

# **ANNUAL REPORT**

**2000 - 2001**

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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

### Community Representatives

Chairperson:	Juliette Ford
Secretary:	Judy Phillips
Treasurer:	Phillip Gleeson
Public Officer:	Marguerite Castello

### Other members

Pat Daniels  
Sara Rizzi (from May 2001)  
Susan Robertson  
Prue Borrman (until September 2000)  
Barbara Chevalier (from October 2000)

## ADACAS' STAFF

### **Management and Administration**

Manager	Colynne Gates
Office Administration	Linda Janssen (part-time) Beatrix Bros (part-time)

### **Advocacy for older people**

Coordinator/Advocate	Michael Woodhead (from August 2000)
Advocate	Judy Phillips (to August 2000)
Advocate (part time)	Joan Suckling (part-time)
Advocate (part time)	Judy Power (from August 2000)

### **Advocacy for people with disability**

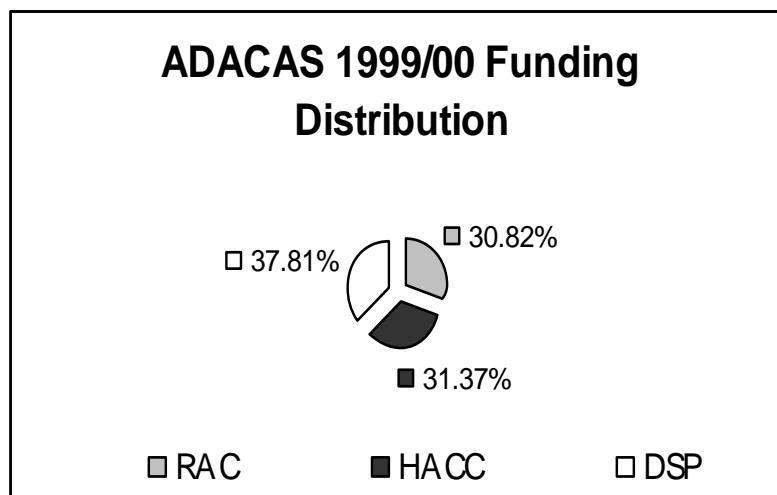
Coordinator/Advocate	Sandra Russet-Silk (from August 2000)
Advocate	Sandra Russet-Silk (to August 2000)
Advocate	Michael Woodhead (to August 2000)
Advocate (part-time)	Jaymmie Midegs (from August 2000)
Advocate (part time)	Melissa Johns (from September 2000)

## ADACAS FUNDING

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

ACT Government:	Health and Community Care Program (31.37% ??)
Commonwealth Government:	Department of Health and Aged Care (30.82% ??)
	Department of Family and Community Services (37.81% ??)

Table 1 Allocation of funds by program



# **CHAIRPERSON'S REPORT**

# **MANAGER'S REPORT**

## **Introduction**

This year has been an exciting and unusual one. It commenced with the intake of new staff and a re-structure of the organisation, and concluded with the, as yet, unfinished business of the Inquiry into Disability Services. The impact of these events has caused ADACAS to closely examine who we are, what we do, and how we do it. This process reaching an interim conclusion with the Planning Day held on 18<sup>th</sup> August 2001. The results of that day will be circulated for discussion and comment this year, and will be reported on in the next Annual Report.

This Annual Report covers the year ending 30 June 2001. However, as occurred last year, significant events have occurred in the early part of the new financial year which warrant inclusion in this Annual Report. I refer of course to the release of part of the Interim Report of the Gallop Inquiry into Disability Services. The Inquiry as a whole has been of such significant importance to people with disability and their families, that ADACAS will be publishing a separate report on the Inquiry when Justice Gallop's final report has been released. In the mean time, some information on the Inquiry, and the role taken by ADACAS, is included later on in this report.

## **Staffing**

In August 2000, Judy Phillips, who had worked for ADACAS for over seven years, left to take up a position with the Department of Veterans' Affairs. As a result, ADACAS was provided with the opportunity to review its staffing structure, with a view to maximising the availability of advocacy resources, whilst maintaining expertise.

ADACAS converted two advocacy positions, (occupied by Ms Russet-Silk and Mr Woodhead) into Coordinator positions, one for each of the advocacy programs for people with disability and people who are ageing.

The remaining full-time advocacy position, vacated by Ms Phillips, was converted to two part-time positions at the lower Social and Community Services Grade 5 level.

The role of the Coordinator positions includes the provision of advocacy, as well as the supervision of the advocates in their team, and the identification of, and development of responses to, systemic advocacy matters impacting on people with disability and people who are ageing.

As a result, ADACAS now has two clearly defined advocacy programs, (one for people who are ageing, and one for people with disability) lead by full time Coordinators, each with two part-time advocates.

The re-structure has enabled ADACAS to have an improved focus on the people to, and for whom we provide advocacy. It has also assisted the organisation to manage work loads better, especially when staff have taken leave.

### **Operations**

There has been a change to ADACAS operations regarding the way we accept new clients this year. In the past, the decision to accept a new client was made by the advocate concerned, having regard to ADACAS policies on eligibility, access and priority of access.

From 1 July 2000, ADACAS implemented an intake process, where-by all new referrals are discussed by all advocates and a joint decision made on whether to accept the referral. The discussion also includes the possible advocacy approaches or, if ADACAS cannot accept the referral, options for other ways of addressing the issues faced by the person seeking advocacy.

The benefits to this approach were soon obvious, and include:

- a consistent approach to access;
- the decision not to accept a referral does not rest solely with one staff member;
- staff training outcomes, especially for new staff, as they become involved in discussion of the advocacy process etc;
- the client receives the benefit of the experience from all ADACAS staff in the early stages of the advocacy.

The primary disadvantage associated with the implementation of the intake process was that people had to wait until the meeting to know whether they had been accepted. In the past they were usually told immediately. However, in recent times, ADACAS has usually been operating under the priority of access policy, which significantly reduces the numbers of people with whom we can work. The intake process has provided a more in depth examination of the alternatives for those people to whom we are obliged to refuse access.

A second disadvantage is that the situation of a person is discussed amongst the whole advocacy team, rather than the advocate and their supervisor and/or Manager. ADACAS has always sought to minimise the discussion, even within ADACAS, of the circumstances in which people find themselves. We see this as an important aspect of maintaining a person's privacy and confidentiality.

