



**NEEDS FOR RESIDENTIAL AGED CARE
AND OTHER SERVICES BY THE
OLDER INDIGENOUS POPULATION
IN THE ACT AND REGION**

August 2000

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Needs for Residential Aged Care and Other Services by the Older Indigenous Population in the ACT and Region

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Abbreviations

ABS	Australian Bureau of Statistics
ACATs	Aged Care Assessment Teams
ACHA	Assistance with Care and Housing for the Aged
ACPAC	Aged Care Planning Advisory Committee/s
ACT	Australian Capital Territory
AHL	Aboriginal Hostels Limited
AIHW	Australian Institute of Health and Welfare
ANU	Australian National University
ATSIC	Aboriginal and Torres Strait Islander Commission
CACPs	Community Aged Care Packages
CDEP	Community Development Employment Project
EACH	Extended Aged Care at Home Packages
GP	General Practitioner
HACC	Home and Community Care
MPS	Multi Purpose Services
NACCHO	National Aboriginal Community Controlled Health Organisation
NCEPH	National Centre for Epidemiology and Population Health
NDS	National Drug Strategy
NHS	National Health Survey
NSW	New South Wales
RCS	Resident Classification Scale
SPSS	Statistical Package for Social Sciences
TAFE	Technical And Further Education

Executive Summary and Recommendations

1. The Study

Ninety-eight older Indigenous people were interviewed. Sixty-two percent were women and 38 per cent were men. Twenty-two per cent were aged 45-49, 19 per cent were aged 50-54, 27 per cent 55-59, 14 per cent 60-64, and 16 per cent were older than 65 years. The highest proportion came from the ACT (43%), but the study also included residents of Queanbeyan (17%), Tumut (18%), Yass (9%), Brungle (6%) and Goulburn (6%). Most identified as Ngun(n)awal (37%), Wiradjuri (27%) or Ngun(n)awal/Wiradjuri (6%).

Figures from the Australian Bureau of Statistics indicate that there are 134 Indigenous people over the age of 50 in the ACT, with another 110 people aged 45 to 49, although the official figures may be an underestimate. There are estimated to be just under 70 Indigenous people over the age of 50 living in Queanbeyan, Yass and Goulburn.

Personal contacts were the most successful form of recruitment to the study.

2. Need for Residential Aged Care Services

Official statistics indicate that there are currently five Indigenous people in residential aged care services in the ACT, out of a total population of 1315 in care. None of the people we interviewed expressed a current need for residential services. In addition, the Commonwealth's Residential Classification Scale was used to provide an indication of need for residential aged care. Four per cent were rated at levels 1 to 4, indicating the highest levels of need; 14 per cent were rated at levels 5 or 6; and 54 per cent at level 7. Only 26 per cent were rated at level 8, indicating that they are not likely to need residential care or Community Aged Care Packages now.

It is likely that the requirement for residential services will change in coming years. Fifty percent of respondents favoured an arrangement where an existing mainstream provider of aged care "clustered" Indigenous people together in the same facility. Thirty-two percent would prefer an Indigenous-run organisation.

Recommendation 1: That the Department of Health and Aged Care – ACT Branch work with existing mainstream services to ensure that they are able to provide “clusters” of places for older Indigenous people. There should be at least two providers to allow a choice of services. Providers need training to ensure that services and attitudes are culturally appropriate and sensitive. The services should be regularly monitored to ensure that high standards of care are maintained.

Recommendation 2: That the Department of Health and Aged Care – ACT Branch establish an Aged Care Advisory Group to monitor needs and the adequacy of existing services on an on-going basis. This Group should include a number of Indigenous elders with specific inclusion of Ngun(n)awal elders and should be linked with the Aboriginal and Torres Strait Islander Health Forum. In 2004 this Group should determine if another in depth analysis of needs is warranted. In particular, such an analysis should consider if the numbers requiring aged care and an Indigenous-run residential service are sufficient to warrant the establishment of such a service.

3. Need for Other Aged Care Services

Ninety-three percent had seen a general practitioner in the last 12 months, with 60 per cent having more than five consultations. Forty-one per cent had been a hospital in-patient and 34 per cent had attended out-patient services. Fifty-eight per cent had seen a specialist and 64 per cent an allied health professional. Over one-quarter reported that they needed help or more help now because of their health problems.

Thirteen percent received help in the house, 11 per cent received HACC services. Just over a quarter said they needed help or more help with housework now. Five per cent received yard services, mostly provided by HACC. Help with yard work was the greatest current need expressed by the people we interviewed, with 39 per cent indicating they needed help or more help now. Seven per cent received help with shopping and 19 per cent said they would like assistance or more assistance. Three per cent reported receiving help with cooking, with eleven per cent wanting help or more help. Twelve per cent reported that they received help with transport from services such as Community Transport, Land Council, Northside Community Service, HACC and Winnunga Nimmityjah Aboriginal Health Service. Twenty-

four per cent said they needed help or more help now. Ten per cent expressed some dissatisfaction with HACC services.

Very few people were aware of existing information which could help them access services, notably the *Directory of services for the ageing in the ACT* by the ACT Council on the Aging and *Care options for older persons in the ACT and Queanbeyan* by the ACT Office of the Commonwealth Department of Health and Aged Care. There would also be value in developing information resources specific to older Indigenous people. Ninety-eight per cent thought a booklet would be useful and 88 per cent thought a video would be useful.

Few were aware of Community Aged Care Packages, but when these were explained, 73 per cent thought this would be their preferred service, rather than Home and Community Care. Sixty three people signed a consent form to allow their names to be forwarded to appropriate services either now or in the future, on the understanding that they would be recontacted first.

Just over half (54%) did not have a preference for an Indigenous or non-Indigenous carer and most of the rest (43%) wanted an Indigenous carer. There was general agreement that the basic requirements were for proper training of staff and for on-going monitoring of the service provision.

Just under one-third of participants had older family or friends who they thought might move to the ACT if appropriate services were available.

Recommendation 3: That Indigenous aged care is given priority in the allocation of Community Aged Care Packages for the foreseeable future, until the level of use in the Indigenous population is comparable to that in the non-Indigenous population. That, where possible, new packages are given to different service providers, so that clients have a choice of service providers, including both mainstream and Indigenous service providers. That the Department of Health and Aged Care – ACT Branch ensures that carers (in-home workers) are adequately trained and supported and that service provision is adequately monitored.

Recommendation 4: That the Department of Health and Aged Care fund a pilot outreach and advocacy program to identify Indigenous advocacy needs and to trial methods for ensuring that older people who are potential applicants for such packages are fully informed

about the packages, including their rights, what they can expect and how they can be considered for packages.

Recommendation 5: That the Department of Health and Aged Care – ACT Branch ensure that the successful tenderer for the ten Community Aged Care Packages that have been allocated to the ACT is made aware of this study and that names of people interested in packages have been collected as part of this study.

Recommendation 6: That the Department of Health and Aged Care – ACT Branch send this report to and liaise with the ACT Department of Health and Community Care and the Department's Aged Care Advisory Committee, as well as the Department of Aged and Disability in New South Wales in order to increase the provision of Home and Community Care services and the monitoring of those services.

Recommendation 7: That the Department of Health and Aged Care – ACT Branch develop information resources specific to older Indigenous people, taking into account that many Indigenous people aged less than 50 also need access to such services.

4. Physical, Mental and Social Health Problems

Significant health problems reported by participants in this study included diabetes (38%), hypertension (30%), history of heart attacks (21%), high cholesterol (17%), arthritis (17%), back problems (17%), incontinence (26%), gastric ulcers (10%), asthma (12%), vision impairment (14%) and dental problems (11%). In general, levels were similar to those reported in the 1994 National Aboriginal and Torres Strait Islander Survey, except that the level of diabetes was considerably higher in our sample. Seventeen per cent had a diet which could be detrimental to their health. Most importantly a third of those with diabetes had an inadequate diet, because of financial problems, dental problems and poor knowledge of nutrition.

Ten per cent suffered from depression and 12 per cent had a current or previous dependence on alcohol or prescription drugs. As has been found in other studies, this group was less

likely to drink alcohol than non-Indigenous people. However, the level of tobacco smoking was high, with 48 per cent smoking an average of 10 cigarettes a day.

Seventy per cent were receiving a pension or unemployment benefits and the average weekly income was just under \$240. Thirty-eight per cent had dependents. Many are adversely affected by illegal drug use among their dependent and non-dependent children and grandchildren. A significant minority are affected by social isolation and recent bereavement.

Although we did not ask about it specifically, many of those interviewed were directly or indirectly affected by the policies that led to the Stolen Generations. There is a need for counselling to resolve issues of grief and loss and there are other impacts including distrust of mainstream services.

Ninety-one per cent used prescription and/or over-the counter medications. On average they took four drugs, with a range of one to 14. Twenty-two percent did not take medications as prescribed and this was worst amongst ACT residents where 35 per cent did not take medications as prescribed.

An important aspect of the study was the ability of the researchers to provide advice about medical conditions, to make appropriate referrals and to help with access to services. At least 26 per cent of those interviewed were helped in this way. This suggests that an outreach service could make a valuable contribution to improving the health of older Indigenous people. Such a service seems to be working successfully in New Zealand.

Recommendation 8: That the Department of Health and Aged Care – ACT Branch send this report to and liaise with the ACT Department of Health and Community Care. ACT Housing and the Department of Aged and Disability in New South Wales to encourage the establishment of outreach services for older Indigenous people. The needs identified by this study that these outreach services should ensure are met, include:

- assistance when older relatives visit for extended periods
- adequate provision of hygiene care
- home modifications and renovations
- yard services

- adequate and appropriate Meals on Wheels and other food services
- transportation to health care services
- respite care
- payment for carers who are friends or family, when other carers would be inappropriate
- monitoring of people with diabetes to ensure that they are receiving adequate care and self-care
- implementation of a range of health promotion programs, including nutrition education programs, anti-smoking programs, gender specific urinary continence programs, specific sexual health programs (including information on menopause, breast screening and prostatitis)
- provision and appropriate use of blood pressure monitors for people with hypertension
- dental services
- counselling services
- TAFE courses and funding for attending those courses
- housing for homeless people
- access to telephones.
- ensuring that client confidentiality is respected by all services with which clients come into contact.

Recommendation 9: That the Department of Health and Aged Care – ACT Branch send this report to and liaise with the relevant ATSIC and Aboriginal Hostels organisations to encourage the establishment of Aboriginal hostels a) in the ACT to accommodate homeless Indigenous people and b) in Goulburn to accommodate people visiting relatives and friends in jail.

Recommendation 10: That the Department of Health and Aged Care – ACT Branch send this report to and liaise with the relevant ATSIC, Greater Murray Health Service and Land Council agencies to encourage further investigation of the needs specified by the Brungle respondents, including paving outside their homes, sewerage problems, a community phone box, a park, a Community centre, exterior lighting, footlights outside each house and a football oval.

Recommendation 11: That the Department of Health and Aged Care – ACT Branch send this report to and liaise with the Department of Aged and Disability in New South Wales and the ACT Department of Health and Community Care to encourage the establishment of a mobile health unit to visit Indigenous people living in regional NSW.

Recommendation 12: That the Department of Health and Aged Care – ACT Branch work with relevant agencies to encourage the establishment of a Cultural Centre and other meeting places for Indigenous people in the ACT and region. These could be used as locations for the provision of a range of health promotion programs and other activities and could contribute to overcoming the social isolation expressed by some of the study participants.

1: Introduction

In mid-1999, the Australian Capital Territory (ACT) Office of the Commonwealth Department of Health and Aged Care commissioned researchers at the National Centre for Epidemiology and Population Health (NCEPH) at the Australian National University (ANU) to conduct an analysis of needs of older Indigenous people in the ACT and Region. In particular, we were asked to focus on needs for residential care and strategies to improve access to aged care programs and services. It was expected that our study would reveal a broad range of other health needs and as we report fully below, this was the case.

