to be hoped that this review is genuinely undertaken to improve services for people with a disability, rather than possibly being part of a hidden cost-cutting agenda. The results will speak for themselves in the next year.

The Commonwealth Government is undertaking a review, also, of the Disability Advocacy Program. ADACAS receives over 40% of its funding from this program. The Review was initiated in early 1997, and has been conducted in a most unsatisfactory manner. Advocacy groups were not consulted about the terms of reference for the review and representatives from groups other than advocacy were appointed advisors and reference group members.

Whilst the report has not been released, informal discussions with Departmental representatives reveal that submissions from key stakeholders have been passed over in the report. The report's recommendations are purported to include a reduction in the numbers of systemic advocacy agencies, and a possible reduction in funding to existing individual advocacy agencies, in order to fund other agencies in rural and remote regions of Australia.

In its submission to the Review, ADACAS pointed out that the total funding provided to advocacy agencies nationally represents the paltry amount of \$19 per Disability Support Pensioner per year. It is difficult to see, given this, how Government can justify cuts to advocacy.

Turning now to internal matters, Mr Dellar announced at the last AGM that ADACAS would be reviewing its constitution in 1997-98. I am pleased to announce that that review has commenced. The purpose of the review is to evaluate the governance/committee structure's accountability to the needs of the agency's client group, and to improve opportunities for community support for ADACAS.

The outcome of the review should be known before December 1998, and opportunities for community discussion and consideration of the review's findings, such as meetings with existing consumer groups, will be provided.

Helen Watchirs

MANAGER'S REPORT

This is the eighth annual report of ADACAS, and my second report as Manager. The format of the report has changed slightly from previous years. In addition to my comments, each of the advocacy workers has prepared a short report on the issues facing specific client groups. Their reports note significant achievements, and systemic issues as yet unresolved.

In addition, following the decision that ADACAS would auspice Advocacy ACTION, (formerly Parent Advocacy,) there is also a report from their Coordinator, Lee Emerson.

Overall results

We have again had a very busy year. The statistics reveal that we have increased the numbers of issues dealt with this year from 514 in 1996-97 to 784 in 1997-98. This is an increase of 52.5% over 1996-97. This has been achieved without an increase in base funding. ADACAS has provided advocacy support to 370 people during the year.

Of note is the fact that the percentage of successful outcomes achieved has reduced, from 92% in 1996-97 to 89% in 1997-98. It is believed that, in part, this reflects the increasing complexity of the issues dealt with by ADACAS. However, there may be other reasons, including a decreased flexibility of government and non-government agencies in responding to the special circumstances of disadvantaged people where appropriate responses to their needs fall outside guidelines or usual practice.

Client satisfaction rating has increased from 95% in 1996-97 to 96.5% in 1997-98.

In addition to direct advocacy support, ADACAS also responded to 589 telephone enquiries during the year.

Full details can be found in the statistical summary, at Appendix A. A note of caution should be exercised when reading the statistical results for 1997-98. At the beginning of this financial year, ADACAS implemented a new data recording system. Whilst definitions of data items recorded were consistent as far as possible with the previous system, some inconsistencies may have arisen.

The agency has been involved with a number of systemic issues, approached from the perspective of groups of clients who have sought our assistance. These include Canberra's Own Options of Living, (COOOL), and the de-institutionalisation of Hennessy and Watson Hostels.

COOOL

ADACAS has provided direct advocacy support to 7 of the current COOOL participants and indirect support to the members of the Fisher Action Group.

The issues raised have been largely connected to support and concerns over the role undertaken by the ACT Government. The systemic issues involve lack of suitable options for younger people with high support needs, especially of a medical nature. The COOOL project was initially proposed and developed as such an option. However, the ACT Government has clearly altered its position, and has now indicated that people with high medical support needs are best accommodated in nursing homes. This revised position has left some prospective COOOL residents without a current community living option.

Aside from a paucity of funds for accommodation support and community living, other systemic issues include the lack of flexible, responsive support options, especially ones which enable people to have maximum control over their support arrangements.

The COOOL project was reviewed earlier this year by Michael Kendrick, an internationally respected consultant in the Disability field. He was very critical of ADACAS, and the community in general, as well as of the Department of Health and Community Care.

Mr Kendrick made several recommendations, and the ACT Government undertook to adopt most of them. However, with the passing of time, the only recommendation to be implemented has been the decision not to renew funding to the independent advocate for the COOOL participants. The advocate had been working with the COOOL participants and their families to maximise the degree of independence and control that might be exercised by the residents in respect of their accommodation support. This advocacy had been the focus of numerous complaints made by the Department, as it had highlighted the inconsistency and other administrative shortcomings later confirmed by Michael Kendrick in his review.

Mr Kendrick also recommended that residents consider other housing options, and this recommendation was supported by the Government. However, attempts by ADACAS to secure guarantees of portability of funding for residents to allow them to move out of a COOOL house into more normal living arrangements have been unsuccessful to date.

We should not lose sight of the fact that all residents are adamant that their current arrangements in the COOOL houses are much improved compared to living in a nursing home. From our experience to date of negotiations with the Department, it would seem that moving into the community through a COOOL house, was and still is the only funded option provided by the ACT Government for younger people with a disability living in aged care facilities.

The time spent on COOOL has been significant this year, and it increased significantly after the government discontinued funding to the independent advocate. The data for the individual advocacy issues are included in the general advocacy statistics. However, records indicate an additional 13 meetings held by the ACT Disability Advocacy Network with Ministers and public servants, with COOOL participants and with service providers over the six month period to June 1998. The data does not record the numbers and duration of telephone calls.

ADACAS will continue to provide advocacy support to those residents who are seeking alternate living arrangements.

Deinstitutionalisation of Hennessy House and Watson Hostel

The ACT Department of Health and Community Care, Mental Health Services, has embarked on a program of reform to Watson Hostel and Hennessy House. ADACAS became aware of the reforms when we were contacted by staff seeking our participation in residents meetings. From these we became aware of some major shortcomings with the process of reform. The most critical of these included:

- no complaints mechanism, or a process of review of decisions;
- no participation by residents in decisions which profoundly affect their lives;
- incomplete, changing and conflicting information on the process;
- lack of recognition of the need for advocacy support for the residents during the process.