However, in reality, ADACAS is a small organisation and staff are required to share office space. In addition, the issues we work on are increasingly complex and challenging, and it was becoming usual practice for many issues to come to a special team meeting where the advocate was experiencing obstacles that were proving difficult to overcome.

In response to our concerns about this matter, we use only a person's first name, and all staff are regularly reminded of the need to respect and maintain a person's privacy and confidentiality.

## **Accommodation**

Our current accommodation is no longer suitable for ADACAS, as mentioned above, because of a lack of privacy. We had been looking for other accommodation at a price we can afford, but this has been made more urgent because our landlord has advised us that they are likely to be requiring our offices in the near future. Finding suitable accommodation is proving very difficult, with few office sites at the right price being accessible for people with physical disability. Never-the-less, we will have to relocate within the year. ADACAS has advised our three funding bodies of our situation, and we are still negotiating for an increase in recurrent grant to cover the likely cost increases.

## **Data summary**

This year is the first full year of the impact of the Social and Community Services award, (SACS). The effect of this is an overall reduction in staffing, but ADACAS has successfully minimised the impact on advocacy staff and contained the decreases to administration and management. In addition, ADACAS has for the first time separately recorded systemic advocacy work, and data is also provided for this area of our work.

Full data in respect of individual and systemic advocacy can be found at Attachment A.

In 2000-2001 ADACAS provided advocacy to 197 people, including 120 new clients. We have assisted people with 557 issues this year and provided 3725.50 hours of advocacy support.

This is a decrease on the number of people and issues when compared to last year, (244 and 634 respectively), but an increase in the total amount of hours of advocacy, (from 3544.75 hours in 1999-2000). These results continue to demonstrate the increased complexity of the advocacy that ADACAS is engaged in, as well as the increasing vulnerability of the people to and for whom we provide advocacy.

For the second year in a row, ADACAS was unable to offer advocacy to many people who sought our assistance. We have refused advocacy to 154 people this year, the majority of whom, (96), as for last year, were people with disability.

In respect of systemic advocacy, ADACAS worked on 26 separate matters. Of these, 18 were related to the aged care sector including specific aged care facilities. The remainder were in relation to issues affecting people with disability and those who access the mental health sector. In all, ADACAS spent a further 926.75 hours on systemic advocacy matters. However, the most time consuming matter was the Inquiry into Disability Services, where 695.25 hours were spent by ADACAS staff in various activities.



In total, therefore ADACAS has, this year, provided 4652.25 hours of advocacy support to people with disability, people who are ageing, and their unpaid/family carers in respect of individual and systemic advocacy matters. This is a significant increase on the reported advocacy hours for the previous year (31.2%). The increase is due to a number of factors, including the restructure, the improved recording of systemic advocacy issues, and the Disability Inquiry. The Inquiry required staff to work out-of-hours, either to work directly on the Inquiry, eg to prepare submissions, or to do work normally done during the day, but which was not done due to Inquiry commitments during the day.

It is unlikely this level of output can be maintained in future years.

In addition to the provision of advocacy, ADACAS also responds to telephone queries, providing advice on rights matters and information on services etc. ADACAS responded to 543 enquiries this year, less than last year.

### **Finances and related matters**

Unfortunately due to time constraints, the audited figures could not be provided in time to be printed in the Annual Report. They are available as a separate attachment.

ADACAS receives recurrent funding of \$<>, including \$<> from the Commonwealth Disability Services Program, \$<> from the Commonwealth's Residential Aged Care Program, and \$<> from the ACT Government's Home and Community Care Program. Without this financial support, ADACAS could not exist in its current form. However, advocacy is not a priority for Governments, especially in the face of overwhelming demand for support services for people with disability, and those people who are ageing. As a result, difficulties continue to be experienced by ADACAS because of a limited budget, increasing operational costs, and increasing demand for advocacy.

In its attempts to "do more with less", ADACAS has managed to retain the level of advocacy, and reduced administration and support. As a result, the agency is now experiencing difficulties due to increased demand for reporting from our funding bodies. ADACAS is now unable to contain cost increases without impacting on advocacy.

*As a result, any further cost increases that are not met by increases in our grant levels, will have to be met through cutting advocacy hours.*

However, I am pleased to advise that the Commonwealth Disability Services Program informed us in May 2001 that we had received \$4,000 recurrent increase to our grant. Unfortunately there is now some question as to whether it was only one-off funding, as our grant for 2001-2002 does not include it. Staff in the Department of Family and Community Services are investigating.

The Commonwealth Disability Services Program and the ACT Government administered Home and Community Care Program both provided funds for indexation for this financial year. These funds are used to meet small increases in running costs and are indexed to the Consumer Price Index, amongst other factors.

The Commonwealth Government has never provided indexation increases for the Residential Aged Care Advocacy Services Program, and this year was no exception. However, the Commonwealth has announced that the Residential Aged Care Advocacy Program will receive indexation in the future, and there has also been an announcement of growth funding for 2001-2002. This is welcome news!

It is likely, however, that all of the expected growth funding will be needed to maintain the existing level of advocacy for residents of aged care facilities around Australia. In addition, it is not clear how much of the growth funds, aside from indexation, ADACAS will receive.

ADACAS also received a one-off grants totaling \$<> from the Commonwealth's Residential Aged Care Advocacy Services Program during this financial year. The majority of this funding was combined with a proportion of the proceeds from the sale of a car, and was used to maintain the level of advocacy for 2000-2001 and the first half of 2001-2002. If ADACAS does not receive growth funding in December, ADACAS will cut its advocacy program for residents of aged care facilities by 1/3<sup>rd</sup> from January 2002.

ADACAS applied for additional funding from the Commonwealth Disability Services Program to meet the unmet demand, (60% of applicants were refused access in the previous year), and to meet expected demand arising from decisions in the Federal Court which had implications for the ACT Discrimination Tribunal. The application was refused.

### **Review of the Commonwealth's National Disability Advocacy Program.**

The review of the Commonwealth Disability Services Advocacy Program concluded in 1999-2000 with the adoption of goal and objectives for the National Disability Advocacy Program. This year has seen the implementation of some other recommendations of the Review, including the adoption, via an amendment to our funding contract, of a "Framework for the National Disability Advocacy Program", (formerly referred to as a "Code of Practice"). The framework includes a definition and principles of advocacy, as well as clearer descriptions of the forms of advocacy that can be funded by the Commonwealth, and the target group. ADACAS has also had to amend its data base to collect, analyse and report data as requested by the Program.