Due to such factors as “poor health and environmental health issues, loss of land, culture and lore”, Australian Indigenous people have, on average, a life expectancy much lower than that of the non-Indigenous population (Tripp, 1997:11). In recognition of this shorter life expectancy, the Commonwealth Department of Health and Aged Care defines an older Indigenous person as being 50 and over. We were asked to endeavour to provide a picture of aged care needs and strategies to improve access to aged care programs and services over the next five years. In order to accomplish this, we set out to interview people aged 45 and over. We succeeded in interviewing one hundred people but have excluded responses from two people who were also service providers and who wished to talk about the needs of the older Indigenous community in general rather than their personal needs.

In addition to the Ngun(n)awal people, who have a traditional heritage connection to the ACT and Region, Indigenous people from other communities also reside here. In 1996 (the most recent available information), there were thought to be 3058 Indigenous people living in the ACT (Australian Bureau of Statistics [ABS], 1998). This is probably an underestimation. According to Julie Tongs (Chief Executive Officer, Winnunga Nimmityjah Aboriginal Health Service), the true figure is currently around 5 000 (2000, January 14, pers comm). One hundred and thirty four of the Indigenous people in the 1996 Census were aged 50 or more, and a further 110 people were in the 45-49 year age bracket.

2: Presentation of the findings

We begin the report by outlining our methods. Before reporting the findings on aged care needs, we set these in context by first discussing sociodemographic findings and the physical mental and social health problems and needs of the people we interviewed.

In order that service providers can better implement our findings we have, where relevant, tabulated needs according to place of residence. In those areas where only a few people were interviewed (6-9), and the numbers are, therefore, too small to draw inferences, we only briefly comment in the text on these findings. Because we interviewed some couples, or carers of couples the needs per household may be a little smaller than indicated in the tables which give the needs for individuals. Respondents often provided multiple responses to the open ended questions. As a consequence, the totals often exceed the total number of respondents. Where this occurs, the totals are not included in the vertical columns of the tables.

The essence of this report is telling the stories of the 98 people we interviewed in a way that accurately portrays the diversity of their often complex needs. Where possible, we intertwine the quantitative findings with some relevant quotes from the people we interviewed. Throughout the document, we make comparisons between our findings and those reported in other studies or reports.

3: Methods

We begin the section on methods by outlining our collaborative research model. We then go on to give an overview of the methods used for data collection before outlining the way we analysed the data. We then focus on our access to respondents and provide some information about the interviews.

3.1: Collaborative research

The researchers used a model developed by NCEPH which involves co-mentoring of Indigenous and non-Indigenous researchers. This involves Indigenous and non-Indigenous researchers working closely together in all phases of the investigation from design and data collection through to analysis, reporting and working with agencies responsible for implementation. This helps ensure that the research is both methodologically rigorous and culturally appropriate and provides training for both researchers.

The funding body approached Gabriele Bammer and Bev Sibthorpe to undertake the research. They then approached Phyll Dance who had recently completed her PhD, had a nursing background and had experience in interviewing people who were disadvantaged.

Before agreeing to conduct the research, we determined whether it would be feasible for NCEPH researchers to work collaboratively with the ACT Indigenous community on the project. We also wanted to be confident that we could gain access to a cross section of older Indigenous People. To fulfil these aims, we consulted eleven Indigenous people from the ACT, Queanbeyan and Yass. These people welcomed the idea of the proposed research and were confident that it could be conducted with the collaboration of Indigenous people. Everyone consulted believed that the long-term issue of the health of older Indigenous people was an important problem that needed to be addressed and that a need for aged care was an appropriate focus. These consultations gave us confidence that we would be able to work alongside Indigenous people in a collaborative way to provide the needs assessment required.

We then proceeded to make enquires about Indigenous people who could form part of a Reference Group. Subsequently, a Reference Group composed of five Indigenous people, two of whom are Ngun(n)awal elders and representatives from the ACT Office of the

Commonwealth Department of Health and Aged Care and the ACT Department of Health and Community Care evolved. Four meetings were held with this Group. We also called on Reference Group members outside of formal meetings when we had issues we needed to discuss. A sitting fee was paid to the Indigenous members of the Reference Group.

The non-Indigenous members of the research team sought the advice of our Reference Group before employing an Indigenous researcher. We wanted someone who had good knowledge of the local Indigenous community, who was interested in health and who wanted to develop research skills. These enquires led us to employ Ros Brown, a Ngun(n)awal woman who is a health education student at the University of Canberra and who has previously been employed in the ACT as a carer of older Indigenous and non-Indigenous people.

During this preliminary stage, one of the members of the research team (Phyll Dance) addressed a Regional Aboriginal and Torres Strait Islander Commission (ATSIC) meeting and gained the approval of this body for the research.

3.2: Ethics

Approval for the research was obtained from the ANU's Human Research Ethics Committee.

3.3: Other preliminary work

Before embarking on the interviews, we set out to inform ourselves of the types of care available for older Australians. We achieved this by reviewing the literature and by meeting with some specialists in the aged care arena who equipped us with further information on available services for older people in the ACT and Region. We then prepared a background paper for one of our Reference Group Meetings. Some of these findings are incorporated into the body of this paper and a shortened version of the background paper is attached as Appendix 1. Our preliminary research provided us with the knowledge to properly inform respondents of the types of care available. When we come to the reports of the findings on the type of care that respondents wanted, we refer those readers who require further background information to this appendix.

Our preliminary investigations also involved visits to agencies providing services for older people. We continued with this process throughout the interviewing period. Time did not allow us to consult with the full range of service providers. A report of the meetings we did have is attached as Appendix 2.

Early on in the research, we presented our preliminary findings to the Aged Care Planning Advisory Committee (ACPAC).

3.4: Questionnaire

Questions on the age respondents left school, qualifications, income, employment, type of housing and the number of people per dwelling are similar to those used by the ABS (referred to by McConnell, 1998). With the permission of Women's Health Australia, Newcastle University, who developed the questions, we asked respondents what medications they were currently prescribed, and whether they had been on them for more or less than six months. A question about respondents' contacts with health service providers in the last 12 months was, also with permission, gleaned from a questionnaire developed by Women's Health Australia, Newcastle University.

Our questions on needs related to finances, shopping and cooking were inspired by those used in a survey conducted by Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation (1995:18 and 127), as were those about the adequacy of respondents' diets (1995:122) and whether respondents had access to hot and cold water, garbage disposal and electricity (1995:123).

We developed questions on needs and preferences for residential or community care and questions about the needs for health care and needs in the home, yard, shopping, cooking, access to money and transport. We also asked about any other needs respondents might have. We have documented responses on whether people were already receiving services, and if so which services, whether the help received was enough and whether people needed help or more help now, or in the future. Finally, we asked about knowledge of services (a copy of the questionnaire is attached as Appendix 3).

Since our funding body wanted us to assess the needs of older Indigenous people for Residential Care, with their guidance we used the Resident Classification Scale (Appendix

4) to assess this need. Although not, the combined experiences of the interviewers as a Registered Nurse (Phyll Dance) and a Carer (Ros Brown or trained as Aged Care Assessment Team (ACAT) assessors) gave us some confidence that we would be able to use this instrument to assist us in assessing the people we interviewed. Sally Koodiaroff (Nurse Educator specialising in the care of older people, ACT Community Care) also kindly spent some time with us teaching us how to use the instrument. We are aware of the limitations of the Resident Classification Scale in the community setting but still found it a useful tool for assessing what level of care the people we interviewed required. When we had a draft of the questionnaire, we cross-checked it with the Resident Classification Scale to ascertain which areas we had not covered. We then included questions 10-14 (Appendix 3).

The questionnaire was piloted with ten people. We only needed to make minor changes which included adding a few questions. This accounts for most of the category “missing” in the tables since we have also included the responses from the ten people we conducted the pilots with and did not interview them again to obtain the missing information.

3.5: Field notes

We made field notes after every interview, and, as was often the case recorded subsequent interventions, such as advocacy. We draw on some of this information as we present our findings.

3.6: Data analysis

The quantitative data were analysed with SPSS (Statistical Package for Social Sciences) (Norusis, 1998). Qualitative analysis requires the researcher to search the transcribed text and explore and interpret its meaning (Richards, 1990). After entering the qualitative data into the computer, the transcripts were searched in this way, then coded by hand before organising them into themes.

3.7: Access

In the early stages of the research we distributed 840 flyers (Appendix 5) advertising the research to a comprehensive list of agencies which provide services to Indigenous people in the ACT and Region. We also asked the people we interviewed if they would be willing to pass on flyers to older Indigenous people they were in contact with. A further 53 flyers were

given to 20 respondents who said they knew older Indigenous people who might be interested in being interviewed. We asked all respondents if they could tell us how they had heard about the survey. Forty seven people (47.9%) were accessed by the Indigenous interviewer (Ros Brown). Another 8 (8.2%) were accessed by both the non-Indigenous interviewer (Phyll Dance) and the Indigenous interviewer, primarily at a Bingo session run by an Indigenous organisation and to which both researchers had been invited. The next largest proportion of respondents (37.8%, n=37) said they heard about the survey through personal contact with other community members, family members, or an intermediary who had seen a flyer. The remaining respondents were accessed via Winnunga Nimmityjah Aboriginal Health Centre (n=4, 4.1%) who, at our request, sent flyers to clients through the post, and the Pejar Local Aboriginal Land Council in Goulburn (n=2, 2.0%).

In agreement with the funder, we accessed older Indigenous people in the Region, as well as the ACT. We began by assuming the Region would include Queanbeyan, Yass and Goulburn. In 1996, there was estimated to be 31 Indigenous people aged over 50 living in Queanbeyan, 17 in Yass and 19 in Goulburn (Commonwealth Department of Health and Aged Care, nd). We primarily took our cue from the people we interviewed about which other areas we should visit. We accomplished this by asking the people we interviewed in the ACT, Queanbeyan and Yass the following questions:

Do you have any friends or relatives aged 45 or over living outside of the ACT or Queanbeyan?

Which town/s do they live in?

If there were appropriate health or community services for Indigenous people in the ACT, do you think they might move here for services?

Of the 72 people asked these questions, 21 (29.7%) said they had older family or friends who might move to the ACT if there were appropriate services available. (We did not ask these questions of the remaining 26 respondents [36.1%] because we were close to completing our interviews.) The areas most frequently mentioned as having a kinship connection were Goulburn, Yass, Griffith, Sydney, and Tumut (Table 1). Another 34.7 per cent of people (n=25) said they did have relatives in other town/s but did not think they would move to the ACT. Twenty three respondents (31.9%) said they did not have family living in other towns. Of the remaining few, 1.4 per cent (n=1) said they were not sure if family would move and 2.8 per cent (n=2) did not know their family because they were of the Stolen Generations.

Our findings show that a little less than a third of the people we asked had friends or relatives over 45 who might move to the ACT if there were appropriate health or community services for them. This may have implications for future planning of services for Indigenous people in the ACT.

Table1: Areas where friends or relatives might move from

Place	n	%
Goulburn	6	28.6
Yass	4	19.0
Griffith	4	19.0
Sydney	4	19.0
Tumut	3	14.3
Harden	2	9.5
Boorowa	2	9.5
Cowra	2	9.5
Young	1	4.8
Moree	1	4.8
Northern Territory	1	4.8
Lismore	1	4.8
Melbourne	1	4.8
Casino	1	4.8
Dubbo	1	4.8
Wagga	1	4.8
South Coast	1	4.8
Wreck Bay	1	4.8
Orange	1	4.8
Wallaga Lake Mission	1	4.8
Gilgandra	1	4.8

Because of the distance involved and the time required, we did not interview anyone in Griffith or Sydney, and we did not visit those places which only one or two people had mentioned. Table 2 shows that in addition to interviewing people from the ACT (n=42, 42.9%) and Queanbeyan (n=17, 17.3%), we proceeded to follow as much of the advice as possible given by respondents by also conducting interviews in Tumut (n=18, 18.4%), Yass (n=9, 9.2%) and Goulburn (n=6, 6.1%). We also interviewed 6 people (6.1%) from Brungle. Brungle is an Indigenous mission situated 12 kilometres from Tumut. The approximately 40 Aboriginal people who live there have extensive kinship ties with the Ngun(n)awal people, including those living in the ACT and Tumut. Since we interviewed such a small number of people from a small population of Indigenous people, we were concerned that their comments might be too identifying and we felt it might be better to accumulate their comments with

those from Tumut. We then contacted the senior elders in Brungle who were adamant that they wished their comments to be documented separately. We did, however, continue to correspond with elders in Brungle to ensure that we had documented their needs in the way they wished.