ADACAS wrote initially to the officer in charge of the reforms, seeking additional funding to support residents through the change process. When we received no reply, and we became aware of more negative consequences occurring for residents, ADACAS wrote to Mr Richard Clarke, Executive Director Mental Health Services, again without success. ADACAS then lodged a formal complaint with the Community Services and Health Complaints Commissioner. After several months, the CS&HCC received a response to our complaint from Mental Health Services which ADACAS is considering. The complaint is still in progress.

In the meantime, stage 2 of the reforms, including the closure of Watson Hostel, is proceeding. Mental Health Services has provided a small amount of additional resources to ADACAS, which enabled us to contract someone to provide advocacy support to the residents of Watson Hostel during their community placement interview. This interview is critical to a successful community placement, as a questionnaire is completed by the resident which enables them to think about what supports they need, where they might like to live, with whom they might live, etc.

The additional support provided by ADACAS enabled the residents to be more informed about what was happening to them, and to participate more fully in the process. Where individual residents had further concerns over the decisions made by Mental Health Services, then ADACAS' regular staff provided advocacy support to enable the resident's concerns to be heard and appropriately responded to.

ADACAS supports the reforms of institutions for people with mental illness, psychiatric, or intellectual disability. ADACAS believes that people should be provided with the opportunity to live in the community, and that institutions are inappropriate support options for people, whatever their disability, age, or level or kind of support needs.

However, it is important that appropriate processes are followed. There have been numerous examples of deinstitutionalisation projects which have not been successful. Key success factors for authentic change have been proven to be:

- Being clear on the purpose for reform; client best interests or financial imperatives?
- The articulation of a clear vision;
- People with the skills to impart that vision to others, to gain their commitment to it;
- People with knowledge about change management, and skills to implement it;
- Involving residents and their families in decisions that affect their lives;
- Full consultation:-
 - with residents and their families;
 - with staff;
 - with the local community.
- Adequate time for attitudinal change to occur;
- Resources are available, often for the operation of parallel systems for some significant period of time, in order to provide safety-nets for former residents.

When, through ADACAS intervention, Mental Health Services were forced to slow the process down and allow residents time to consider the options, their full participation in their community placement was forthcoming. Until this intervention, residents were resistant and unsure of what would happen to them. This was not an environment in which to maximise the chance of successful community placement of someone with a psychiatric disability.

This, and other examples, including the time-table for reform, the pressing need to close Watson Hostel in order to release staff for community support, and the fact that a mere 10 minutes had been allocated by Mental Health Services for each client to undertake their community placement interview, has lead ADACAS to the conclusion that the motive behind these reforms is more likely to be financial rather than client best interests.

Funding

ADACAS is funded by three government programs, and funds were continued, although the Commonwealth Residential Aged Care Program again did not provide indexation funds to meet general increases in costs of service delivery. The net result of this means that the proportion of ADACAS activity that can be directed towards people in nursing homes and hostels has been steadily declining in recent years.

The applications for additional funding for people with acquired brain injury, and to support clients of Disability Programs through its reforms, as noted in last year's report, were all declined as the Government did not see this as a priority. A small grant was received from Mental Health Services for institutional reform of Watson Hostel and Hennessy House, as noted above.

ADACAS implemented the Social and Community Services Award, (SACS) effective from 16 October 1997. The full impact will not be felt until the 1999-2000 financial year.

ADACAS has sought supplementation from all three funding bodies, with only the ACT Government indicating it has funds available. The financial impact of this

award cannot be met from within ADACAS existing resources. If additional funding is not provided ADACAS' operations will be significantly affected from July 1999. Options will be reviewed closer to the time, however it is possible ADACAS will be forced to curtail its operations by 20%, or the equivalent of one day a week.

Evaluation and review

ADACAS undertook an audit under the National Disability Services Standards as part of our funding obligations to the Commonwealth Disability Services Program. There was one change required under administrative procedures, which has now been attended to.

As part of the audit an independent survey was undertaken of clients with a disability. Fifty-five questionnaires were mailed to previous and current clients, with 18 responses being received by the consultant. The comments were, overall, very favourable.

There were, however, some negative ones which were in relation to not contacting people promptly or not keeping people as well informed as we used to. Both of these factors are likely to be related to increasing workload, and will be monitored over the coming year.

The consultant, who is engaged by the Commonwealth's Disability Services Program to provide consumer support for standards monitoring to services in the ACT and NSW, noted:

“ In conclusion, the positive responses to this questionnaire indicate to me that ADACAS provides a vital service to its clients. No other client group, through responses to a questionnaire has presented such a strong case in favour of the service they receive.”

Conclusion

The provision of advocacy to some of the most vulnerable people in our society is vital. It needs to be recognised and understood, and appropriately resourced by the community. There are numerous indicators which show that this is not happening. The COOOL project and the reforms at Watson Hostel and Hennessy House are but two examples which indicate that advocacy, and its role in the lives of vulnerable people, is little understood by many in positions of influence over advocacy and/or the lives of such people.

For its part, ADACAS will continue to advocate for the rights of people with a disability and those people who are ageing, to the best of its ability and to the maximum of its resources. Through this activity, ADACAS seeks to inform and educate others on the importance of advocacy, and to foster inclusive communities which are responsive to the needs of all people.

STAFF REPORTS

Advocacy for people who are ageing

ADACAS employs two staff in this section, both of them working with older people in nursing homes and hostels or in the community.

Judy Phillips has been at ADACAS for over five years. Her background is in psychology and graduate studies in special education. Originally, Judy worked in the disability area for three years and then moved across to the aged area when the job became available. She tells us that she wanted a fresh challenge; and she certainly has been presented with that!

Judy has the responsibility of coordinating ADACAS' work with older people in nursing homes and hostels, and provides the following comments in that context.