## **Implementation of the outcomes of the Residential Aged Care Advocacy Services Strategic Plan.**

As for the Commonwealth's Disability Services Program, the major impact for ADACAS of the Strategic Plan was the collection, analysis and reporting of data, requiring significant changes to the data base.

### **Data collection, analysis and reporting**

I have already mentioned the changes to the data base required by both the Residential Aged Care Advocacy Services Program, and the Commonwealth's Disability Services Program. However, the major impact in this area has been the implementation of the Home and Community Care (HACC) Minimum Data Set, (MDS).

The requirements from all three funding bodies to provide data on people to and for whom we provide advocacy has required a major modification to our data base. This work was estimated at \$10,000, 80% of which was due to the HACC MDS requirements. Neither HACC nor the Commonwealth's Disability Services Program have provided funds for this work to be carried out. The Commonwealth's Residential Aged Care Program provided \$2,000.

However, ADACAS has had to provide data in the new formats, from 1 January 2001, for all three funding bodies. Our IT consultant has therefore been providing us with his advice free of charge, until funds are made available by HACC and DSP. The staff and Committee of ADACAS would like to thank Mr Bill Barker for his generous assistance to ADACAS during this time.

In addition to the cost, another major impact has been on ADACAS' approach to and underlying philosophy on data collection. ADACAS has a commitment to accountability for the funds we receive, and transparency in our operations. However, ADACAS also has a responsibility to preserve our clients' privacy and confidentiality.

ADACAS has never, and would prefer not to collect personal details on the people to whom and for whom we provide advocacy. This is a position that is welcomed by the people to whom we provide advocacy, and many have refused to have their details reported to the Government.

In relation to the HACC MDS, the usefulness of the data we provide is at best marginal. As far as we are able to ascertain there are less than 10 advocacy programs funded nationally under HACC. ADACAS' experience of the refusal of many people to be included in the data set is common to all the other HACC advocacy agencies with whom we have been in contact.

*All this serves to seriously compromise the integrity of the data and raise questions about its usefulness for planning and policy purposes.*

In addition, as people refuse permission for their data to be included, we under report the amount of advocacy we have done, *which makes the HACC MDS inappropriate for accountability purposes.*

Finally, also of major concern is the lack of useful data relating to advocacy, such as the advocacy issues that people with disability and/or people who are ageing confront in their daily lives, or the level of unmet need.

### **Complaints against ADACAS**

ADACAS has a complaints policy and process, and is pleased to receive feedback on our work. Client satisfaction with our work is generally high and most complaints come from people against whom we have been advocating. This is sometimes because they do not understand what we do. But unfortunately, on some occasions, complaints are lodged in an attempt to prevent us from doing our job. This year has been no different.

We have received two complaints from clients. Neither has, to date, been put in writing, and attempts to clarify the details of the complaints have been unsuccessful. Another organisation is assisting one client to lodge their complaint in writing, and the other client has been provided with other options for lodging their complaint, eg with the Community and Health Services Complaints Commissioner.

In recent months, and into the 2001-2002 financial year, ADACAS has received complaints from people about whom ADACAS gave evidence at the Disability Inquiry. These complaints have been made in evidence at the Inquiry, or by phone and/or letter to the Chairperson of the Committee. ADACAS has corresponded with some community based organisations and discussions are continuing in respect of two of these matters.

ADACAS will await the findings of Justice Gallop, and respond to any criticisms he might have of ADACAS, or advocacy generally.

### **Systemic advocacy issues**

ADACAS is primarily an agency providing advocacy for individuals. However, where it is considered appropriate, ADACAS also undertakes systemic advocacy work. When this occurs, the advocacy is usually as a result of individual advocacy work, and seeks to resolve deeper underlying issues which have the capacity to affect a large number of people.

Whilst not strictly systemic advocacy, ADACAS is well placed to provide feedback to Government directly, or indirectly through ACTCOSS and other fora, in respect of policy initiatives etc, as they might affect people with disability or those people who are ageing.

As I write this section of my report, I am tempted to “cut and paste” from last year’s Annual Report: so little has changed. Some of the systemic issues ADACAS has been involved in this year are detailed below.

### **Systemic issues affecting people with disability**

The Gallop Inquiry into Services for people with disability: Our involvement in the Inquiry came about because of a number of concerns we had that were long-standing. Many of these matters were reported in last year’s Annual Report, and arose out of the individual advocacy we had undertaken for people with disability. These included:

- Staffing and other matters in relation to the Disability Program;
- The role of the Office of the Community Advocate, especially in relation to the Disability Program;
- some operations of government and community based mental health services;
- the lack of options for people with disability and their families, especially as it relates to support to live in the community; and
- the general lack of accountability and meaningful quality and standards monitoring of all services for people with disability undertaken by the funding bodies

ADACAS has been involved in the Inquiry in a number of different ways. These include:

- contribution to the 3 ACTCOSS submissions;
- a separate submission from ADACAS;
- support to 25 people with disability and their families who wanted to write a submission, give evidence, meet informally with the Board of Inquiry, or just support other people’s active involvement;
- attendance at the Inquiry hearings; and
- the provision of evidence to the Inquiry;

Copies of all ACTCOSS submissions and the ADACAS submission are available from ADACAS. In addition, ADACAS maintains a complete copy of the transcript at the office for people to read.

In our opinion, the Terms of Reference of the Inquiry could have enabled it to investigate services for people with a psychiatric disability. To this end ADACAS provided a submission as part of the ACTCOSS papers, on issues of concern in respect of services for people with psychiatric disability. However, this material was withdrawn, and ADACAS will continue to pursue these issues in other fora.

It was also unfortunate that so much attention was given to the Disability Program, and that community services, and the role of the Government funders, at ACT and Commonwealth levels, was not more closely scrutinised by Justice Gallop. In the end, time and resources ran out.

Indeed, the lack of resources was a significant issue for ACTCOSS and ADACAS. Funds were eventually made available by the Government for ACTCOSS' legal representation before the Inquiry. However, the decision was late, and the amount was insufficient to enable legal representation to the same degree as that available to the Government.