Table 2: Area of residence

Area	n	%
ACT	42	42.9
Queanbeyan	17	17.3
Tumut	18	18.4
Yass	9	9.2
Brungle	6	6.1
Goulburn	6	6.1
Total	98	100.0

Most of the Town Centres were represented in the postcodes of the 42 ACT residents we interviewed (Table 3).

Table 3: ACT residents, by area

Area	n	%
Inner North	11	26.2
Woden	11	26.2
Tuggeranong	7	16.7
Belconnen	6	14.3
Weston Creek	3	7.1
Itinerant	2	4.8
No disclosure	1	2.4
Missing	1	2.4
Total	42	-*

*When working out percentages we rounded numbers off to the nearest decimal point. As a consequence, some did not reach a round 100 per cent. The cell is left blank here and elsewhere as necessary.

3.8: The interviews

We started the interviews on 22.11.99 and completed them on 11.5.00. By February 2000, four people we intended to contact for interview had died. This had its impact on the local Indigenous community, including the Aboriginal member of the research team for whom these losses were felt personally. It was important for her to deal with her own grieving, and

it was also important to demonstrate a proper respect by postponing further interviews until there had been an appropriate mourning period.

When we were first in contact with respondents, we provided them with information about the interview, then organised a mutually convenient meeting place. Most people were interviewed in their own home (n=66, 67.4%), some were interviewed in their workplace, the home of a family member or a friend. Other places included cafes, parks and NCEPH (Table 4).

Table 4: Interview venue

Venue	n	%
Home	66	67.4
Workplace	12	12.2
Family or friend's home	6	6.1
Other	14	14.3
Total	98	100.0

Except in 5 instances where the Indigenous researcher was unavailable for some or part of the interview, the interviews were conducted by the Indigenous and non-Indigenous researchers together. Before the interviews commenced we ensured there was informed consent. A copy of the consent form is attached as Appendix 7. To compensate them for their time, and to acknowledge our gratitude, respondents were provided with an honorarium of twenty dollars. We informed everyone that if they wished, they could have someone else present at the interview. Approximately two thirds of respondents were interviewed alone. Most of the remaining people were interviewed in the presence of a family member or friend (Table 5). The length of the interviews ranged from 20-160 minutes with an average of 55 minutes.

Table 5: Others present at interview

Who present	n	%
Alone	65	66.3
Family or friends	32	32.7
Other	1	1.0
Total	98	100.0

4: Respondents' involvement with other research

We are aware of the danger of people being over-researched. This is a particular problem with older people who are perhaps experiencing health problems and who might find an interview exhausting. Because we knew of two other recent pieces of research involving older Indigenous people we asked the people we interviewed if they had previously been interviewed by researchers. No one reported that this was the case.

5: Sociodemographic characteristics

We begin the section on sociodemographics by documenting whether respondents were potential clients or carers. We then move on to report on the communities respondents belonged to before commenting on their age, gender and marital status.

5.1: Type of respondent

In addition to wanting to interview potential clients, we also made it known on our flyers that we were interested in interviewing carers. Table 6 shows that the majority of people we interviewed were potential clients (83.7%, n=83). Nine people were both a potential client and carer and seven were carers who reported on the person they cared for. Of the 16 respondents who identified themselves as carers, half were a partner and half were a child of the person needing care.

Table 6: Type of respondent

Respondent	n	%
Potential client	82	83.7
Potential client <i>and</i> carer	9	9.2
Carer	7	7.1
Total	98	100.0

5.2: Community

We present in Table 7 an exhaustive list of communities. Thirty six respondents (36.7%) identified as Ngun(n)awal. This was followed by 26 people (26.5%) who identified as Wiradjuri. Six people (6.1%) said they were Ngun(n)awal/Wiradjuri. Four people (4.1%) said they did not know what their origins were because they were of the Stolen Generations.

Table 7: Community

Community	n	%
Ngun(n)awal	36	36.7
Wiradjuri	26	26.5
Ngun(n)awal/Wiradjuri	6	6.1
Don't know	4	4.1
Moorawary/Brewarrina	2	2.0
Bundjalung	2	2.0
Bundjalung/Eora	1	1.0
Barygul/Bundjalong	1	1.0
Malara/Bundjalong	1	1.0
Ngumba	1	1.0
Gamilarraay	1	1.0
Yawaarlaaray	1	1.0
South Coast	1	1.0
Nguro	1	1.0
Kamailory	1	1.0
Yuin	1	1.0
Yuin/Darug	1	1.0
Kukuyalanji	1	1.0
Budjtyli	1	1.0
Yankunytjatjarta	1	1.0
Eastern Island	1	1.0
Gulargumbone	1	1.0
Northern Territory	1	1.0
Victoria	1	1.0
Lightening Ridge	1	1.0
Dubbo	1	1.0
Gunnedah	1	1.0
“Just Aboriginal”	1	1.0
Total	98	100.0

5.3: Age

Although the target age for respondents for our research was 45 and over, we were asked (by two of his relatives) to interview a younger man who was homeless and had several health problems. We have included him in this report. We were also contacted by two younger women who wished to discuss the range of problems they had. They suggested that since many Aborigines were dying in their thirties and forties, more research needs to be done on the needs of people in these age groups. Their view is confirmed in research findings. According to Ring:

The really exceptional feature of Aboriginal and Torres Strait Islander health is the enormously high adult mortality, particularly in middle age, and I have been unable to find any other population in the world (for whom figures are available) that has rates as high – with estimates ranging from 6 to 12 times that of the total population in various parts of Australia for those in their forties and late thirties (1995:228).

The largest numbers of respondents were in the age brackets 45-49, 50-54 and 55-59 (Table 8). Reflecting the low age of mortality among Indigenous people, there were gradually smaller numbers in the older age brackets.

5.4: Age and gender

We interviewed more women (n=61, 62.2%) than men (n=37, 37.8%) (also shown in Table 8). The breakdown of age by gender reveals that the gender proportions are fairly comparable until we reach age group 55-59 when we see a greater proportion of women (31.1%) than men (18.9%). The next age category: 60-64, however, shows a larger proportion of men (21.6%) than women (9.8%). The numbers in the other age brackets are too small to make any inferences but some can be made about the total overall differential. Firstly, two women conducted the interviews and it is possible that if there had been a male researcher we would have had more male respondents. We believe, however, that most of the gender differential in our sample relates to the fact that males in general die earlier than women. This is even more profoundly so in the Indigenous population. In 1995 to 1997, 53 per cent of deaths among Indigenous males occurred in men below the age of 50 years. Though still alarming, there was a smaller proportion of 41 per cent of deaths amongst Indigenous women younger than 50 (Cunningham and Paradies, 2000).

Table 8: Age, by gender

Age	Men		Women		Total	
	n	%	n	%	n	%
40 - 44	1	2.7	0	0.0	1	1.0
45 - 49	9	24.3	13	21.3	22	22.4
50 - 54	7	18.9	12	19.7	19	19.4
55 - 59	7	18.9	19	31.1	26	26.5
60 - 64	8	21.6	6	9.8	14	14.3
65 - 69	1	2.7	5	8.2	6	6.1
70 - 74	2	5.4	5	8.2	7	7.1
75 +	2	5.4	1	1.6	3	3.1
Total	37	100.0	61	100.0	98	100.0

5.5: Marital status

The gender differential is apparent in our findings on marital status which demonstrate that we interviewed a slightly greater proportion of widowed women (18.0%, n=11) than widowed men (10.8%, n=4) (Table 9). Most people we interviewed were married or in a *de-facto* relationship (n=60, 61.2%).

Table 9: Marital status, by gender

Marital Status	Men		Women		Total	
	n	%	n	%	n	%
Single	6	16.2	10	16.4	16	16.3
Married/ <i>de-facto</i>	25	67.6	35	57.4	60	61.2
Separated/divorced	1	2.7	3	4.9	4	4.1
Widowed	4	10.8	11	18.0	15	15.3
No disclosure	1	2.7	2	3.3	3	3.1
Total	37	100.0	61	100.0	98	100.0

6: Health

Indigenous Australians “die almost 20 years younger than other Australians and are more likely to be hospitalised, to smoke and to suffer from obesity or chronic illness. In the period 1991-96, life expectancy at birth for Indigenous Australians was 56.9 years for males and 61.7 years for females compared to 75.2 years and 81.1 years respectively for all Australians” (House of Representatives Standing Committee on Family and Community Affairs, 2000:159).

In order for there to be a turnaround in these depressing statistics, there needs to be, as documented in the Ottawa Charter, a recognition of the importance of physical, mental and social health (World Health Organisation, 1986). Though these domains are not mutually exclusive we have, with one exception, separated them for ease of discussion as we document our findings on health.

The problem that we could not categorise was that of the Stolen Generations and we begin this section by discussing findings relevant to this problem. We then go on to discuss physical and mental health problems. Five people said they did not have any physical or mental health problems and two chose not to report this information. In order to protect confidentiality we have only documented problems when they were reported by five or more people. We have aggregated the remaining problems into the category of “other.” In addition to asking people what their health problems were, and collecting information relevant to social health, we also asked people what their health needs were. Other information relevant to health was also frequently mentioned when, at the end of the interview we asked people if they had any other questions or comments. We also report these findings below.

After discussing respondents’ physical and mental health we go on to provide some information on use of medications before reporting on their other drug use behaviours and contact with health service providers. We then go on to discuss a range of findings related to social health.

6.1: Stolen Generations

Since it is the problem of Stolen Generations, which, perhaps above all those reported to us, impacts on the three domains of physical, mental and social health, not only for the individual who was Stolen but on the whole of the Indigenous Community, we discuss it separately here. We did not ask people if they were one of the Stolen Generations, but during interview four people talked about their experiences of being Stolen. We believe the actual number was much greater and, in retrospect, regret not including this question in our interviews. Whilst not being Stolen themselves, several respondents spoke about family members being Stolen, or the general impact the Stolen Generations had on their lives. For example, a woman whose “Mum had been Stolen” said she was “wary of Social Workers.” One woman who was one of the Stolen Generations said:

I think that counselling for unsolved grief related to separation is an immediate requirement and should be set up. Grief cripples you, and while you're holding on to that pain you can't move on with life. I've met older people in this community and they haven't had proper counselling for their grievances.

Another respondent who was also one of the Stolen Generations specified that there must be a “code of conduct” for counsellors. We spent some time phoning counselling services to find someone who would be willing and experienced enough to counsel this man. We were eventually successful.

6.2: Physical health

The House of Representatives Standing Committee on Family and Community Affairs reports that

“three out of four deaths among Indigenous Australians now result from one of the following:

- *diseases of the circulatory system, (heart attacks and strokes);*
- *injury and poisoning (road accidents, suicide and murder);*
- *respiratory diseases (pneumonia, asthma and emphysema);*
- *neoplasms (cancer); and*
- *endocrine, nutritional and metabolic disorders (diabetes)”*

(2000:4).

We found only small numbers of people with a history of cancer or injury and poisoning and these are recorded as “other” in Table 10. Many people had more than one problem

and many of the health problems experienced by the people we interviewed fell into the other categories of life-threatening diseases described above.

6.2.i: Cardiovascular diseases

Table 10 reveals that the physical health problems most commonly reported by the people we interviewed were cardiovascular in origin. Many people reported more than one of these diseases. Apart from a history of heart attacks, the gender proportions were quite similar. Large numbers of people reported hypertension (n=29, 29.6%). This finding is similar to the 1994 National Aboriginal and Torres Strait Islander Survey where 29.7 per cent of men and 35.2 per cent of women aged 45 and over reported this problem (Madden, 1995).