“This year has been very busy in the aged area. I have had to close my books on three occasions and go on priority of access, which meant that I was only able to take on urgent issues.

There was a flurry of activity during the period just prior to the introduction of the Age Care Act last year with potential residents and their families being very concerned about the proposed accommodation bond for nursing homes. With the amended outcome of an accommodation charge, distress levels seemed to diminish. ADACAS had input into the Senate Standing Committee about the issues which had been raised with us in respect of the reforms.

We continue to be concerned about the fear of retribution expressed by residents in some facilities in respect to making complaints. We are aware from discussions with our counterparts in other states that this is a national concern. We are hoping that the accreditation process will effect a change in culture and residents will be encouraged to voice their opinions as part of the facility getting meaningful feedback.

We have been involved in a number of abuse cases:

- physical abuse, (eg on an elderly parent by their family)
- domestic violence (yes it still happens to elderly people!)
- financial abuse (eg abusing Power of Attorney and emptying a bank account]
- neglect (eg an elderly person not receiving enough or the correct food)
- harassment of elderly people by staff

Elder abuse and neglect is a concern that I share with other professionals. ADACAS is hoping to hold an event later this year that will raise awareness of this issue afresh. Also I am on a steering committee organised by Council on the Ageing which is looking at this issue.”

Joan Suckling has worked for ADACAS for over two years. Joan was initially employed to undertake a project researching and promoting the need for advocacy for people with acquired brain injury.

Joan now works part-time as advocate for older people, and coordinates the agency's work in respect of older people living in the community. She has provided the following comments.

“This has been a hectic year during which issues relating to equipment, health, finances and accommodation have arisen on a regular basis. However, during this time we have also seen a rise in the number of cases involving abuse and the need for support to go through the legal system.

While most issues have been resolved satisfactorily, one in particular stands out as requiring further attention. This was the case of a woman who had moved into an Aged Persons unit owned by the ACT Housing Trust. Her unit was a mid-terrace unit, with a backyard. After moving in, she found that she did not have an automatic right of access from her backyard, as there was no gate in the fence, and that this could only happen through the generosity of her neighbours.

Unfortunately this was not forthcoming, and this not only raised both safety and security issues for her, but also meant that any maintenance or gardening work required in the backyard could only occur via access through her home, for example, transporting soil, fertilisers, grass and tree clippings, and equipment through the lounge room.

After much negotiation with the Housing Trust and the Minister for Urban Services, this client was eventually relocated to a more suitable property. However, the issue of poor design of some properties owned by the Trust continues to be unresolved.”

Advocacy for people with a disability

ADACAS employs two full-time staff to provide advocacy for people with a disability.

Michael Woodhead has held the position of Advocacy Worker for People with a Psychiatric Disability with ADACAS for three and a half years. He has a background in education, community development and social justice. Michael has provided the following report.

“In 1997-98 I have supported 94 clients, 84 with a psychiatric disability, 3 who are carers for a person with a psychiatric disability and 7 with an intellectual or physical disability or with an acquired brain injury. A number of clients had a dual diagnosis.

The clients have had a total of 260 issues, including 13 for clients who are residents of Watson or Hennessy Hostels. Issues were largely in the following areas; Health (48 issues), Legal (40 issues – not including Restraining or Domestic Violence Orders), Accommodation (39 issues), Abuse/Violence (34 issues – including Restraining and Domestic Violence Orders), Rights/Standards/Discrimination (22 issues), Access to Services/Eligibility – 17 issues, Financial (14 issues) and Community Options (12 issues).

Major systemic issues include: -

- the lack of full participation of residents and advocates in the process of deinstitutionalisation of Watson Hostel;
- lack of credibility given to people with a disability when requesting police assistance;
- lack of appropriate public housing for people with a psychiatric disability; increased obstacles faced by people with a psychiatric disability when applying for priority transfers in public housing;
- delays and obstructions in the processing of workers compensation claims which, in turn, leads to stress-related illnesses;
- increased bullying and harassment of workers by managers and fellow workers which, in turn, also leads to stress-related illnesses;
- clients of Mental Health Services, who have previously been victims of sexual abuse, are unable to receive appropriate counselling and support in respect of their assault through MHS, which may be a significant factor in their state of mental health.

Unfortunately, many of these issues were identified by ADACAS in previous years and referred to appropriate authorities for action. It is not a satisfactory situation that so many of our generic agencies are ignorant of, and in some cases, blatantly abusive of, people's human rights. ADACAS will be considering more effective strategies for resolving these systemic issues."

Sandra Russet-Silk has worked as the Disability Advocate at ADACAS for the past 2 years. From 1987 Sandra worked in a voluntary capacity with people who have been victims of sexual assault, and since 1991 she has held positions working in direct care with people with intellectual disability and employment for people with psychiatric disability. Sandra has provided the following information.

"It has been an incredibly busy year for me. Some of the main issues that I have dealt with in 1997-98 are accommodation issues, domestic violence and abuse issues, work related issues and issues in relation to rights and standards.

I am pleased to report that I had several major successes during the 1997-98 year, the first involving a person with a physical disability. I was able to support this person out of a domestic violence situation of 23 years. I assisted her to access the legal system and put in place Restraining Orders to keep her and her children safe. The process of going through the Family Court helped her to obtain her home and gain her lawful right to assets.

The second situation has been to arrange for services to support a person with psychiatric disability to be supported in the community rather than receive a custodial sentence in the gaol system.

One issue that is of great concern to me is the seemingly increasing situations involving young men with autism. There have been a number of issues involving young men in their early or mid teens. The onset of puberty seems to bring with it an increase in behaviour that is difficult to manage, and families often find themselves unable to cope with their sons.

It is hoped that the need for appropriate care both in the home and in respite can be brought to the Government's attention and that services will improve as a result."