At this time, there is minimal information available as to what Justice Gallop's findings will be. The Government has released part of his interim report, which has identified as a concern many of the issues raised by ADACAS in its evidence. It seems unlikely however, that the final report will be released before the October election. This is unfortunate, as it leaves the community only partially informed as to the performance of the Government, and what Justice Gallop's recommendations will be on these very important matters.

One concern ADACAS has is the possibility that his recommendations, or the Government's interpretation of his recommendations, will further bureaucratise service provision, alienating people with disability and their families.

Already, the Disability Program has introduced more forms for staff to complete, and new policies and procedures will be introduced in response to those problems they acknowledge are occurring. Whilst it is a good thing that some changes are happening, eg extra time at shift change etc, it is unfortunate that the Disability Program has still not heard the key theme arising time and again in evidence before the Inquiry:

*that group home models, as they are currently operated by the Disability Program, are out of date and in urgent need of reform.*

The improvements implemented by Disability Program since the Inquiry was announced are welcome, but may only serve to provide people with a "better deck chair".

The Inquiry heard exciting evidence from Michael Kendrick and from Tony Shaddock, about the Local Area Coordinator scheme from Western Australia, and initiatives in Queensland. The common thread in all these activities was the flexible manner in which the service systems responded to people with disability and their families and their needs. The key to many was informality and a minimum level of bureaucracy that ensured quality and accountability. However, of critical importance to these programs was the shared vision of, and a commitment to, a good life for people with disability: *and a practice that moves the rhetoric out of the pages of policy manuals into reality for people with disability.*

I felt that the response from Government was disappointing, in that it continually denied that there was a problem. In addition, I feel that their response lacked leadership and vision, in that it emphasised their focus on cost, maintaining the status quo, and an unwillingness to consider other, proven models of support.

Once Justice Gallop's final report has been released, ADACAS will be working towards developing a shared vision between people with disability, their families, advocates and allies, and people in services, both Government and Community based. For the staff of ADACAS, our vision is reflected in our 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.”

Management of people with personality disorder: This was also raised last year, and because there was no response from Government, ADACAS raised it in the Disability Inquiry, especially in relation to the position taken by the Management Assessment Panel. Earlier this year ADACAS wrote to the Government requesting a meeting to discuss other options for the management of people with personality disorder.

We have not received a reply to our letter. However, ADACAS has recently learned that Mental Health Services has established a working group to look at other options. Unfortunately, ADACAS has not been formally notified of the group, its terms of reference or the time frame. Never-the-less, we see this as a positive development, and look forward learning about the outcomes of its deliberations.

Continued emphasis on institutional service models for people with psychiatric disability: This was also mentioned in last year's Annual Report, where we specifically noted our concerns about the possible development of a “clubhouse” model. These concerns are now a reality, with funds being provided for a “consumer space”, which, it appears, will resemble the “clubhouse” models operating elsewhere in Australia and overseas.

ADACAS is concerned about the segregation and congregation of people with psychiatric disability that this model promotes. In our opinion and experience, the long term consequences for disadvantaged and marginalised people accessing such services are increased isolation, devaluation and marginalisation of people. This in turn exposes them to increased risk of abuse and negligent treatment.

The role, resourcing and support of consumer representatives, advocates and consultants.

ADACAS continues to be concerned at the inadequate level of resourcing of the Consumer Consultants, the increasing expectation that they will provide advocacy, and the lack of support in the face of the extraordinary pressure associated with their work. In its report last year, ADACAS raised concerns about the pressure being placed on staff employed in these roles and possible negative health outcomes.

Finally, we remain concerned at the attempts by Government to undermine the independence of advocacy, especially prevalent in the area of psychiatric disability and mental health services. This is accomplished through Governments funding advocacy in connection with direct service provision, including their own.

## **Systemic issues affecting older people**

Quality of care: ADACAS remains concerned, as mentioned last year, about the quality of care in aged care institutions. The reasons may be due to insufficient funding from the Commonwealth, profit taking by providers, insufficient numbers of adequately trained staff, or the inadequacies of the Accreditation system. Whatever the reasons, whilst there has been some improvement in recent years, the quality is below what most people would accept for themselves.

The following was included in last year's report: it is still valid today:

“ADACAS is in a fortunate position in that we visit every nursing home and hostel in the ACT 4 or 5 times a year, and have been doing so for 9 or 10 years. It is obvious some facilities do provide a good standard of care, and others work hard at improving what they are doing. However, a few proprietors are either unaware of the true standard of care provided in their facilities, or are more interested in profits.

Negative reports from the Aged Care Standards and Accreditation Agency often come as a surprise, and in many cases cause significant concern and distress to residents and relatives. However, if goodwill is present, the facility can learn from this experience, and improve the quality of care it is providing to residents.

ADACAS is not convinced that the Agency processes used at the moment are delivering informed feedback on the true quality of care in the facilities. At the core of the new standards and accreditation process is the need for a change of attitude of the staff, management and owner, (or board of management) towards residents and their relatives.

The standards reviewed by the Agency are necessarily objective in nature. ADACAS' experience has been that many facilities may be able to meet the accreditation requirements, yet fundamentally, the culture of the facility has not changed from earlier years.

In such cases, the quality of life for residents will leave much to be desired, and yet without external advocacy support, (or alternatively staff willing to take action,) these living conditions will rarely be exposed.

This is especially the case where there is retribution, and intimidation of residents and relatives. Evidence of this is unlikely to be found during Agency visits.”

### Retribution, intimidation and payback:

Continuing with comments from last year's Annual Report:

“The fear of retribution is common in institutions, unfortunately in some facilities, with good reason. ADACAS believes that the institutional



environments of the aged care facilities will automatically work against open feedback to the Aged Care Standards and Accreditation Agency, (the Agency) staff during audit and accreditation visits. This will occur even in those facilities which work hard at providing good quality care, and fostering an open, positive attitude to complaints. It is imperative therefore that the Agency recognise this, and a method be found of enabling informed feedback to be provided to the Agency staff during visits. Residents and relatives should feel able and safe to disclose critical information to the Agency. In our opinion, this is not the case at present.

ADACAS will continue to raise the need for the Agency to secure informed feedback from residents and relatives. We believe this is best facilitated through the provision of information and education to residents and relatives by an agency which is independent to that being accredited.”