A history of heart disease was reported by 21 people we interviewed (21.4%). Thirteen of these people were men (35.1% of men) and 8 were women (13.1% of women). A history of heart disease was generally articulated by the people we interviewed as “heart attacks.” These reports are fairly comparable with National Survey reports of “heart problems” (Madden, 1995:17). The proportion in our sample of men with a history of heart attacks was a little higher than reports of “heart problems” found in the 1994 National Aboriginal and Torres Strait Islander Survey where 18.3 per cent of men over 45 reported this problem. The proportion of women over 45 with “heart problems” in the National Survey (15.3%) was similar to our sample of women with a history of heart attacks.

Four (4.1%) people we interviewed had undergone bypass surgery. Seventeen (17.3%) said they had high cholesterol levels and 6 (6.1%) had a history of one or more strokes.

Few of the people we interviewed had their own blood pressure machine and one person with hypertension articulated such a need. It has become commonplace for people with hypertension to be advised by their medical practitioners to purchase their own blood pressure machine. In that way, they are more in control of their own health and they can monitor their own blood pressure on a regular basis and keep a record of any changes, particularly if there are any changes in their medication, or if there are any changes in their life which may affect their blood pressure. It does not place too much of a financial burden on those with higher incomes to find the hundred dollars or so to purchase their own machine. But for most of the people we interviewed with hypertension, one of the diseases

which contributes to the lower age of mortality amongst Indigenous people, it would be very difficult for them to find that hundred dollars.

6.2.ii: Musculoskeletal diseases

The next highest category of health problems fell under the heading of musculoskeletal diseases. Whilst these are not usually life threatening, the respondents who reported a problem of this nature were often obviously in a great deal of pain. This impacted on their ability to carry out normal living activities. The problem most commonly reported was arthritis. A higher proportion of women (23.0% of women, n=14) than men (8.1% of men, n=3) reported this problem. Men, however, reported a higher proportion of “back problems” (27.0% of men, n=10) than women (11.5% of women, n=7). Most of these back problems were a consequence of work-related injuries. There were also several complaints of “knee problems” (n=7, 7.1%). Respondents commonly associated these problems with a work or sports injury, or to arthritis.

6.2.iii: Endocrine diseases

As reported above, diabetes is one of the illnesses associated with the lower life expectancy of Indigenous Australians. This was the health problem most frequently reported by our respondents. More than a third had a history of diabetes (n=38, 38.4%). The gender proportions were almost identical. The proportions in our sample are rather higher than found in the 1994 National Aboriginal and Torres Strait Islander Survey where 18.3 per cent of men and 23.5 per cent of women over 45 reported a history of diabetes (Madden, 1995).

One woman with diabetes told us that her feet were going numb. She was not receiving any podiatry services and after we recommended that she did, we gained her permission to intervene on her behalf. She is now regularly receiving this service. Three other people said there was a need for improved podiatry services. Some people we interviewed, others we were told of, have had amputations secondary to their diabetes. One of these people was experiencing delays in obtaining a prosthesis. Not everyone had access to a Blood Sugar Level monitor. One person asked us how they could obtain one. As reported below, one woman who did have a monitor had stopped using it. Other people identified a range of needs related to diabetes. One man with diabetes said he needed to have his “eyes and kidneys checked.” A woman with diabetes referred to a need for nutrition classes and

another woman identified a need for exercise classes. A general need for Indigenous people to have a “diabetes check” was referred to by another respondent.

6.2.iv: Genitourinary problems

One of the questions designed to address the Resident Classification Scale was related to incontinence (Appendix 3, Question 11). Around one quarter of the people we interviewed (n=25) reported urinary incontinence. There was a gender differential since 13.5 per cent (n=5) of male respondents reported this problem compared to 32.8 per cent of females (n=20). Some of the men associated their incontinence with times they were heavily intoxicated, others to genitourinary conditions. For others it appeared to be due to nerve damage suffered as a consequence of a back injury. From the descriptions we heard of the nature of this problem in women, we surmised that most were suffering from stress incontinence (that is incontinence when coughing, laughing or sneezing). Stress incontinence is often a sequela of inadequate care during pregnancy, childbirth and the post natal period. Where people wished further advice, we recommended that they should contact the Incontinence Helpline. We have no way of knowing whether this advice was followed but because of the embarrassing nature of the problem we believe that few people would have done so.

In the context of genitourinary health, one man we interviewed said: “Blackfellas feel shamed to go and see about their prostate, if I go to [a medical service] they haven’t got a male to talk to, a counsellor, about it.”

Seventeen women had gynaecological problems. When we asked people about their health needs, seven women talked about women’s health issues. Three concerned the need for mammograms; one of these women said there should be a free service for Indigenous people and another said there should be an Indigenous-specific mammogram program. Three women said they would like workshops on menopause and another woman talked about the need for a general women’s health program.

6.2.v: Gastrointestinal problems

Ten respondents reported they suffered from gastric ulcers and, indicating a need for service provision, six people reported faecal incontinence.

6.2.vi: Respiratory problems

As previously noted, respiratory diseases account for some of the younger age of mortality among Indigenous people. Twelve people reported a history of asthmatic attacks and there was an additional 14 reports of other respiratory conditions. One of the asthma sufferers was a man (2.7% of men) and the remaining 11 were women (18.0% of women). A greater proportion of reports of asthma among men was found in the 1994 National Aboriginal and Torres Strait Islander Survey (Madden, 1995) (12.6% of men aged over 45) but there was a similar proportion of women in that survey (23.0% of women over 45) compared to women in our sample.

6.2.vii: Neurological and sensory problems

Twenty four people reported a wide range of neurological problems. Most of the other problems were sensory: 14 people had eye problems, 5 a hearing impairment and 5 a skin or nail disorder.

6.2.viii: Dental problems

Eleven people reported a dental problem. Dental health services were the subject of most comment in terms of physical health needs. Fifteen people said there was such a need (7 from Tumut, 5 from the ACT, 2 from Queanbeyan and 1 from Brungle). Most of these people talked about wanting a “dental van” to visit their area.

Table10: Physical health problems

Health problem	Male		Female		Total	
	n	%	n	%	n	%
<u>Cardiovascular</u>						
Hypertension	12	32.4	17	27.8	29	29.6
History of heart attack/s	13	35.1	8	13.1	21	21.4
High cholesterol	6	16.2	11	18.0	17	17.3
History of stroke/s	2	5.4	4	6.6	6	6.1
Other	5	13.5	10	16.4	15	15.3
<u>Musculoskeletal</u>						
Arthritis	3	8.1	14	23.0	17	17.3
Back problems	10	27.0	7	11.5	17	17.3
Knee problems	4	10.8	3	4.9	7	7.1
Other	8	21.6	5	8.2	13	13.3
<u>Endocrine</u>						
Diabetes	14	37.8	24	39.3	38	38.4
Other	1	3.7	6	9.8	7	7.1
<u>Urinary tract</u>						
Incontinence	5	13.5	20	32.8	25	25.5
Other	8	21.6	3	4.9	11	11.2
<u>Gastrointestinal</u>						
Gastric ulcers	3	8.1	7	11.5	10	10.2
Faecal incontinence	2	5.4	4	6.6	6	6.1
Other	7	18.9	9	14.8	16	16.3
<u>Respiratory</u>						
Asthma	1	2.7	11	18.0	12	12.3
Other	6	16.2	8	13.1	14	14.3
<u>Neurological</u>	15	40.5	9	14.8	24	24.5
<u>Gynaecological</u>	-	-	17	27.8	-	-
<u>Vision impairment</u>	8	21.6	6	9.8	14	14.3
<u>Dental</u>	2	5.4	9	14.8	11	11.2
<u>Hearing impairment</u>	2	5.4	3	4.9	5	5.1
<u>Skin or nail disorders</u>	0	0.0	5	8.2	5	5.1
Other physical health problems	5	13.5	8	13.1	13	13.3

6.2.ix: Comparisons between the health problems reported by the people we interviewed and those in the 1994 National Aboriginal and Torres Strait Islander Survey

For ease of comparison, we have tabulated the reports of health problems from the people we interviewed with those from people aged 45 and over interviewed in the 1994 National Aboriginal and Torres Strait Islander Survey (Madden 1995) (Table 11). This Table shows the samples to be roughly comparable. The findings in the National Survey were based on interviews conducted in 1994 when “Approximately 90 Aboriginal and Torres Strait Islander people ... interview[ed] over 15,700 Aboriginal and Torres Strait Islander people selected in the survey” (Madden, 1995:iii). Ours was a much smaller sample conducted six years after the National Survey. We conducted in-depth interviews and obtained qualitative and quantitative data. We also inquired about medications respondents were prescribed. Whilst most people were able to list all their health problems, in some instances we discovered a health problem (sometimes as serious as diabetes) that someone had forgotten to inform us of by relating a medication to a health problem that had not been mentioned. For example, when one carer we interviewed showed us the medications her Mother was taking we discovered one that is prescribed for diabetes. When we asked her if her Mum did have diabetes, she said: “No”, thought for a moment, then said: “She’s got sugar, is that the same thing?”

Table 11: Comparisons between the health problems reported by the people we interviewed and those in the 1994 National Aboriginal and Torres Strait Islander Survey

Health problem	People we interviewed		National Survey	
	Male	Female	Male	Female
	%	%	%	%
Hypertension	32.4	27.8	29.7	35.2
Heart disease	35.1	13.1	18.3	15.3
Diabetes	37.8	39.3	18.3	23.5
Asthma	2.7	18.0	12.6	23.0

6.2.x: Need for assistance with mobility, reports of aggression and need for help at night

The results of the findings for the extra questions we added to address the Resident Classification Scale are shown in Table 12. We have already discussed those related to incontinence. This table also shows that there were 79 people who could “get around without assistance” leaving 19 who could not. The severity of this problem ranged from people who were confined to wheelchairs and needed assistance (n=3) to people with mental health problems who were afraid to go out on their own, and people whose bad backs incapacitated them such that they had problems with mobility. There were also 8 people who needed help during the night, three whose carers said they were “sometimes aggressive” and two whose carers said they “sometimes go wandering.” Including our findings on urinary and faecal incontinence, there is an indication that some respondents and their carers are burdened by these problems.

6.2.xi: Hygiene needs

We now relate a pertinent story from our field notes on a woman who was receiving care and support from various service providers in the ACT. The support included housework, food preparation and three days a week of hygiene care. Although this woman appreciated and praised her quality of care, she was concerned that she was not receiving enough hours a week to address her daily hygiene needs. She asked us for assistance to enable her to receive daily hygiene care, largely because of her incontinence. We contacted an outreach supervisor and arranged for her to meet with the respondent to inquire about an extension of hours. We were told that because the respondent was already receiving nineteen and a half hours of care a week, she was not eligible for any more hours. The outreach supervisor explained that the existing care packages were not flexible.

Table 12: Extra questions included for Resident Classification Scale assessment

Assessment	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Can get around without assistance	31	73.8	15	88.2	8	88.9	16	88.8	4	66.7	5	83.3	79	80.7
Sometimes doesn't make it to the toilet in time	13	31.0	5	29.4	2	22.2	6	33.7	2	33.3	4	66.7	32	32.7
Needs help at night	5	11.9	0	0.0	0	0.0	2	11.1	1	16.7	0	0.0	8	8.2
Sometimes aggressive	3	7.1	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1
Sometimes wandering	2	4.8	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	2	2.0

6.2.xii: Nursing advice and assistance with accessing services

One woman with some quite rare medical conditions said she required more information about her own health problems. The nursing qualifications of one of the interviewers enabled her to provide medical advice when requested or when, as a health professional, she deemed advice to be necessary. In addition to the advice about incontinence (reported above) a further nine people were given advice. The advice included a lengthy consultation with someone who had recently had a heart attack and was due for more investigations, recommending that someone with a history highly suggestive of diabetes seek medical advice (this woman followed our advice and was diagnosed with diabetes), information about travel reimbursement for interstate medical appointments and advice to two women who related symptoms which required investigation. One of these women had a male doctor and she had not informed him of her symptoms. We arranged for her to see a female doctor and also organised the necessary transport. The other woman felt able to make her own medical appointment.