Work Places' Project

ADACAS receives funding from Work Places to employ staff to assist their clients to understand and use Work Places' policies and procedures. The staff also educate the Work Places' clients in the Commonwealth's Disability Services Standards, and assist them to participate in the annual evaluation of the service by the Commonwealth Government. **Joanne Duffy** is employed by ADACAS as the Education and Training Officer, and has worked in this position for 18 months. Joanne's report follows.

"I am employed by ADACAS to provide education and support to clients of Work Places, an employment service for people with disabilities. The major parts of my role in the last year have included,

- Supporting the Work Places Client Committee;
- Educating clients about the Disability Service Standards, their rights and responsibilities at work;
- Working with clients to put information into accessible formats;
- Supporting clients through their individual employment plans.

A significant achievement this year has been the establishment of the Work Places Client Committee. It followed several months of planning, including helping Work Places' clients to understand committee processes and the different roles of committee members. We have also been working at improving the communication and representational skills of committee members so that their participation in, and effectiveness of, the committee, can be maximised."

Ann Macduff is employed as an advocate for Work Places' clients on a casual basis. Ann is studying Law, works part-time for another advocacy agency, and has just become a mother for the first time! In between all of her responsibilities, Ann has found the time to provide the following report.

"My role is to provide support to those clients to speak up if they are unhappy about something at work. I also provide support to clients for issues arising outside work, especially if they are causing the client to work less effectively. Over the last year, Jo (the previous advocate) and I have noted that:

- Work related issues requiring advocacy have generally arisen from either uncertainties for clients, or staff, about working rights and responsibilities, or from the relationship between staff and clients;
- Issues arising outside work requiring advocacy have generally related to lifestyle issues. These include recreation, accommodation or relationships matters.

One of the successful outcomes in recent months has been an agreement to increase the information provided to the clients on their pay-slip."

ADVOCACY ACTion

On the 1st March 1998, ADACAS became the auspicing body for Commonwealth and State government grants to Advocacy ACTion (formerly Parent Advocacy). The mission of Advocacy ACTion is to provide information, education and representation to effectively advocate for positive outcomes and changes in systems for people who have a disability.

Advocacy ACTion commenced as a small community based organisation, known as Parent Advocacy, in April 1994 with funding from the Commonwealth and ACT governments to employ one full time worker and cover basic administrative costs. It came about following a study of need and the development of a funding submission to provide support to change systems which did not provide for the needs of people with a disability. Early plans were for an independent incorporated body, but the size of the organisation has worked against this. A working alternative which provides accountability for public monies as well as integrity and independence for the advocacy undertaken, was met by an auspicing arrangement which supports a management committee responsible for maintaining the philosophy and aims of Advocacy ACTion. The very active management committee consults, directs and advises on policies, priorities and strategies for the systemic advocacy undertaken. Under current arrangements, the chairperson of the management committee is an executive member of the ADACAS committee.

The key activities of Advocacy ACTion are to provide information, education and representation to effectively advocate for positive outcomes and changes in systems for people who have a disability. In 1997-98 priorities have included access to quality education, the ACT Disability Programs reform, accommodation issues, promoting Social Role Valorisation training, and providing information, advice and support to community members. During the year we convened an ACT election forum with candidates invited to address policies as they impact on people with a disability, organised an information forum on CHOICES in education, met with government members including Ministers for Health and Community Care, Education and Green Independent Kerrie Tucker on education, accommodation and advocacy issues, contributed to "A Question of Equality" report to government recommending improvements to access for young people and children with disabilities within Outside School Hours Care. 1997-98 also saw substantial work in areas relating to the government's reform strategy for Disability Programs, the 1996 special education review and its implementation, the development of an assessment tool for resourcing students with a disability in government schools, the provision of education and support services for children who have autism and processes around the development and implementation of the COOL project. We continued to participate on consultative bodies such as the Child Health and Development Services (CHADS) client consultative group, and made submissions to the Commonwealth's Advocacy review, the ACT government's Mental Health Strategy, the elements of the ACT Disability Programs reform strategy (including all the operational policies), and ACT autism working party on education services.

Committee members and staff attended a number of valuable conferences and seminars including the Social Advocacies event in Queensland, John Armstrong's

Social Role Valorisation workshops, Michael Kendrick workshops in August 97 and 98, as well as presenting material at meetings, workshops, seminars and courses. We actively participate in the ACT Advocacy network to liaise with other advocacy services. We put out newsletters to our Education Network and organised events and information for people interested in achieving inclusive education options for children who have a disability. In conjunction with “Skills for Carers”, we established and support a network of people interested in SRV.