ADACAS has raised these points at every meeting with the Agency and with Departmental Officers this year. We have received positive feedback and support from Departmental officers on this matter, but attempts to have the Agency acknowledge issues with their process have been less successful.

Our level of concern is such that, this year, we opened a new systemic issue on retribution, intimidation and payback in residential aged care institutions. We are recording incidents of retribution, intimidation and pay-back, as reported to us by residents, relatives and staff. Where possible, (that is where the resident and/or family agrees), we will take these matters forward through the available avenues of complaint resolution. Where information received by us indicates a possible criminal offence has occurred, then we have no choice but to refer it to the relevant authorities.

However, most cases of this nature are not overt, but rather a collection of small, (inconsequential to some people), isolated incidents that are either difficult to verify or easily discounted or excused.

ADACAS will continue to pressure the Agency and the Department on this matter, until such time as measures are in place to eliminate this most insidious practice.

Financial Abuse: As reported last year, financial abuse is the most common form of elder abuse reported to ADACAS, although all too often physical abuse is also present. There seems to be a lack of, or rather an ineffectiveness of the controls over powers of attorney. Whilst there are controls in place, it seems that they are rarely used.

As a result ADACAS continues to receive several referrals from people who allege misuse of the power of attorney. For many, however, the prospect of losing contact with a daughter, son, or grandchildren, is too high a price to pay for taking action to stop the abuse.

In order to reach a balanced view on the need for reform, ADACAS sought a legal opinion from Blake Dawson Waldron. The firm has accepted the referral for their Pro-bono Scheme, and provided a response recommending a number of legislative reforms. ADACAS would like to acknowledge the assistance provided by Blake Dawson Waldron on this matter.

ADACAS provided information to the Legislative Assembly's Standing Committee on Health and Community Care in respect of its inquiry into elder abuse. The Report, released in mid-August 2001 highlights several examples provided by ADACAS, and recommends actions to address some of these concerns. These include measures around the registration and monitoring of powers of attorney; the provision of appropriate crisis accommodation for older women; and tighter controls on the recruitment of staff working in aged care facilities and home based services, including mandatory police checks.

### **Systemic issues affecting all of ADACAS target groups**

Younger people with disability in aged care facilities: ADACAS is concerned about the inappropriateness of placing younger people with disability in aged care facilities. Our concerns centre on the institutionalisation of people with disabilities, which is contrary to the Commonwealth and State/Territory Disability Services Acts and National Disability Services Standards. That they are institutionalised in facilities for older people is even more disturbing.

We have raised this with both the Commonwealth and ACT Governments, as well as with consumer groups, the Aged Care Standards and Accreditation Agency, and other advocacy groups. I am pleased to report that there is now a nation-wide group formed around this matter, which will continue to seek alternatives for people with disability. In the meantime, ADACAS has prioritised this matter, and will be working to assist at least two younger people currently in an aged care facility and wishing to leave, to find more suitable alternatives.

Accessible taxis: We thought that we had resolved this matter last year. However, it seems that the fleet of new accessible taxis will not allow the transport of some scooters. Increasingly, people with mobility difficulties are choosing scooters where possible, because they are less stigmatising than wheelchairs: they look better! This matter has now been referred to Human Rights and Equal Opportunity Commission in Sydney, and ADACAS has provided a submission for the Commission's Inquiry.

In the meantime, many people are stranded in their homes because they cannot use public transport and the taxis will not take them. ADACAS' advice to anyone thinking about buying a scooter, and to Government and Community agencies providing them to people with mobility difficulties, is to check for their suitability for transport in a taxi before you enter into any agreement!

**ADACAS STATISTICAL SUMMARY**

**ADVOCACY**

ADACAS changed its data base on 1 January 2001 to reflect the requirements of our funders. As a result, not all of the data provided in previous annual reports is provided this year because of inconsistencies in the data base between the two halves of the year.

In 2000 - 2001 ADACAS continued to restrict access to people seeking advocacy because of the high workloads of staff and insufficient resources to meet the demand. This situation continued for most of the financial year, but even so 120 people were accepted.

The total numbers of advocacy hours is significantly higher than for 1999 – 2000, but the total numbers of people and issues we worked with and on is lower than last year.

The issues raised by people continue to increase in complexity, and many of them have several issues, frequently interlinked. This results in people remaining with ADACAS for longer periods, with longer time being required to resolve the issues. This is clearly indicated in the statistics, in that, as for last year, the number of people and issues reduced this year, but the amount of advocacy provided them increased.

In the year ending 30 June 2001, ADACAS provided 3725.50 hours of individual advocacy, (compared with 3544.75 hours in the previous year), an increase of 180.75 hours over 2000 - 2001. ADACAS has also recorded systemic advocacy separately to individual advocacy hours this year. ADACAS has undertaken 926.75 hours of systemic advocacy this year, providing a total of 4652.25 hours of advocacy in 2000 - 2001. This is a 31% increase in workload over the previous year.

**Individual advocacy**

This year, ADACAS provided advocacy to 197 people with 557 issues, compared to 244 people with 634 issues last year. ADACAS records the time spent, by each advocate in respect of each issue for each person, in respect of 4 different types of activity. They are

- administration. Because of the increasing demand for data collection etc, ADACAS has started to collect data on time spent on administrative functions by advocates. These functions include form filling, data collection and recording, and requests for ad hoc information.
- Information: time is recorded in respect of time spent providing written information and verbal information to a person for whom we are advocating. This category is most used when ADACAS is providing information to someone who is choosing to advocate for themselves;

- Education and support: this is time used by the advocate for:
  - getting to know the person for whom we are advocating,
  - gathering information about the issue,
  - working with the person to identify the advocacy goal,
  - identifying strategies,
  - working with the person to assist them to understand the pros and cons of each strategy,
  - discussion on the role the advocate and person will each take in respect of the advocacy action;
  - evaluation with the person of the effectiveness of the advocacy action/strategy, and review of other options.
- representation; this is the time spent by the advocate representing the person directly, and/or supporting the person to advocate for themselves.

This year, the time recorded in respect of individual advocacy was distributed as follows:

- Administration (data recorded from 1/1/01): 104.5 hours
- Information provision: 74.75 hours
- Education and support: 2196.00 hours
- Representation: 1350.25 hours

Table 2



Of the 197 people:

- 83 were people with disability and their carers;
- 84 were older people and their carers who are clients of the Commonwealth's Residential Aged Care Program,
- 30 were older people living in the community and their carers.