We also gave advice to another four people about issues such as funeral arrangements and how to get help from Centrelink.

The need of the type of assistance described above as well as those identified below informs us that there is an overwhelming need for Indigenous community outreach workers. One of us (Bev Sibthorpe) has recently returned from New Zealand where she visited a number of primary healthcare centres. There was a consensus that this type of intervention was what was most needed in order to improve Indigenous health.

6.2.xiii: Physical health needs

Related to the advice we gave to our respondents are the needs expressed by our respondents for more health services for Indigenous people. Four people in Brungle and one in Tumut said they wanted a “Mobile Health Unit” to visit the area. One person in the ACT and one in Tumut said there was a need for “health promotion workers.” Two people in Queanbeyan thought there should be an “Aboriginal Health Centre” situated there and two people from the ACT thought there should be provision for Indigenous people to have “Annual check ups.”

From the qualitative data we gleaned 64 comments related to additional physical health needs. We have already discussed some above. The remaining needs are shown in Table 13.

Table 13: Other physical health needs, by area

Need	n	Area
Wood gathering/cutting	6	Tumut (n=4), Goulburn (n=1), ACT (n=1)
Physiotherapist	3	ACT (n=2), Queanbeyan (n=1)
More funding for Indigenous health	2	Goulburn (n=1, Tumut (n=1)
More Koori Nurses	1	Queanbeyan
Koori art in hospitals	1	Queanbeyan
Occupational Therapist	1	ACT
Optician	1	ACT
Chiropractor	1	ACT
Dog for hearing impaired people	1	Yass

6.2.xiv: Nutritional needs

We asked respondents about the adequacy of their diets. The majority (n=89, 93.6%, 3 missing values) reported that they ate something every day. We also asked people what their daily diet consisted of and coded it as code of good, mediocre and poor. Sixty one (64.2%) were eating a healthy diet. In some instances these people had made healthy eating choices because they had been diagnosed with an illness such as diabetes. Other people we interviewed had, however, continued with an inappropriate diet despite such a diagnosis. Of the remaining respondents, 18.9 per cent (n=18) bordered between an adequate and an inadequate diet, and 16.8 per cent (n=17) were assessed as having a diet which could be detrimental to their health. Table 14 shows examples of our coding from three randomly chosen daily eating patterns given by respondents.

Table 14: Rating of respondents' diets

Meal	Good diet	Mediocre diet	Poor diet
Breakfast:	Porridge	No breakfast	Tea and a smoke
Lunch:	Sandwich	Salad sandwich	Picks*
Dinner	Meat and vegetables	Meat and vegetables	Picks at whatever's there

*This person had no teeth and no dentures.

Because of the high incidence of respondents with diabetes we have concentrated on the diets of these people. Of the 38 people with diabetes, we deemed thirteen to be consuming an

inadequate diet. We consider the main reasons for this to be financial difficulties, dental problems and poor knowledge of nutrition.

6.3: Mental health

Citing from a submission from the Royal Australian and New Zealand College of Psychiatrists, The House of Representatives Standing Committee on Family and Community Affairs reports that the underlying causes of mental health problems among Indigenous people are:

the loss of loved ones, childhood trauma, alcohol and drug related misery, violence, ongoing racism, stereotyping and discrimination, and the accumulated loss of two hundred and eleven years of cultural destruction and dispossession

(2000,5).

Ten people we interviewed (10.2%) had a mental health problem (Table 15) such as anxiety, stress, depression and psychosis. The majority of the 12 reports of current or previous alcohol or prescribed drug dependence concerned alcohol-related problems. This occurred more commonly in males (n=9, 24.3% of males) than in their female counterparts (n=3, 4.9% of females).

Table 15: Mental health problems

Health problem	Male		Female		Total	
	n	%	n	%	n	%
<u>Mental health</u>						
Depression	5	13.5	5	8.2	10	10.2
Other	5	13.5	11	18.0	16	16.3
<u>Current or previous alcohol or prescribed drug dependence</u>	9	24.3	3	4.9	12	12.2

6.3.i: Mental health needs

In addition to the counselling services needed specifically for people of the Stolen Generations, another 8 people said there should be a counselling service for Indigenous people. There were some specifications on the type of counsellor required: “an older Koori”, “a male counsellor” and “a sympathetic counsellor.”

Two women talked about the need for a “Respite Home” for people who were alcohol dependent and whose families needed a break. One said:

They need somewhere for alcoholics to stay, other than home. There's pressure on the family, they feel guilty if they throw them out. They need a hostel. It puts stress on you when they hang around drinking. Because I love them so much, I can't kick them out [there's nowhere for them to go]. They need somewhere to live. They need workshops like art and craft, or something like that.

Another person spoke of the need for an Indigenous Rehabilitation Centre for people who were alcohol dependent. Those needs are relevant to the needs articulated for an Indigenous hostel and which we discuss below.

6.4: Use of medications

We asked respondents what medications they were currently using and whether they had been on them for more or less than six months. When we were interviewing people in their own homes (the majority of the people we interviewed), we also asked if we could be shown the medications that were being used. When we interviewed people outside of their homes we had to rely on their memory. We were usually confident that people had provided us with a comprehensive list of the drugs they were taking. Where we were not, for example, usually by a respondent saying they could not name a particular drug, we either recontacted them when they were at home to check if they had missed out any drugs, or simply recorded what illness the drug was prescribed for. The drugs respondents were prescribed correlated with the health problems they reported. Some of the prescription drugs most commonly used were those for the treatment of diabetes, antihypertensive drugs, hypolipidaemic agents (for lowering cholesterol levels) and powerful analgesics.

As noted above we were able to obtain a comprehensive history of health problems by correlating medications people were prescribed with their health problems. We, therefore, found these questions on prescribed drug use to be a very useful method of obtaining a complete history of current health problems.

Ninety five people provided us with information on whether or not they were prescribed drugs, and if so, what the drugs were (3 people chose not to report this information). Eighteen people were not prescribed any medications. Of the 77 remaining, there was an average of 3.6 prescription drugs used (range 1-12).

The majority of respondents who were prescribed drugs took them as prescribed (n=59, 77.6%) (Table 16). ACT residents had the lowest proportion in this category (64.7%). The proportions for residents in other areas ranged from 77.6 per cent to 93.3 per cent.

The ten people who did not take their medication as prescribed made comments such as: “I hide them from the grand children, then forget to take them.” One woman with a range of health problems gave several reasons for not taking her medications:

I stopped taking the cholesterol tablets, I can't be bothered with them. I've stopped taking my blood sugar levels [related to her need for diabetes medication]. I got so depressed. The last time I took it was in January ninety-nine. I don't take Aspirin. I don't care any more. I don't like taking them. Aboriginals have a low tolerance for drugs.

Indicating a need for outreach workers, this woman later added that she thought there was a need for nurses to check that Indigenous people were taking their prescription drugs.

Two people said they ran out of money to buy medications and then went without until payday. A comment from a carer was also indirectly related to finances:

When he's on the grog [four to six week "binges"], he won't take the tablets. So he'll be off for a few weeks, when he doesn't have any money, then he's on again.

The six comments regarding the need to monitor the use of prescription drugs also came mainly from carers. With regard to her mother who visited her frequently and who had dementia, as well as insulin dependent diabetes, one woman said:

She has to be given [her medications]. She'll inject anything in the syringe ... She'll also sometimes have a double dose of insulin. That is a scary thing, we have to phone the hospital.

In the other less dramatic examples, a respondent said something along the lines of: “My wife gives them to me. I'd forget otherwise”, or a carer would make a comment such as: “He needs me or Mum to give them to him.”

Table 16: Current medication use*

Medication	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Taken as prescribed	22	64.7	14	93.3	5	100.0	11	91.7	3	60.0	4	80.0	59	77.6
Not taken as prescribed	7	20.6	1	6.7	0	0.0	1	8.3	0	0.0	1	20.0	10	13.2
Needs monitoring	4	11.8	0	0.0	0	0.0	0	0.0	2	40.0	0	0.0	6	7.9
Uses others' drug	1	2.9	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.3
Total	34	100.0	15	100.0	5	100.0	12	100.0	5	100.0	5	100.0	76	100.0

*There are 2 missing values, 2 people chose not to disclose this information and 18 people were not prescribed any medication. The calculations are based on the remaining 76 people.

We also asked respondents if they used over the counter drugs. A majority of 67.3 per cent (n=66) answered “Yes.” Fifty-six were only using one drug. Two people were using 4 drugs (average 1.1). The over the counter drugs most commonly used were analgesics such as Panadol. Ninety-one people were using prescription and/or over the counter drugs. Including both prescription and over the counter drugs, the average number used was 4.3 (range 1-14).

6.5: Alcohol use

Table 17 shows that the majority of respondents (n=58, 59.2%) did not consume alcohol and the majority of those that did (n=25, 25.5%), only drank occasionally. Four people consumed 1-3 drinks a day and 2 consumed 6-10 drinks a week.

Several studies have found that Indigenous people are less likely to be drinkers of alcohol than non-Indigenous people (for example, Commonwealth Department of Human Services and Health, 1996). In our survey, 40.8 per cent of respondents consumed alcohol (n=40). This is a slightly higher proportion than found in the 1994 National Drug Strategy (NDS) household survey where the proportion of urban Indigenous people who consumed alcohol was 33 per cent (Commonwealth Department of Human Services and Health, 1996). It is, however, still lower than the 45 per cent found in the general urban population (Commonwealth Department of Human Services and Health, 1996).

Nineteen of the people who were current alcohol consumers were women (31.1% of women) and 21 were men (56.8% of men). Previous studies on Indigenous alcohol use have similarly revealed a gender difference in frequency of use. They have also found that Indigenous people who do drink are more likely than non-Indigenous people to consume alcohol at hazardous levels. Citing a National Health Survey (NHS) conducted by the ABS, McLennan and Madden report that “some 21% of Indigenous adult males who drank alcohol were classified as high risk drinkers ... compared with 8% of non-Indigenous male drinkers. High risk drinking was less common among females with 9% of Indigenous female drinkers and 3% of non-Indigenous females in that category” (1999:55). We found 9 people (9.2%) whose drug consumption could be considered to be hazardous. Eight were men (42.1% of male drinkers) and one was a woman (4.8% of female drinkers).

Table17: Frequency of alcohol consumption

Frequency	n	%
None	58	59.2
Occasionally	25	25.5
Hazardous (8-23 some days or every day, or said “binge” or “dependent”)	9	9.2
Daily 1-3	4	4.1
6-10 a week	2	2.0
Total	98	100.0

6.6: Tobacco use

In 1995, 24 per cent of Australian women and 28 per cent of Australian men were regular tobacco smokers (NDS, 1996). Forty eight per cent of people (n=47) in our survey smoked tobacco. There was an average of 10 cigarettes smoked a day (range 1-50). Several studies have shown tobacco smoking to be more common in Indigenous than non-Indigenous people. The NHS, for example, found that 56 per cent of Indigenous men and 46 per cent of Indigenous women currently smoked tobacco (cited in McLennan and Madden, 1999). Eighteen of the tobacco smokers we interviewed were men. This constituted 48.6 per cent of men interviewed, a slightly lower proportion than found in the NHS. Twenty-nine of the smokers in our sample were women. The proportion of 47.5 per cent was very similar to that reported by Indigenous women in the NHS.

6.7: Other drug use

We also asked about any other drug use, including marijuana use; which only four people said they used. Three of these people gave us information about their frequency of use (2 people used it once a day and one used it several times a day). Four people used traditional medicine. Two specified that the type used was “old man weed.” This is an Indigenous plant which grows around water places.