Lee Emerson
Coordinator

Data Summary

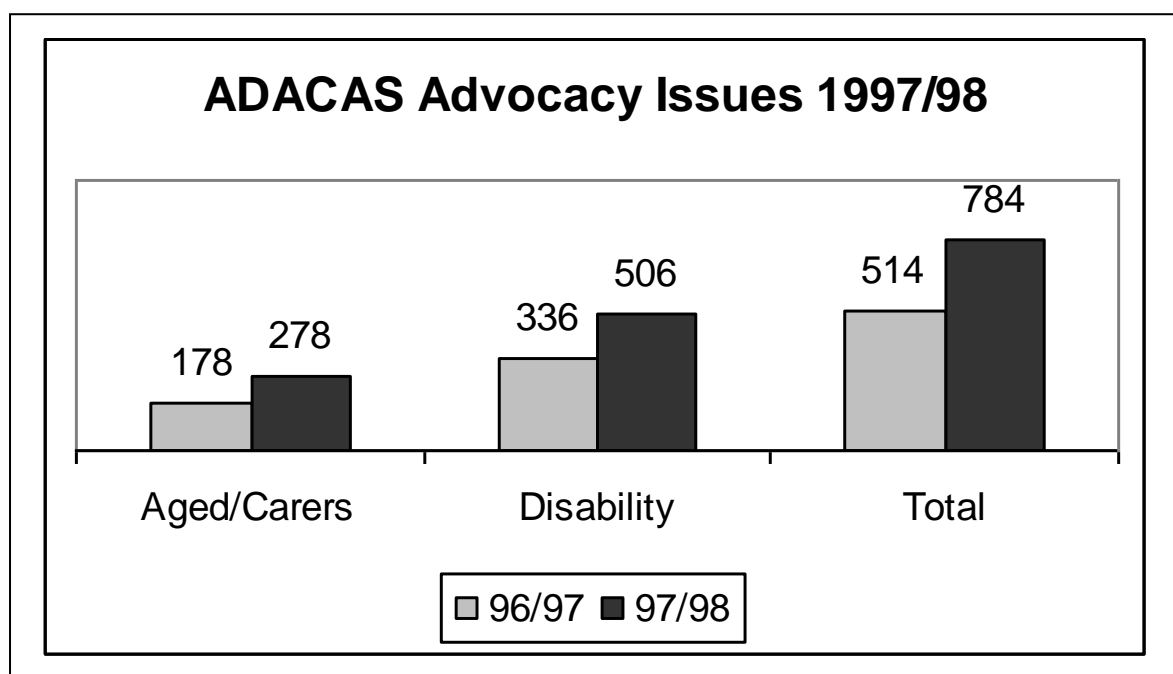
Part I – Advocacy

The data reveals significant increases in all indicators of organisational activity. Information on last year has been provided for comparison. However some caution should be exercised in comparing outputs with the previous year. There has undoubtedly been a significant increase in ADACAS workload. However, some of the results may be attributable to new methods of data collection and analysis.

In the year ending 30 June 1998, ADACAS provided 3986 hours of advocacy support to 370 people in respect of 784 issues. The time spent was distributed as follows:

- information provision: 71.5 hours (1.79%)
- Education and support: 2073.25 hours (52%)
- Representation: 1841.25 hours (46.19%)

Table 2



Of the 370 clients:

- 96 were people with a psychiatric disability;
- 110 were people with other disabilities including 16 people with acquired brain injury;
- 116 were people who are ageing;
- 24 were carers of people with a disability; and
- 24 were carers of people who are ageing.

and:

- 6 people were of Aboriginal or Torres Strait Islander descent, (1.6%);
- 54 people were from a non-English speaking background, (14.4%);
- 20 people were diagnosed with dementia, (14.28% of aged clients).

ADACAS responded to 589 enquiries in the year. This is a 126% increase on last financial year. Part of the increase can be attributed to the fact that, from 1 July 1997, ADACAS also counted enquiries handled by administration staff. These enquiries are of a less complex nature, often involving information about services etc. Where the issues are complex, or might involve advocacy, the enquirer is referred to the appropriate advocacy worker.

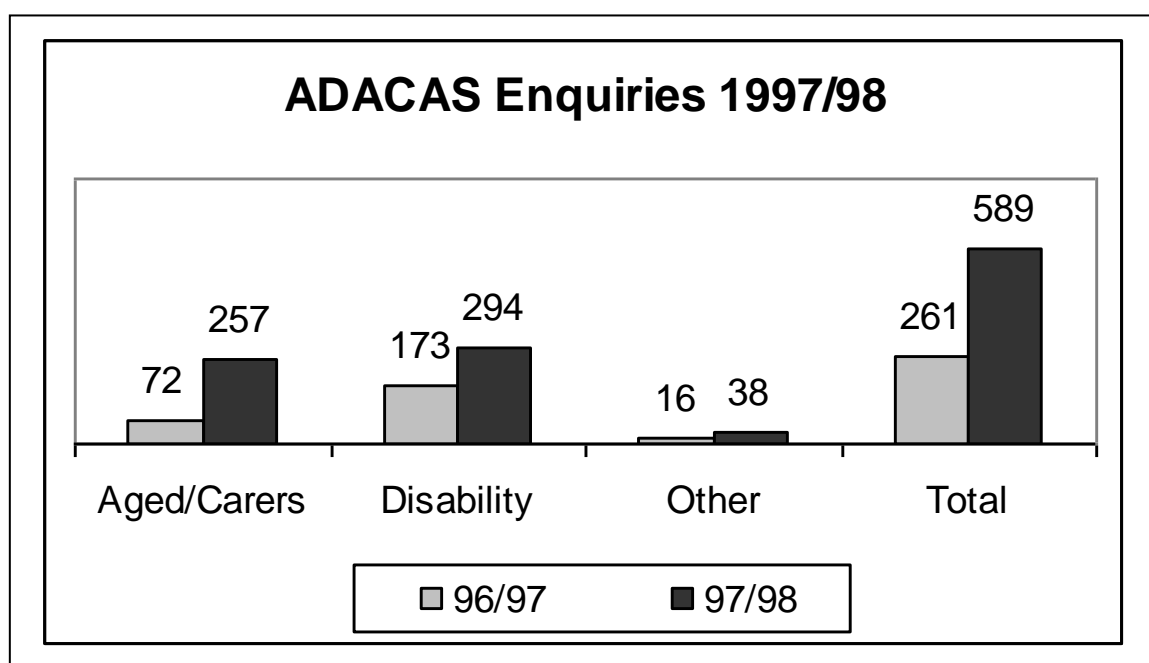
Of the 589 enquiries:

- 126 were from, or on behalf of, older people in institutions;
- 131 were from, or on behalf of, older people in the community; and
- 294 were from, or on behalf of people with a disability.

Thirty-eight were general enquiries, not related to ADACAS' client group.

The total time spent in responding to the 589 enquiries was 193.25 hours.

Table 3



Advocacy for people with a disability

Advocacy for people with a disability is funded by both the Commonwealth, (Disability Services Program) and ACT Governments, (Home and Community Care Program). The funding from the ACT Government also enables carers of people with a disability to access ADACAS.

ADACAS employs a full-time worker specifically to provide advocacy for people with a psychiatric disability. ADACAS employs one other full-time worker, and some advocacy is undertaken by the Manager.