ADACAS has continued to maintain representation in our client group of people from other cultures, with 29 people receiving advocacy. Unfortunately, no-one of Indigenous background sought advocacy this year. In addition, 4 people with dementia were provided with advocacy.

## **Advocacy for people with a disability**

Individual and systemic advocacy for people with a disability is funded by both the Commonwealth, (Department of Family and Community Services) and ACT Governments, (Home and Community Care Program, Department of Health, Housing and Community Care). The funding from the ACT Government also enables carers of people with a disability to access ADACAS, and people with disability in nursing homes are funded by the Commonwealth Residential Aged Care Program.

ADACAS employs one part-time worker (25 hours per week) specifically to provide advocacy for people with a psychiatric disability. A second part-time worker provides 20 hours of advocacy a week for people with disability, 10 of which is for people with psychiatric disability. The Coordinator provides advocacy primarily for people with disability. All the advocates work on systemic issues.

### Individual advocacy

Of the 83 people with a disability, and their carers, seeking individual advocacy this year:

- 35 were people with a psychiatric disability;
- 1 person had autism;
- 2 were people with acquired brain injury;
- 19 people had a diagnosis of intellectual disability; and
- 18 people had a physical disability

There were also 8 people who were family carers of someone with a disability.

ADACAS provided 2172.5 hours of advocacy for people with a disability and their carers, which included 1242.5 hours of education and support, and 819.5 hours of representation.

### Systemic advocacy

In addition, ADACAS provided 859.5 hours of advocacy in respect of 8 systemic issues, including 695.25 hours on the Inquiry into Disability Services, and 117.5 hours in respect of services for people with a psychiatric disability.

## **Advocacy for people who are ageing**

The Advocacy Program for People who are Ageing is staffed with a full-time Coordinator and 2 part-time staff. The Coordinator and one part-time (3 days a week) staff person work primarily providing advocacy for people living in the residential aged care facilities, and their family carers. The second part-time staff person works 15 hours per week to provide advocacy to and for older people living in the community and their family carers. All staff provide some advocacy for systemic matters.

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. The part-time position working with people living in aged care facilities was funded from one-off funds provided by the Commonwealth and some funds made available after the sale of an ADACAS car.

Individual advocacy

This year, ADACAS provided advocacy to 114 people including:

- 35 people living in a high care facility, (nursing home), and 3 carers;
- 39 people who are living in a low care facility, (hostel);
- 2 people who are receiving Community Aged Care Packages, and 1 carer; and
- 29 older people living in the community, and 1 carer of an older person living in the community; and
- 4 younger people with disability living in an aged care facility.

ADACAS has provided 776.25 hours of advocacy support to older people and younger people with disability living in an aged care facility, and 27.5 hours for carers of someone living in an aged care facility. This is a total of 803.75 hours this year, a reduction of 177 hours on the previous year. ADACAS has provided 749 hours of advocacy for older people living in the community and their carers, .

Systemic advocacy

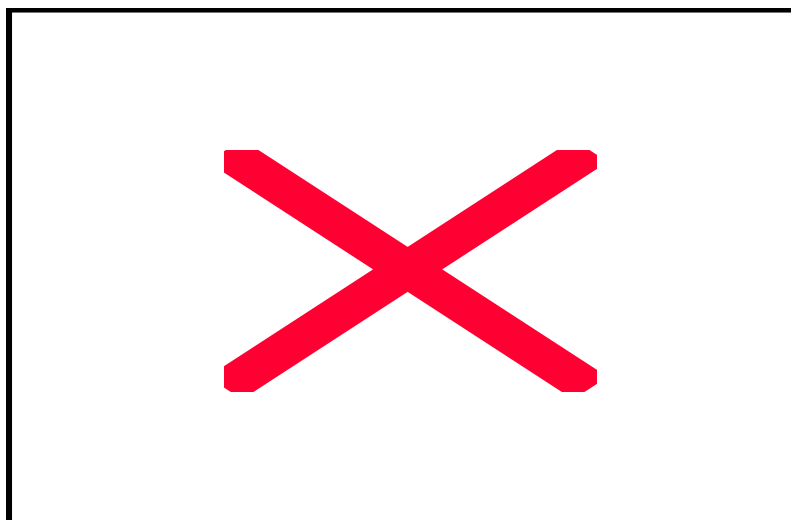
Finally, ADACAS has provided 351.25 hours of advocacy in respect of 18 systemic issues in the aged care sector.

Table 4

Table 5

Table 6

Table 7



### **Issues raised**

Information is recorded on each advocacy issue and enquiry dealt with by ADACAS. This recording details whether the person has disability or is ageing, or a carer, and whether they are living in the community, or in an institution. From 1 January 2001 ADACAS has 17 major issues categories against which advocacy and enquiries can be reported and analysed. These are different from the previous year, and therefore no direct comparison can be made, but there are similarities.

#### Issues for people with a disability

The data shows that the most common issue (38 cases reported) for people with disability was “consumer rights”. This category has 15 separate sub-categories and includes:

- abuse by service provider staff, 6 cases;
- lack of choice and decision making, 8 cases; and
- inadequate internal complaints mechanisms, 16 cases.

The next most commonly reported issue, with 26 cases, was “legal”. The sub-categories include:

- criminal, 8 cases;
- civil, also 8 cases;
- “other”, with 5 cases. This sub-category will be reviewed for next year’s annual report; and
- children’s court, with 4 cases.

The next most commonly reported issue, (23 cases) were “level of care” and “health service interaction”. The sub-categories for “level of care” include:

- access to specialised services, 11 cases; and
- assessment/care planning, emotional needs not met, falls, and lack of rehabilitation each having 2 cases reported this year.

Inadequate hospital discharge procedures was the most widely reported sub-category under “health service interaction” with 18 cases which were reported by mostly by people with a psychiatric disability.

Financial issues were the next most commonly occurring issues with 17 cases, including:

- \* income support problems, eg with Centrelink processes, 7 cases;
- debt, 3 cases; and
- 7 cases recorded as “other”. This will be researched and the codes amended to better identify the financial issues.