6.8: Contact with health service providers

We asked about contact with health service providers in the 12 months prior to interview and emphasised that these contacts should be related to the respondent’s own health. Reflecting the degree of health problems reported above, there had been a great deal of contact with health service providers during this period (Table 18). Most respondents had seen their General Practitioner (GP). Fifty-nine (60.2%) had seen her or him more than 5

times. Forty people (40.8%) had been a hospital in-patient. There were also 33 people (33.7%) who had attended out patient services. Most respondents had seen a specialist doctor (n=57, 58.2%) and a majority had also been in contact with an allied health professional (n=63, 64.3%) (examples include opticians, dentists, physiotherapists, podiatrists and dieticians). The majority of people accessing in-patient and out-patient treatment, a specialist doctor and an allied health professional had accessed the services once or twice. Only a comparatively few people (n=11, 11.2%) had seen an alternative health practitioner or another form of health service provider (n=19, 19.4%). Diabetic services constituted the biggest proportion of respondents in the latter category (n=7, 7.1%).

Table 18: Consultations with medical and health service providers in the 12 months prior to interview

Consultations Last 12 months	GP		Hospital in-patient		Hospital out-patient		Specialist		Allied health services		Alternative health services		Other health services*	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
0	7	7.1	58	59.2	65	66.3	41	41.8	35	35.7	87	88.8	79	80.6
1 – 2	16	16.3	34	32.7	18	18.4	32	32.7	31	31.6	6	6.1	5	5.1
3 – 5	16	16.3	4	4.1	8	8.2	17	17.3	9	9.2	3	3.1	2	2.0
More than 5	59	60.2	2	2.0	7	7.1	8	8.2	23	23.5	2	2.0	12	12.2
Total	98	-	98	-	98	100	98	100	98	100	98	100	98	-

*Specified: Diabetes Services (n=7), “Traditional” (n=4). Another six services were mentioned only once (2missing values).

6.9: Help with physical and mental health problems

In addition to asking about contact with health service providers, we asked respondents if they were receiving any help with their health problems. In particular, we wanted to ascertain what services (such as HACC, which only one person mentioned) other than those reported above respondents might be accessing. Thirty-one people reported receiving help from health services. The majority reported that the services were sufficient. Most people, however, mentioned services such as Winnunga Nimmityjah Aboriginal Health Service (n=13), Doctor (n=8), and Hospital (n=3). Table 18 shows, for example, that 91 people had been in contact with a GP and 57 had been in contact with a medical specialist. From the comparatively small number of reports of help from a Doctor (when we asked about help people were receiving with their health problems [n=8]) it is apparent that most people did not mention a service they must have been receiving help from. We suggest, therefore, that our findings here be interpreted with some caution.

Twenty-six people (26.5%) reported that they needed help or more help now because of their health problems. Nearly everyone else (n=57, 58.2%) thought they might need help in the future (Table 19).

Table 19: Help, or more help, needed with health now, or in the future, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Now	14	33.3	3	17.6	2	22.2	5	27.8	0	0.0	2	33.3	26	26.5
Not needed	2	4.8	1	5.9	0	0.0	2	11.1	1	16.7	0	0.0	6	6.1
Sufficient already	2	4.8	4	23.5	0	0.0	0	0.0	0	0.0	1	16.7	7	7.1
May need help in the future	23	54.8	9	52.9	7	77.8	11	61.1	5	83.3	2	33.3	57	58.2
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Missing	1	2.4	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
Total	42	-	17	-	9	100.0	18	100.0	6	100.0	6	100.0	98	100.0

6.10: Social health

Factors such as children, dependants, education, employment, income, housing and amenities have an important bearing on social health. We begin this section by reviewing our findings in these realms before moving on to discuss needs related to housework, yard work, shopping, cooking and transport. We conclude with other needs relevant to social health.

6.10.i: Children

As well as conducting the needs analysis of older Indigenous people, our funding body asked us to provide some information on illegal drug use amongst young Indigenous people. These findings have already been presented to the ACT Office of Commonwealth Department of Health and Aged Care (Dance, Brown and Bammer, 2000). Our research indicated that the burgeoning problem of illegal drug use, most commonly amongst young Indigenous people, is having a detrimental impact on older members of the Indigenous community. For this reason we have included information about children in social health rather than in the section on sociodemographics.

Recognising that many Indigenous people play a major role in rearing grand children, or other family members, as well as their own children, we asked respondents if they could tell us the number of children they had “reared.” Eighty-seven provided this information. The other 11 people had either reared no children or chose not to report this information. The number of children reared ranged from 1 to 16 with an average of 5 to 6.

Eighty-four respondents gave us information about the age of their youngest and oldest child. The age of the youngest ranged from 1 to 40 years with an average of between 19 and 20. The age of the eldest ranged from 15 to 60 years with an average of between 35 and 36.

In addition to the concerns raised in relation to a man being unable to obtain child endowment (reported below), three other people made comments concerning children. One was a plea for help and we organised a medical appointment and made inquiries about financial assistance for this respondent’s family member who needed to see an Interstate medical specialist. A woman who was rearing her grandchild talked about the responsibility involved in this care. Another person mentioned a general need for schoolchildren to have older Indigenous mentors.

6.10.ii: Dependants

We asked respondents whether they had anyone who was financially or in any other way dependent on them. Ninety-six people provided us with this information. Thirty six (37.5%) said that they had dependants: 34 reported family members; mostly their children, and 4 (2 multiple responses) were other sorts of dependency such as “cultural dependency.”

6.10.iii: Education

In 1996, around 60 per cent of Indigenous people nationally said they had left school before the age of 17 (House of Representatives Standing Committee on Family and Community Affairs, 2000). Our results indicate an even higher proportion (Table 20). Of the 97 people for whom we had data, nearly everyone had left school before the age of 17 (n=94, 96.9%). Around half (n=49) had left school below the age of 15 and around a third at the age of 15. According to McConnell, Census data reveal that “in line with the overall trend in the ACT, Aboriginal and Torres Strait Islander people are staying on at school longer when comparing 1991 and 1996 data” (1998:11). It is likely that this trend has been going on for some time. Given the age group of the people we interviewed, the higher number of early school leavers, when compared to the National sample of all Indigenous peoples, is probably age-related.

Table 20: Age left school

Age	n	%
Under 15	49	50.5
15	35	36.1
16	10	10.3
17	2	2.1
18	1	1.0
Total	97	100.0

A majority of 61 people (62.2%) had done a total of 70 post-school courses (Table 21). Most were Technical And Further Education (TAFE) or work-related courses. Very few people had been to university (n=7, 11.5% of those who had undertaken a course).

Table 21: Post school courses

Courses	n	%
TAFE courses	42	68.9
Work related courses	17	27.9
University courses	7	11.5
Cultural training	4	6.6

Four people talked about a need for intellectual stimulation. Two women had been informed that their TAFE courses had been curtailed. One said:

I've been told I can't get Abstudy to get to TAFE, half way through last course, and they won't pay for our courses. Centrelink took it away. They say we [plus two other friends] are too old.

6.10.iv: Employment

At the time of the 1996 National Census, the unemployment rate for Indigenous Australians was 23 per cent compared to 9 per cent for the non-Indigenous population (House of Representatives Standing Committee on Family and Community Affairs, 2000). Many of the people we interviewed reported 2 or even 3 types of employment status (total of 122). These included various levels of employment (full-time, part-time and casual), home duties, students and volunteer workers. The majority were, however, receiving some sort of pension (aged, disability, sole parent, widow or carer) or unemployment benefits (n=69, 70.4%) (Table 22).

Table 22: Employment status

Employment	n	%
Pensioner/benefits	69	70.4
Employment: full time, part time casual	22	22.4
Student	5	5.1
Volunteer	4	4.1
Home duties	22	22.4
No disclosure	1	1.0

6.10.v: Income

The 1996 National Census revealed that the median income of Indigenous Australians was \$190 per week, only 65.1 per cent of the median income for all Australians (House of Representatives Standing Committee on Family and Community Affairs, 2000). Information about income was provided by 65 of our respondents. Income ranged from

\$50 a week to \$1350 a week, with an average of \$238.86 a week. This is a little more than that reported in the National Census. McConnell makes a salient point about Indigenous income: “Aboriginal and Torres Strait Islander families tend to be bigger so their weekly income must go further” (1998:12).

Table 23 shows the sources of income of our respondents. In keeping with the findings on employment status, most people (n=71, 72.4%) reported pensions or benefits as their source of income.

Table 23: Sources of income

Income source	n	%
Pension or benefits*	71	72.4
Employment*	18	18.4
Compensation & superannuation	1	1.0
Household/partner income	4	4.1
Other	2	2.0
No disclosure	4	4.1

*Two respondents reported both pension and employment.

No one reported receiving help with money from services. One of the only two people (Table 24) who said they needed help now was a carer for both her parents. This woman had other family responsibilities and was in full time employment. She said she would like a carer to escort her parents to the Automatic Teller Machine because “I’m worried about them getting their money and being robbed.” One man’s problems were related to child endowment, which he said he often did not get.

Although we tried to focus the question on whether people required help with obtaining their money, six people made comments about financial difficulties (in addition to the two people already mentioned above who said they ran out of money to purchase prescription drugs and those reported below who ran out of money to pay phone bills). One man said he could not afford to buy reading glasses.

Table 24: Help, or more help, needed with money now, or in the future, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Now	2	4.8	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	2	2.0
Not needed	7	16.7	2	11.8	0	0.0	2	11.1	3	50.0	1	33.3	15	15.3
Sufficient already	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
May need help in the future	28	66.7	15	88.2	9	100.0	16	88.9	3	50.0	4	66.7	75	76.5
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	33.3	1	1.0
Missing	5	11.9	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	5	5.1
Total	42	-	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	98	-

Five people made pertinent comments with regard to receiving a Senior's Card, superannuation or a pension at an earlier age. We told them we would inform our funding body of their comments. One man, for example, said: "The Government says we're old at fifty, so why can't we have the benefits earlier?" A comment of a similar nature came from another man who said: "I can't get a Seniors Card. I'm too young, as an Aboriginal I'm classed as aged. Why can't I get a card? By golly, that would help us." A woman asked: "What will happen to my super' if I die young?" After asking a similar question another woman said: "People die before they get [superannuation] and it goes back to the Government."

6.10.vi: Housing

Most people lived in a separate house (n=72, 73.5%) (Table 25). This proportion almost exactly mirrors that of all Indigenous people in the ACT: in 1996, 71 per cent of Indigenous dwellings were separate houses (ABS, cited in McConnell, 1998). These proportions are lower than that of the total ACT population: 79 per cent lived in a separate house in 1996.

Table 25: Type of housing

Type	n	%
Separate house	72	73.5
Semi-detached row or terrace	11	11.2
Flat, unit or apartment	8	8.2
Other	7	7.1
Total	98	100.0

Most respondents also had stable living arrangements. Eighty (81.6%) had only lived in their current home during the past 12 months and most of the remaining people had lived in just one other place (Table 26).

Table 26: Number of places lived in past 12 months

Number of places	n	%
Only current home	80	81.6
1 other place	11	11.2
2-5 other places	6	6.1
"Don't know"*	1	1.0
Total	98	100.0

*This response was from a carer.

In order to get a complete picture of the number of people living in their homes we asked respondents for the number residing there all the time and how many were there when there were visitors. Ninety-one respondents provided this information. Four did not give specific figures saying that the numbers were very variable. For the other respondents, the reported minimum number of people was 1 and the maximum was 7 (always) and 8 (including visitors). The average number living in the household was between 2 and 3 people “always” and between 3 and 4 when there were visitors. This finding is similar to the overall picture for Indigenous people in the ACT. According to the 1996 Census, the average number of Indigenous people per household is 3.03, higher than the 2.72 reported for other ACT dwellings (McConnell, 1998).