Of the 230 people with a disability, and their carers, seeking advocacy this year, -

- 33 were people with an intellectual disability
- 96 were people with a psychiatric disability;
- 60 were people with a physical disability;
- 1 person had a sensory disability;
- 16 people had acquired a brain injury;

and

- 10 were carers of someone with an intellectual disability;
- 5 were carers of someone with psychiatric disability;
- 7 were carers of someone with a physical disability; and
- 2 were carers of someone with acquired brain injury.

ADACAS has provided 2886.5 hours of advocacy for people with a disability and their carers.

Of the 589 enquiries received this year, 294 were in respect of people with a disability

Advocacy for people who are ageing

ADACAS employs one full-time and one part-time (15 hours per week) worker to provide advocacy for older people and their carers. Some advocacy is also provided by the Manager. Funds are provided by the Commonwealth Residential Aged Care Program in respect of people living in aged care facilities (formerly nursing homes and hostels), and by the ACT Government, Home and Community Care Program, in respect of older people and their carers living in the community.

Of the 140 people who sought ADACAS assistance:

- 26 were people living in a high care facility (nursing home);
- 44 were people living in a low care facility, (hostel);
- 46 were people living in the community;

and

- 10 were carers of someone in a higher care facility;
- 4 were carers of someone in a lower care facility; and
- 10 were carers of someone in the community.

ADACAS has provided 1099.5 hours of advocacy support to older people and their carers.

Of the 589 enquiries responded to by ADACAS, 126 were in respect of older people in aged care facilities, and 131 were in respect of an older person living in the community.

Table 4

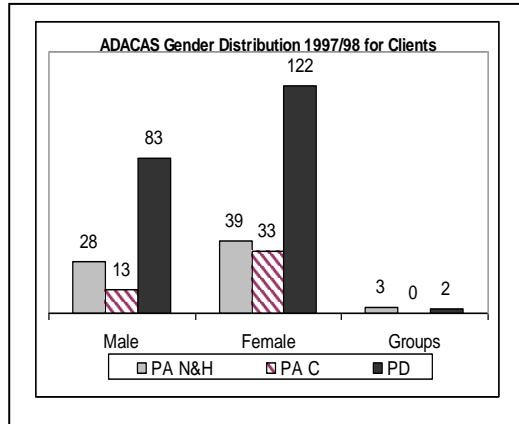
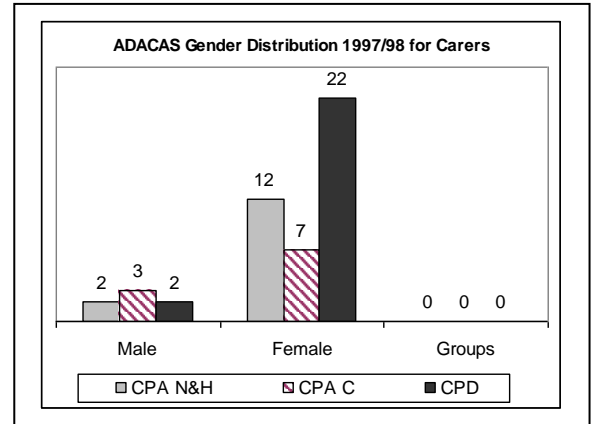


Table 5



- PA N&H: People in nursing homes or hostels
- PA C: Older people living in the community
- PD: People with a disability
- CPA N&H: Carers of people in a nursing home or hostel
- CPA C: Carers of older people living in the community
- CPD: Carers of someone with a disability