The next most common issue reported related to “significant others” with 16 cases including the following sub-categories:

- abuse accounted for 11 of the 16 cases this year;
- family disputes, 2 issues;
- “other”, 3 cases this year.

“Accommodation” records issues with a person’s housing, and there were 11 cases this year. This issue includes interaction with ACT Housing, and has the following sub-categories:

- disputes, 4;
- 2 cases each of homelessness and “other”; with
- personal safety, OH&S and repairs and maintenance, 1 case each this year.

“Environment” was the next most commonly reported issue, with 10 cases overall, with security being the most common with 6 cases.

There are many issues that rate highly this year that were also rating highly last year. These include level of care, (recorded as “health” last year), abuse in all its forms, legal matters, financial matters, and consumer rights, recorded as “quality of service” last year.

#### Issues for people who are ageing

The most frequently raised issue for people in aged care institutions was “consumer rights” (47 cases). The major sub-categories reported this year include:

- abuse by the service provider, 11 cases;



- lack of choice and decision making, 11 cases;
- 7 cases this year in respect of inadequate internal complaints mechanisms and service does not support or promote independence; and
- privacy/ dignity compromised, 6 cases.

The next most common issue in aged care facilities was “level of care” with 27 cases this year. The most commonly reported sub-categories were:

- medication issues, 7 cases; and
- access to specialised services, 6 cases;

“Alternate decision making” was the next most commonly reported issue, with 15 cases this year. They included:

- issues with powers of attorney, 7 cases;
- guardianship, 5 cases; and Financial Management, 3 cases.

“Financial issues” recorded 8 cases this year, including:

- income support/pension cases, 5 cases; and
- debt, 3 cases this year.

“Administration and fair trading”, with 7 cases this year (including 3 cases in respect of fees and charges) was the next most common issue, followed by “legal” with 5 cases this year, (1 criminal and 4 civil matters).

Again, whilst direct comparison with last year is difficult there are some similarities. The highest rating category this year, (consumer rights) correlates with homelike environment, social independence, and abuse which all rated highly last year. Legal, financial matters and guardianship are also rating highly this year as last, and again health matters (called “level of care” this year) rate highly in both years.

For older people living in the community, the most common issues raised with 16 cases each were “financial matters” and “accommodation”. This is identical to 1999-2000.

For finance, the major sub-categories were:

- debt, 8 cases; and
- income support/pension, 2 cases.

There were also 4 cases recorded as “other”. This sub-category will be reviewed for next year.

In respect of “accommodation”, the most frequently occurring sub-categories were :

- safety, eligibility/regulations and repairs and maintenance all with 3 cases this year;
- 2 cases of housing debt, and

- physical access, homelessness and disputes all registering one case this year.

The next most common issue for older people living in the community was “level of care”, 12 cases, with the following sub-categories:

- access to specialised services, 5 cases; and
- 2 cases each for assessment/care planning and lack of emotional support.

“Legal” matters came next, with 9 cases, including:

- 3 criminal matters;
- 4 Family Court matters; and
- 1 civil matter.

“Environment” recorded 7 cases this year, including 3 matters related to cleaning.

“Significant others” recorded 6 cases this year, 5 of which were abuse.

### **Results**

Of the 315 issues dealt with and closed by ADACAS, 278 achieved the desired outcome, (88.25%), which is a slight improvement on 1999-2000, (up from 87.3%).

Advocacy for people living in aged care institutions was more successful, with 92% of matters achieving the client’s desired outcome. The outcome rate for older people in the community was higher again, at 94%. However, the outcome rate for people with disability was only 83%.

Clients’ satisfaction rate with the advocacy they received from ADACAS has reduced slightly from 91.7% last year to 91.1% this year. Older people in the community had the highest rate of satisfaction with ADACAS advocacy, at 94%. Older people in aged care institutions recorded a 93% satisfaction rate, and people with disability recorded an 88% satisfaction rate.

The satisfaction rate remains high, although slightly lower than previous years, and the consistently lower rate for people with disability in respect of outcome achieved and satisfaction with our advocacy is disappointing and of concern.

Some of the dissatisfaction could be attributed to the drop in successful outcome. In addition, the independent consumer survey conducted under the Disability Services Program demonstrated high satisfaction with ADACAS work, with the major dissatisfaction being the fact that we turn people away, or are slow to respond eg returning phone calls. In the main both these matters are due to a lack of resources to meet the demand.

### **INFORMATION**

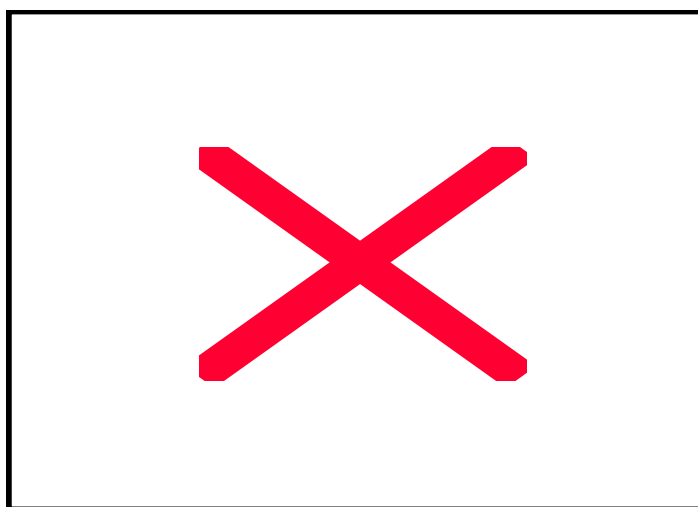
Of the 543 enquiries ADACAS responded to this year:

- 109 were from, or on behalf of, older people in institutions;
- 117 were from, or on behalf of, older people in the community; and
- 302 were from, or on behalf of people with a disability.

There were 15 general enquiries, not related to ADACAS' client group. The total time spent in responding to the 543 enquiries was 218.5 hours, almost the same as last year, even though the total number of enquiries has reduced by 114. Enquiries from residents of aged care facilities have increased this year, from 86 in 1999-2000 to 109 this year. Enquiries from people with disability was down from last year by 24%, and from older people in the community by 21%.

The most common issues raised by enquirers were health/level of care, and consumer rights. Guardianship/financial management also rated highly, as did abuse within the family.