We also asked respondents if they had any housing needs (Table 27). The findings in this table reveal that overall the majority of respondents were totally satisfied with their housing (60.2%, n=59). There are some differences in place of residence. Only 50 per cent of ACT respondents (n=20) were totally satisfied with their housing. Apart from Brungle where only 2 out of 6 people were totally happy with their housing, the proportions in the other areas were higher than in the ACT. They ranged from 64.7 per cent in Queanbeyan (n=11) to 83.3 per cent in both Tumut (n=15) and Goulburn (n=5).

Table 27: Housing needs, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
None	20	50.0	11	64.7	6	66.7	15	83.3	2	33.3	5	83.3	59	60.2
Railings bathroom and/or toilet	11	27.5	4	23.5	2	22.2	2	11.2	2	33.3	0	0.0	20	20.4
Transfer	9	22.5	0	0.0	1	11.1	0	0.0	0	0.0	0	0.0	10	10.2
General maintenance/improvements	1	2.5	3	17.6	0	0.0	2	11.1	2	33.3	1	16.7	9	9.2
Outside steps: railings/ramp	4	10.0	0	0.0	0	0.0	2	11.1	2	33.3	0	0.0	8	8.2
Homeless	3	7.5	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1

Satisfaction with housing was most frequently voiced by a comment such as: “Yes, we’re very happy.” To give an indication of the racism that still pervades in present-day Australia, one woman said:

Yes I am [satisfied], it took me three months to get it. I’m renting privately. Some people wouldn’t give it ‘cos’ I’m an Aboriginal, I’m black. I was walking everywhere and I walked into a real estate in town and they found me somewhere.”

Whilst some people were generally satisfied with their home, they wished for some modifications. Twenty people said they would like railings in the bathroom and or toilet, or railings or a ramp for outside steps. One example is this woman who said:

Yes, darling yes [I am satisfied], I don’t have stairs I just go out the laundry door so that’s excellent. I want bars in the bathroom. I’d like rails, it’s very slippery. I can’t have a bath, I have a shower. I’d like a bath but I’m frightened of hurting myself.

Another respondent, one of the several men with a work-related back injury said:

Things and that in the bathroom, the bars you have in there, mainly those. You’ve got to be very careful in the shower, I can’t move quickly, when I go to the bathroom, I’m always very nervous, very fidgety. [I’m nervous] of slipping on the tiles [because of my back].

Other people said their home, or the exterior of their home, was in need of some general maintenance. This woman, for example said: “The door fell on Auntie. It needs maintenance. It jams all the time, I’m frightened of it falling.” Some people said they would like both interior and exterior modifications. This man was recuperating from a recent heart attack:

When I had a heart attack, I had to walk out [the stretcher] couldn’t get in here. I have trouble walking on the slopes here. [I also] have a problem with the garden – it slopes. If I had a wheelchair I couldn’t get around.

Another respondent who had recently undergone major surgery indicated a need for interior and exterior modifications, as well as maintenance:

If I need other operations, I need handles on the tub to help me get in and out of the tub. You can’t get an ambulance or a stretcher in here. If we spill the water, it runs on to the carpet, everything’s slap happy. The water from the bathroom was running under the house ... everything smelt.

One woman said she would like modifications, such as railings on the steps and in the bathroom for herself, as well as for visiting friends. Another woman whose very dependent mother visited quite frequently from Interstate said: “If Mum came [to live here], we’d need some modifications, she’s incontinent, we’d need rails. Mum’s here every few months, they [Mother and Father] could stay a week or a few weeks.”

We were asked by four people to try and get modifications to their home. One couple wanted us to organise railings for the bathroom and toilet. We spent some time in trying to achieve this but the couple then decided to wait for a later date for these modifications. Our attempts to contact Occupational Therapy for an assessment for the third person were unsuccessful. The fourth person wanted us to try and get the fence in her back garden repaired since she was worried about strangers walking through her garden when she was at home alone. We contacted Housing on her behalf. We can not take credit for this, but this woman is now being rehoused.

Another woman’s comment was of a general nature and is not included in Table 27. She suggested that all older people should have hot water regulators fitted so that they did not scald themselves.

Two elders we interviewed from Brungle, and who were spokespersons for the Brungle community, spoke with one voice about a variety of needs concerning their home and the area in close proximity. They specifically asked us to document their needs for paving outside their homes and their request to have the problem with the sewerage attended to:

You can smell the sewerage all the time, from the pond. And there’s the mosquitoes. There’s a tip near us, white people were using it, the sewerage was running down here.

Ten people said they would like a housing transfer. Most did not specify whether they wanted Indigenous or non-Indigenous housing but one woman wanted a transfer from her current Indigenous housing to another Indigenous housing. Two people currently in mainstream housing wished for a transfer to Indigenous housing. This came across most forcefully from one woman resident in the ACT:

I worry about security, the house isn’t secure - I spoke to Housing about a transfer, the stairs are getting harder and harder. They said they’ll only give

me a bed sit, but I told them to stuff that because of the drugs and the alcohol [used by tenants in some Government flats]. I've made enquires about a village [an Indigenous-specific village in Canberra] for people like us. There's nowhere for them to go, they're not sick enough for a nursing home. Like a self-contained cottage ... I know lots of people who've puts lots in, they deserve something better than this. I want something for women and men, with two bedrooms [to accommodate family and other visitors] a village, with a common room.

This respondent is currently living alone in an ACT Housing Trust story townhouse, which includes the bedroom/bathroom on the top floor. To access these two rooms she has to climb a staircase. Because of her numerous health problems, she finds it increasingly difficult to do this. She also expressed her fear of “dying in the house alone” and at times not being in contact with other members of the local Indigenous community for “days on end.” As she told of her loneliness due to her isolation from the rest of the community, this Indigenous woman often broke into tears.

Because of her emotional state we decided to make an attempt to help her. Before doing so we gained her permission to act as advocates. We then made contact with a Member of the Legislative Assembly who agreed to write a letter to the ACT Housing Trust on her behalf. The letter was sent but, due to negotiation inconsistencies, the matter progressed no further. At the time of writing (June, 2000), the respondent is still living in the same situation she was living in when we first met her.

Another woman also currently living in ACT Government housing, wished for a larger home to accommodate her extended family and which could be also be modified to accommodate a disabled relative who often lived with her. She had mixed feelings about her preference for Government or Indigenous housing:

If we could get an Indigenous house, you wouldn't have to declare your finances and the number of people living in the house. But the Government don't seem to understand that Kooris have extended families. [But if Kooris] need maintenance done, they don't get it [with Indigenous housing]. The Government is good like that. That's why I've always lived in an ACT Housing house.

In 1996-97, it was estimated there were about 12 000 homeless Indigenous Australians (House of Representatives Standing Committee on Family and Community Affairs, 2000). Two of our male respondents were itinerant. One said “I'd like the Community or Government to set up a refuge for men.” At the time of interview, the other man said he

was “Happy with the way things are.” Following some particularly cold weather, he contacted us some time after the interview to ask if we would write a letter to Housing to support his need for accommodation. This we did and with the help of Terry Sutherland, the Health Liaison Officer at Winnunga Nimityjah Aboriginal Health Service, this man has been placed on a six-week priority waiting list.

The third homeless person was a senior elder without a home of her own. She was in desperate need of having somewhere safe to live because of her age. She also saw a need for her to have her own home so that she could teach her people, particularly younger members of the community, about Ngun(n)awal culture. At the time of our data collection we were not able to arrange an interview with another senior elder. This was partly due to the fact that she did not have a home of her own but moved from place to place. Because of her age and homelessness, she also needs a safe and stable home.

Some other comments about housing emerged during the interview. One person feared that the Indigenous Housing Corporation, who owned his home, would cease to be funded and he and his wife might have to move. Another woman saw a need for an Aboriginal Unit in housing. We return to this point towards the conclusion as we comment on the various advocacy services we undertook on behalf of the people we interviewed.

One woman said she would like Social Security to deduct her rent. Three other people indicated that in general there was a need for more housing for Indigenous people. One added: “There’s not enough housing in [city], just redneck Real Estate people.”

One man spoke about the need for a hostel for Indigenous women affected by domestic violence. Three Goulburn residents and one ACT resident passionately talked of the need for a hostel in Goulburn to accommodate Indigenous people who were visiting prisoners there. They said Indigenous residents in Goulburn were often swamped with relatives and friends visiting prisoners. They had heard of people having to accommodate twenty or more visitors in their home.

Some people were in need of a housing transfer. In order to better facilitate this, one woman saw a need for an Indigenous housing officer. As demonstrated above, we interviewed some people who although not in need of home modifications for themselves,

required modifications to make their home safer for visitors, some of whom were quite frail.

We added to the questions developed by Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation on whether respondents had access to hot and cold water, garbage disposal and electricity (1995:123), a question about access to a phone. Almost everyone had access to hot and cold water, garbage removal and electricity and 84.7 per cent (n=83) had constant access to a telephone (Table 28). Saying that they could not always pay their phone bills on time, another 11 people (11.2%) only sometimes had access to a telephone.

Table 28: Access to amenities

Service	Yes		Sometimes		No		Total	
	n	%	n	%	n	%	n	%
Hot water	96	97.9	0	0.0	1	1.0	97*	98.9
Cold water	96	97.9	0	0.0	1	1.0	97*	98.9
Garbage removal	97	98.9	0	0.0	0	0.0	97*	98.9
Electricity	97	98.9	0	0.0	0	0.0	97*	98.9
Telephone	83	84.7	11	11.2	2	2.0	95**	96.9

*One missing value.

**Three missing values.

Three people in Brungle expressed a need for a community phone box (in case of emergencies). A respondent in the ACT who was without a phone asked us to try and organise one for her. Our attempts to do so proved unsuccessful.

Thirteen respondents received help in the home. Eleven of these services were from HACC. A small majority reported that the services were sufficient (n=7). Twenty-seven people (27.7%) said they needed help, or more help with housework now and 56 (57.1%) thought they might need help in the future (Table 29).

Table 29: Help, or more help, needed with the housework now, or in the future, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Now	13	30.9	4	23.5	1	11.1	5	27.8	1	16.7	3	50.0	27	27.6
Not needed	2	4.8	1	5.9	0	0.0	1	5.6	0	0.0	0	0.0	4	4.1
Sufficient already	1	2.4	5	29.4	0	0.0	2	11.1	0	0.0	0	0.0	8	8.2
May need help in the future	24	57.1	6	35.3	8	88.9	10	55.6	5	83.3	3	50.0	56	57.1
Missing	2	4.8	1	5.9	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1
Total	42	-	17	100.0	9	100.0	18	-	6	100.0	6	100.0	98	-

A couple living in a home they had bought for themselves feared having to move. They each had several debilitating illnesses and were in desperate need of help in the house (as well as the yard). The wife said:

Ironing and washing kills me. I do the work when I can. We're thinking of moving. We'll die if we have to move, this is our life. What's important to everyone is to stay in your own home.

Other people also expanded on their need for assistance with housework by specifying the type of help they needed. This was mostly with heavy-duty housework. Seven people said they'd like help with cleaning windows, three with vacuuming, four with washing walls one with cleaning doors and one with carpet cleaning. Five people indicated a need for general help with housework and one person stipulated a need for "a handyman."

Because of the seemingly unusual requests for wall washing, we make some further comment on it here so that service providers will be aware of the genesis of this need. Those people who asked if they could have help with washing the walls of their house were senior elders. The policy of the perpetrators of the Stolen Generations was that Indigenous people were recruited as domestic servants to perform such duties as washing walls. This has left its effect. We conclude that the psychological programming of the Stolen Generations era is still embedded in the memory of these people. Like other Indigenous people, the Aboriginal researcher has been affected during her lifetime with the insistence of her mother that the walls of her family home be constantly washed.

6.10.vii: Help with the yard

Five people received yard services, mostly provided by HACC. Three people said the services were sufficient and two said they were not. Help with yard work was the greatest current need expressed by the people we interviewed. Thirty eight (38.8%) said they needed help, or more help with yard work now and 45 (45.9%) thought they might need help in the future (Table 30). Some people specified the type of help they needed. Four wanted general garden maintenance, two wanted help with lawn mowing and two with rubbish removal.