Table 6

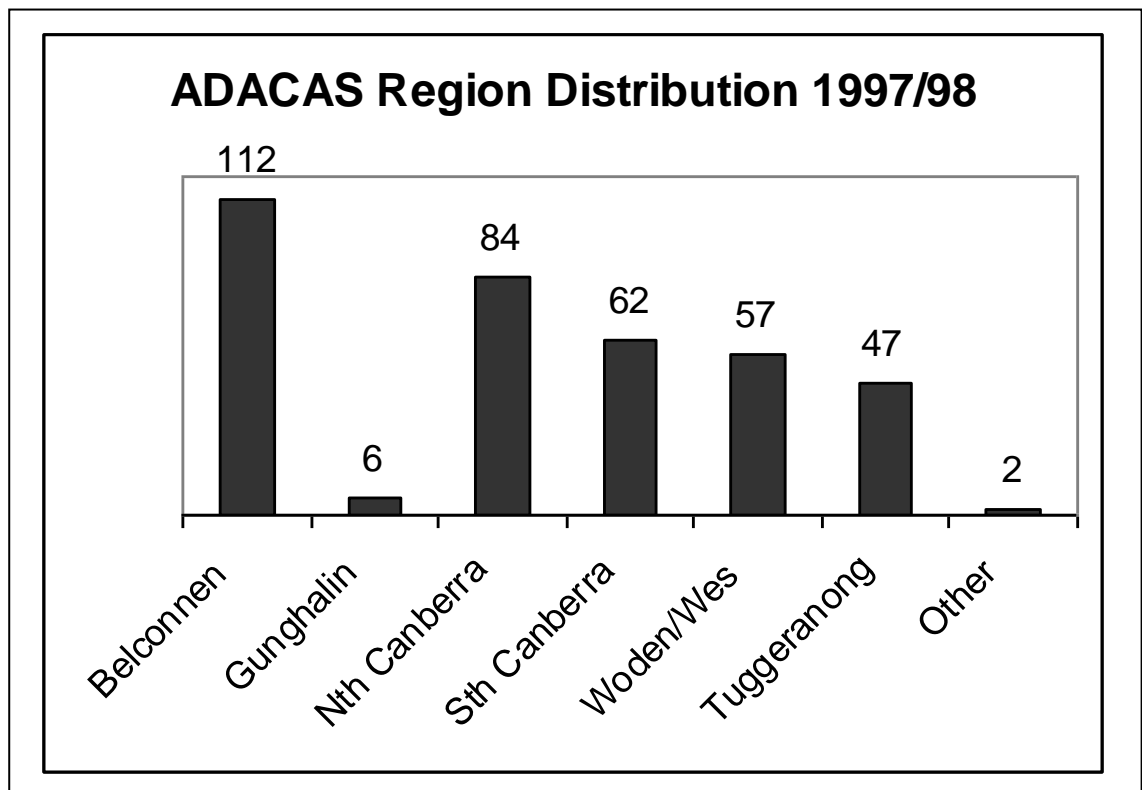
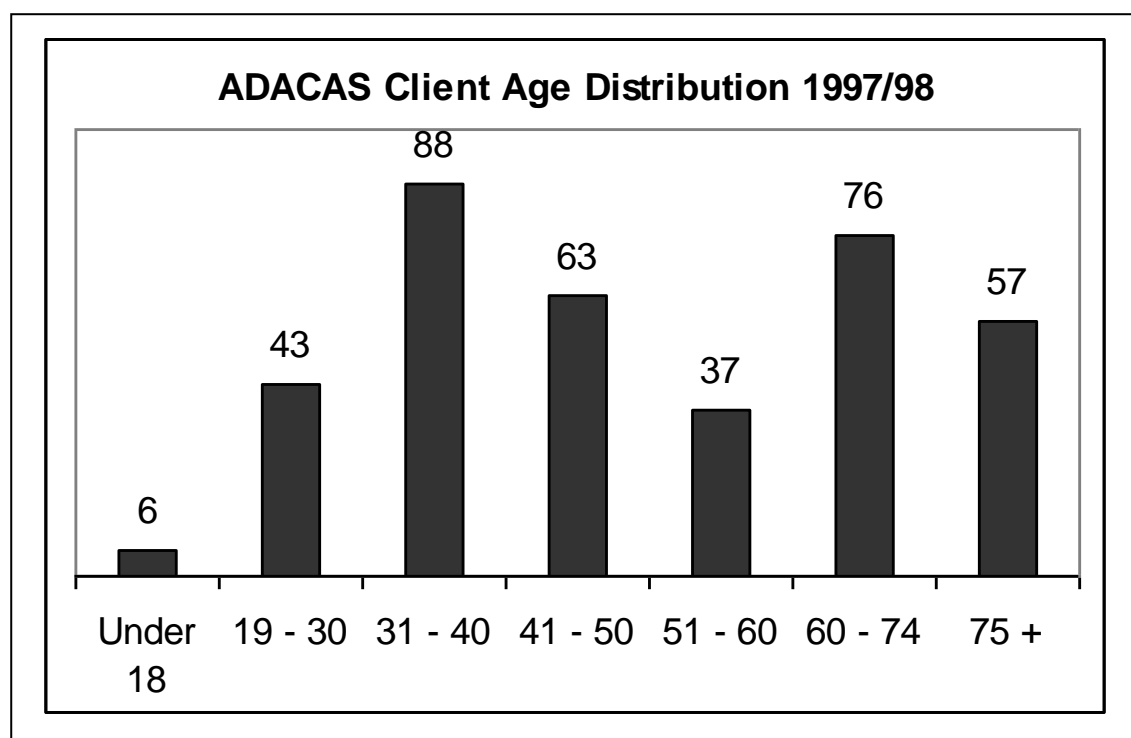


Table 7



Issues raised

Information is recorded on each issue and enquiry dealt with by ADACAS. This recording details whether the person is living in the community, or in an institution, as well as a code identifying the type of issue.

The most common issue, for clients in the community and in institutions, was access to suitable accommodation. (There were 107 community client issues, and 32 issues for clients in institutions.) This might mean that existing accommodation was inappropriate, or the person was seeking alternate accommodation as a matter of choice. For people in institutions, this also included the concept of “homelike environment”.

As mentioned in the Manager’s Report, ADACAS has found that there are very few options that provide support to people, and yet allow those that are able, to have maximum control over their support arrangements. Very few funded accommodation support options are portable, that is the person being able to change service providers without having to move houses. Whilst the concept of portability is known in Disability Services, the notion that nursing home funding should be client focused and portable is not well understood.

Finally, a number of these issues involved ACT Housing. These matters ranged from clients requiring ADACAS assistance to go through the application process, through to support with appeals and complaints. Other ACT Housing issues have concerned transfers, maintenance and rental arrears.

The next most common issue, also for people in the community and for people in institutions is health care, (83 community client issues and 31 issues for people in institutions). ADACAS has had a number of people seek assistance with gaining access to medications that are no longer in the Pharmaceutical Benefits Scheme, PBS. The Commonwealth Government continues to be very resistant to including some medications unless and until the drug companies have conducted trials to demonstrate the drug's cost-effectiveness when compared to others approved for the PBS.

Other health issues, especially for people with mental illness or psychiatric disability, are access to emergency assistance at Canberra and Calvary Hospitals, access to Psychiatrists that bulk-bill, and medication issues.

At this point, the most common issues for people in the community, as against those for people in institutions, diverge.

For people in the community, the next most common issues were legal matters. (These exclude restraining orders and Domestic Violence Orders, as these are coded under abuse/violence, and Guardianship matters which are also coded separately.) These numbered 70, and included issues such as support with Family Law Court matters, matters before the Magistrates and Supreme Courts, as well as Small Claims Tribunals. There have also been an increasing number of people seeking support through negligence claims.

It should be pointed out that ADACAS does not have any legal expertise, and clients are referred to appropriate agencies for legal assistance if they do not already have this. The support provided by ADACAS is usually one of moral support through the process which can be long and demanding for anyone, but more so if someone has a disability. Advocates also have a role in assisting people to understand the information being presented to them, and ensuring as far as possible that they make informed decisions eg in respect of a plea.

For people in the community, the next most common issue was rights and standards. This covers quality of services received, and includes most issues with service providers. Flexibility of service offered was again an issue here.

Abuse/Violence was the next most common issue, (54 issues). ADACAS sense is that the incidence of abuse and violence against younger people with a disability, and older people in the community is increasing. ADACAS will be looking closely at this question in coming months and hope to produce a separate report later in the year.

Finance issues, (43 issues), followed by DSS benefits matters (30 issues) were the next most common issues for people in the community.