Table 3

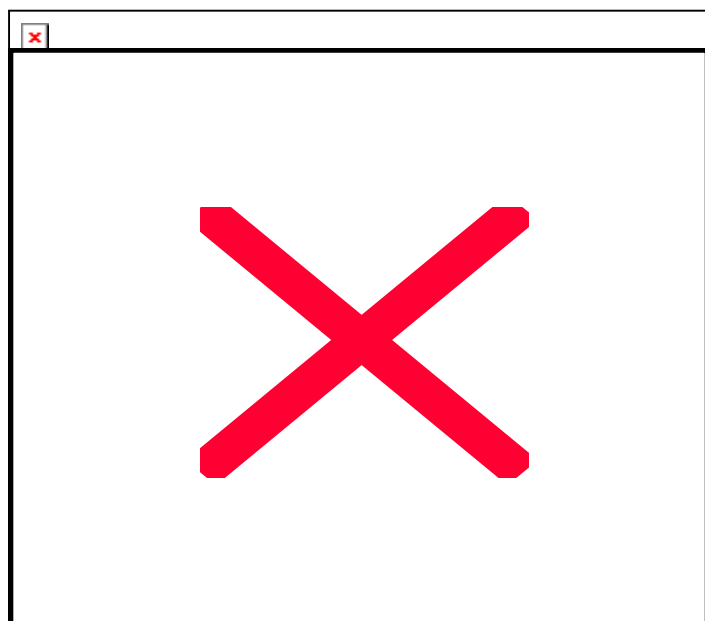


### **PEOPLE TO WHOM WE WERE UNABLE TO PROVIDE ADVOCACY, (DEFERRALS)**

Of the 543 people who made enquiries, 154 were people seeking advocacy and were deferred by ADACAS due to insufficient resources. This is an increase of 12% over last year, which is of concern given ADACAS' likely future decrease in capacity due to increasing costs and consequent reduction in advocacy staff. When one considers that ADACAS accepted 120 new people last year, both advocacy programs are severely under-resourced.

Of these 154 deferrals, 96, (or 62%) were in respect of a person with disability. This is a reduction on last year, but still means that the Advocacy Program for people with Disability needs to be virtually doubled to meet the demand. Of the remainder, 18 were in respect of people living in Commonwealth funded aged care facilities, which is a significant increase over 1999 – 2000, when only 2 people were deferred. Forty older people living in the community were deferred this year, also a staggering increase over 1999 - 2000, when only 21 people were deferred.

The following table is a comparison of the rate of deferrals for 2000 - 2001 compared with the previous 2 years by client group.



## **COMMUNITY EDUCATION AND INFORMATION**

A table showing all ADACAS education activities is at Attachment B. ADACAS has continued its program of community education and information this year. The purpose of ADACAS Education Program is to improve knowledge and understanding about the rights of people who are ageing, or who have disability, and to assist people to understand about advocacy and ADACAS.

There were 160 education activities in 2000 - 2001. These included 141 in respect of people who are ageing, down from 163 in 1999 – 2000. The reduction was due in part to not attending Residents' Committee meetings, but also because there was a complete turn-over of staff in the Residential Aged Care Advocacy Program, and some time was needed for staff training.

There were 13 in respect of people with a disability and 4 activities in respect of ADACAS in general.

All of the activities were general information sessions about ADACAS, rights and responsibilities, and advocacy. The majority, (131) of the sessions used an ADACAS' prepared education kit, and 29 required the development of a special education program. Of the 141 activities in respect of older people, 65 were regular visits to higher care facilities (nursing homes), and 76 to lower care facilities, (hostels).

A total of 2943 people attended these activities, including 2113 residents and 579 staff of aged care facilities; 46 carers of older people; and 15 staff of community based agencies. Total time spent in these activities was 404.25 hours, including preparation.

## **STAFF TRAINING AND OTHER ACTIVITIES**

The focus for staff training this year has been induction of new staff, and in-house training of Coordinators on administration, financial management and data reporting. The Coordinator of the Disability Advocacy Program attended the ASSID/NCID Conference in 2000.

There were 11 meetings with our funding bodies, including 3 meetings with staff from the ACT Department of Health, Housing and Community Care; 2 with staff of Department of Family and Community Services; and 6 with staff from the Department of Health and Aged Care.

ADACAS held 5 meetings with the Aged Care Standards and Accreditation Agency; and there were 12 meetings, teleconferences and conferences with the other members of the Aged Care Advocacy Agency Network, (NAN). There were 8 other meetings etc attended in relation to older people, including:

- Blake Dawson Waldron;
- Centrelink Aged Pension News;
- Pfizer;
- Centre for Ageing and Pastoral Care.

There were 19 meetings with local and national Disability Advocacy Networks, and 11 meetings with Mental Health Consumer groups, service providers and peak bodies.

ATTACHMENT B

**COMMUNITY EDUCATION ACTIVITIES**  
**2000 – 2001**

<b>ORGANISATION</b>	<b>NUMBER OF ACTIVITIES</b>
<b>Residential Aged Care Program:</b>	
Brindabella Gardens Hostel	5
Brindabella Gardens Nursing Home	8
Canberra Nursing Home	7
Carey Gardens	3
Croatian Village	4
Eabrai Lodge	7
Ginninderra Gardens Hostel,	8
Ginninderra Gardens Nursing Home	9
Goodwin, Ainslie	7
Goodwin, Farrer	5
Goodwin, Monash	5
Jindalee	4
Kalparrin	7
Kankinya	8
Mirinjani, Hostel	4
Mirinjani Nursing Home	6
Morling Lodge	8
Mountain View	8
Ozanam	7
Morshead Home	4
St Andrews Village	5
St Nicholas' Home for the Aged	3
Villagio Sant' Antonio	5

<b>ORGANISATION</b> Cont.	<b>NUMBER OF ACTIVITIES</b>
<b>Other activity:</b>	
Australian Association of Gerontology	1
Canberra Legacy	1
CAPS	2
Dept of Education	1
Dept of Health, Housing and Community Care	4
Hartley Life Care	2
Labor Party Forum	1
Narrabundah Health Centre Aged Day Care	1
Students, UC ,CIT	3
TRAHCS, Cert III and IV in Aged Care, Community Care, and Disability Studies	5
WORK Resources Open House Program	2
<b>TOTAL:</b>	<b>160</b>

**FINANCIAL STATEMENTS**