For people in institutions, the most common issue after accommodation and health as noted above, was social independence, (21 issues). This covers matters such as

visitors, managing own finances, freedom of movement, cultural issues and community access. One of the major issues reported last year with no resolution to date, is the lack of affordable transport for people in aged care facilities. Residents of aged care facilities are not eligible to use HACC transport. When people have paid their fees, there is little left in the pension to meet other expenses including the cost of taxis. ADACAS is aware of a number of circumstances where residents have not been able to go to doctor's or specialist's appointments because of difficulties with transport.

The next most common issue for people in institutions is finance matters, (19 issues). (This excludes DSS pension issues, as they are recorded separately.) This may involve assisting someone to establish a power of attorney, or access to the Public Trustee. Alternatively it might involve paying debts, or sorting out family finances following admission to an aged care facility.

Freedom of choice and variety of experience were the next most common issues, (both recording 13), followed by legal issues, recording 12 issues. There were 10 issues concerning the Aged Care Reforms.

Results

Of the 546 issues dealt with and closed by ADACAS, 486, or 89%, achieved the preferred outcome. Interestingly, success rate for carers of older people, in institutions or in the community was 100%. Lower rates were achieved for:-

- older people in high care facilities, (nursing homes): 75%
- carers of people with a disability: 84%
- older people in low care facilities, (hostels): 87%
- people with disabilities: 89.5%
- older people in the community: 93%

Satisfaction rate was increased this year to 96.5% overall. The lowest satisfaction rate was recorded from residents in high care facilities, 84%, and the highest from carers of older people, in the community or institutions; 100%. Others were:-

- carers of people with a disability: 92%
- older people in the community: 96%
- people with a disability: 98%
- people in low care facilities: 98%

Part II – 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.

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. As part of its contractual arrangements with the Commonwealth Residential Aged Care Program, ADACAS visits every high care facility in the ACT every month and every low care facility every second month. This provides us with the opportunity to meet with residents and to provide information, for example the Charter of Rights For Residents of Aged Care Facilities, and individual 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 1997-98, ADACAS has provided 102 education sessions in high care facilities; and 92 sessions in low care facilities.

In addition, ADACAS also provides support to Residents' Committees in nursing homes and hostels. ADACAS has, in the past, organised a forum for members of Residents' Committees to meet to discuss issues of common concern and to discuss strategies to improve their effectiveness. As no funds were provided for this in 1997-98, a forum was not held in this financial year. However, ADACAS is planning to hold a forum in August 1998.

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 222 compared to 271 in 1996-97. The numbers of people attending has increased from 4561 people in 1996-97 to 5631 in 1997-98. Of the 5631 people attending:

- 3919 were residents of aged care facilities, (2958 in 1996-97);
- 949 were staff of aged care facilities, (653 in 1996-97);
- 69 were people with a disability;
- 230 older people in the community, (130 in 1996-97);
- 350 people who were carers, (226 in 1996-97);
- 19 staff of community based service providers;
- 6 were people connected with community organisations generally, eg board members; and
- 89 were other people, for example public servants etc.

The total time spent on community education was 524.25 hours, including 61 hours preparation and 321 hours in delivery. The balance, 142.25 hours, was spent on travel.

When data on sessions in aged care facilities are excluded from the overall data, the balance of the community education sessions, (28 sessions) were provided to other community groups for people with disability, older people in the community and their carers. The numbers of such sessions has reduced this year, due to resource constraints, and the priority of responding to direct requests for provision of advocacy.

Part III – Staff Training and development

Staff have attended a variety of training and development courses this year. A priority has been given to increasing our familiarity with and understanding of, the principles of Social Role Valorisation and related theories. For this reason, staff attended the workshops on advocacy and human service systems, presented by Professor Wolf Wolfensberger. A staff member renewed her SRV and PASSING, and others attended a series of workshops by Michael Kendrick on advanced SRV concepts, quality assurance, threats to people with a disability, and authentic change for people with a disability.

Staff and the Committee met with Michael Kendrick over two days to discuss his review of ADACAS (undertaken in 1996), and how to progress and consolidate the networks of advocacy and advocacy-like organisations in the ACT.

Staff have also attended a number of conferences during the year. These have included

- Carers Conference;
- Spirituality in Ageing
- Effective Complaints Handling; CS&HCC
- Effective Complaints Handling: Commonwealth Aged Care Program

Staff have attended a number of forums during the year. Attendance may have had a training purpose, or it might have been as part of an information exchange and/or support to consumer based groups. Examples include:

- ACT Social Policy Review Committee
- The Future of Mental Health Services Forum
- Residential Tenancies Act workshop
- Review of Crisis and Assessment Teams workshop
- ACTCOSS Quality of Life Project
- Review of the Mental Health Act workshop
- Disability Programs Parent/Guardian Forum
- Alzheimer's Association, launch, information booth etc
- Forum on healthy ageing
- COTA Elder Abuse and Neglect steering committee

- COTA ACT Budget consultation
- Dementia Network
- DDA; education standards workshop
- DDLS advisory group
- Aged and Community Care Access and Equity working party
- Dept Health and Community Care Catchment Forums
- Commonwealth Aged and Community Care Consultation strategy
- Planning forum for Mental Health Week
- Implications of Workplace Relations Act
- Implications of SACS award
- ACT Shelter, various activities

ADACAS administration staff have attended training sessions to enable them to maximise use of the new computer systems. These have included Word 97 and Access 97.

Part IV - Networks

ADACAS is a member of three advocacy networks. These are:

- National Advocacy Network, NAN; a network of advocacy organisations funded under the Residential Aged Care Program;
- ACT Disability Advocacy Network: a network of agencies in the ACT providing advocacy for people with a disability; and
- Australian Advocacy Network, AAN; a national network of agencies and individuals interested in the development of strong and effective advocacy for people with a disability.

In 1997-98, ADACAS participated in:

- 2 teleconferences of the AAN;
- 3 teleconferences and two conferences of the NAN; and
- 11 meetings of the ACT network.