Table 30: Help, or more help, needed with the yard work now, or in the future, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Now	14	33.3	2	11.8	6	66.7	6	33.3	2	33.3	3	50.0	38	38.8
Not needed	3	7.1	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	5	5.1
Sufficient already	1	2.4	1	5.9	0	0.0	0	0.0	0	0.0	0	0.0	2	2.0
May need help in the future	19	45.2	11	64.7	3	33.3	3	16.7	4	66.7	3	50.0	45	45.9
Missing	5	11.9	3	17.6	0	0.0	9	50.0	0	0.0	0	0.0	8	8.2
Total	42	-	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	98	100.0

We contacted one particular agency on behalf of two women who needed immediate assistance. In the first instance we had quite a frustrating time. For example, we were told there was a very long waiting period and at one point we were referred to look for services: "In the back of *The Canberra Times*." When we demonstrated our displeasure at this response, then identified ourselves by title and institution, we were diverted to a more senior person. She advised us that the woman concerned should make direct contact with the appropriate service. This lady eventually received the help she needed. The other case was more straightforward and we were simply advised that the person who needed help should contact the service herself.

Some time after the interview, another woman, whose illnesses were such that she could not clean up her yard, contacted us to say she was in conflict with two related agencies. One was demanding that she clean up her yard but her payment to the other was in arrears and they would not help her. With her permission, we contacted the ACT Office of the Commonwealth Department of Health and Aged Care who arranged for an advocate to go in to attempt to sort out this problem.

Another woman who was in full time employment said she got very tired and lethargic and needed help in the yard (this was one of the people who related symptoms suggestive of an underlying health problem and whom we strongly advised to seek medical help):

I certainly do [need help in the yard], that's the biggest problem, sometimes I need to do it and I get puffed and nearly keel over ... I asked HACC to help, they said because I'm working I couldn't get any help. I'm working now but what about in three years time. It gets worrying.

6.11: Shopping

Seven respondents received help with shopping. Most thought the help was sufficient. Nineteen people (19.4%) said they would like assistance or more assistance with shopping now and 64 (65.3%) thought they might need help in the future (Table 31). Ten people from the ACT and two from Brungle offered additional comments (these were related more to transport needs and are included in the subsection on transport). Two people from the ACT said they needed to have their shopping delivered. Another woman said: “it kills me sometimes. Even [one] bag, it’s hard, the lifting.” Two women mentioned the problem of having to shop in stages: “Yes I do [need help], I can’t carry it all, I have to do it in stages. It’s more expensive that way”, and “I’m on a hill and I’ve got to walk, I can’t buy a load.” The other respondents said something like: “I can’t do it at all” or “If I’m not well, I don’t go.”

Table 31: Help, or more help, needed with shopping now, or in the future, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Now	11	26.2	3	17.6	1	11.1	2	11.1	2	33.3	0	0.0	19	19.4
Not needed	4	9.5	1	5.9	0	0.0	2	11.1	1	16.7	0	0.0	8	8.2
Sufficient already	1	2.4	1	5.9	0	0.0	1	5.6	0	0.0	0	0.0	3	3.1
May need help in the future	24	57.1	11	64.7	8	88.9	13	72.2	3	50.0	5	83.3	64	65.3
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Missing	2	4.8	1	5.9	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1
Total	42	100.0	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	98	-

6.12. Help with cooking

Three respondents reported receiving help with cooking. Two thought the service was enough and one did not. This lady was receiving Meals on Wheels Monday to Friday and although she was very grateful for the service, she said she would like it expanded to weekends. Altogether, 11 respondents (11.2%) reported that they would like help, or more help, with cooking now (Table 32). Most of the remaining people thought they might need help in the future (n=73, 74.5%).

Another eight people made comments related to help with cooking. One person had tried Meals on Wheels and did not like it. A possible solution for this problem came from three people in the ACT who suggested an Indigenous-specific Meals on Wheels Service. Another woman said she would like: “fruit and veg drops”. Similarly, one woman said she would like “food drops.” One ACT woman said she did not think Meals on Wheels was well advertised. Another ACT woman spoke of how older Indigenous people often run out of food because they give their provisions to other family members.

Table 32: Help, or more help, needed with cooking now, or in the future, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Now	6	14.3	1	5.9	1	11.1	3	16.7	0	0.0	0	0.0	11	11.2
Not needed	4	9.5	2	11.8	0	0.0	2	11.1	2	33.3	0	0.0	10	10.2
Sufficient already	1	2.4	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
May need help in the future	29	69.0	14	82.3	8	88.9	13	72.2	4	66.7	5	83.3	73	74.5
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Missing	2	4.8	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	2	2.0
Total	42	100.0	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	98	-

6.13: Transport

Twelve respondents reported that they received help with transport from services such as Community Transport, Land Council, Northside Community Service, HACC and Winnunga Nimmityjah Aboriginal Health Service. Most reported that the transport services were sufficient but 4 respondents from Brungle (who wanted this information documented) reported that they were not. A woman from Brungle said:

Yes [it is a problem], we have to travel, there's only transport once a week. You have to take the kids and there's not enough space on the bus. You want fresh food for the kid's lunches.

Another person from Brungle who was not currently receiving transport services also saw a need for them to be more frequent. Altogether, there were 23 people (23.5%) who said they needed help or more help now with transport (Table 33). Twenty people made further comments about transport needs. Some were of a general nature, respondents simply saying transport was a problem. Ten people specified that they would like transport for medical appointments. One person in the ACT and two in Goulburn said they would like a Community bus. One man was at risk because he: "hitchhiked everywhere." Four people said they relied on buses. Two were happy using this form of transport but one added: "older people need help."

Table 33: Help, or more help, needed with transport now, or in the future, by area

Need	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Now	8	19.0	0	0.0	4	44.4	4	22.2	4	66.7	3	50.0	23	23.5
Not needed	5	11.9	1	5.9	0	0.0	2	11.1	1	33.3	0	0.0	9	9.2
Sufficient already	1	2.4	2	11.8	0	0.0	0	0.0	0	0.0	1	16.7	4	4.1
May need help in the future	26	61.9	13	76.5	4	44.4	12	66.7	1	33.3	2	33.3	58	59.2
Missing	2	4.8	1	5.9	1	11.1	0	0.0	0	0.0	0	0.0	4	4.1
Total	42	100.0	17	100.0	9	-	18	-	6	100.0	6	100.0	98	-

6.14: Other social problems

There were 10 other reports of a disparate range of problems related to social health. These included a sense of social isolation and recent bereavement. Some people also talked about their social health needs and these are shown in Table 34.

Table 34: Other social health needs

Need	n	Area
Aboriginal Meeting Place	5	ACT
General Socialisation	3	ACT
Park	3	Brungle
Community Centre	3	Brungle
Exterior Lighting	3	Brungle
Footlights each house	3	Brungle
Football Oval	3	Brungle
To be taken for holidays	1	ACT
Self esteem Workshops	1	ACT

7: Aged care preferences

We begin this part of the document by discussing our findings from the Resident Classification Scale assessment. We move on to describing what type of care the people we interviewed wanted. We include some brief information on the types of care available. Further information can be found in Appendix 1

7.1: Resident Classification Scale

We showed a copy of the Resident Classification Scale to the 96 respondents we assessed and gained their permission to use this tool. (One person was not assessed because he was below the age of 45 and we did not have enough information to assess another person because he did not want to tell us his medical problems or what medications he was on.). According to the Resident Classification Scale, the highest most dependent level of care required is 1 and the lowest least dependent level is 8. Our results (Table 35) reveal that the biggest proportion of people we assessed had an Resident Classification Scale level of 7 (54.1%, n=53). The next highest proportion of people fell into an Resident Classification Scale level of 8 (25.5%, n=25) thus indicating that they did not need any help now but may require help in the future. Twelve people had an Resident Classification Scale level of 6 and there were only 1 or 2 people assessed as levels 1-5.

These scores do not accurately reflect the health problems experienced by the people we interviewed. We have concluded that many of the sorts of illnesses that lead to higher mortality and morbidity amongst Indigenous people do not attract high Resident Classification Scale scores. For example, people with circulatory problems and diabetes are normally able to take care of their personal hygiene and toileting needs. These domains are the ones that the Resident Classification Scale is most heavily weighted towards (14.61 and 13.70 respectively). We have had frequent discussions with the ACT Office of the Commonwealth Department of Health and Aged about how to deal with this problem.

With the appropriate guidance from the Indigenous interviewer, we always scored people highly on questions related to “Emotional dependence” (Question 12), “Social & human needs - care recipient” (Question 15) and “Social & human needs – families and friends” (Question 16). Without this guidance the non-Indigenous interviewer would not have properly recognised these needs.

Table 35: Resident Classification Scale, by area

Level	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
1	1	2.4	0	0.0	0	0.0	0	0.0	1	16.7	0	0.0	1	1.0
2	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
3	1	2.4	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
4	1	2.4	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
5	1	2.4	1	5.9	0	0.0	0	0.0	0	0.0	0	0.0	2	2.0
6	4	9.5	4	23.5	0	0.0	3	16.7	5	83.3	1	16.7	12	12.2
7	21	50.0	9	52.9	4	44.4	9	50.0	0	0.0	5	83.3	53	54.1
8	12	28.6	3	17.6	5	55.6	5	27.8	0	0.0	0	0.0	25	25.5
Not assessed	1	2.4	0		0		1	5.6	0	0.0	0	0.0	2	2.0
Total	42	-	17	-	9	100.0	18	-	6	100.0	6	100.0	98	-

7.2: Community or Residential Care

When discussing the type of care a respondent wished for, we first asked whether they preferred community or residential care. No one specified residential care (Table 36). Fewer than 1 in 10 older Australians live in aged care facilities (Commonwealth Department of Health and Aged Care, 1998). At the end of June, 1998 there were five Indigenous people out of a total population of 1315 people in residential care in the ACT (Australian Institute of Health and Welfare, 1999).

Table 36: Preference for community or residential care

Preference	n	%
Community Care	94	95.9
Other *	3	3.1
“Don’t know”	1	1.0
Total	98	100.0

*Two people specified family and one said “Aboriginal hostel.”

7.3: Type of community care

Ros Brown’s experience as a carer enabled her to explain to respondents what was involved in “Packages” (Community Aged Care Packages [CACPs]) and Home and Community Care (HACC). After ensuring that respondents understood what the types of care involved, we asked them which would be their first choice. Most people chose a “Package” (n=69, 71.9%) (Table 37). Greater proportions of respondents in Queanbeyan (82.4%, n=14) and Tumut (77.8%, n=14) than those in the ACT (60.0%, n=24) chose a “Package.” The numbers of people in the other areas are too small to make inferences, except to point out that either a majority (Yass and Goulburn) or all respondents (in Brungle) chose a “Package.” A couple who wanted a “Package”, one of whom scored very highly on the Resident Classification Scale, was due to move out of the area where we interviewed their carer. Their carer wished us to pass on their details to service providers in the town they were due to move to. We intend to follow this up.

Table 37: Order of preference HACC or “Package”, by area

Preference	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
CACP 1st choice	24	60.0	14	82.4	6	66.7	14	77.8	6	100.0	5	83.3	69	71.9
HACC 1st choice	15	37.5	1	5.9	3	33.3	4	22.2	0	0.0	1	16.7	24	25.0
Other*	1	2.5	2	11.8	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1
Total**	40	100.0	17	-	9	100.0	18	100.0	6	100.0	6	100.0	96	100.0

*One person said they would not use the service, one said “Depends on need” and was already receiving HACC services.

**Two missing values.

7.4: Indigenous or non-Indigenous organisation

We then moved on to ask people if they wanted their community care delivered by an Indigenous or non-Indigenous Organisation. Forty-one people (42.7%) chose an Indigenous organisation (Table 38). None of these people were Yass residents but everyone in Brungle chose an Indigenous organisation. Only 5 people from Tumut (27.8%) wanted an Indigenous organisation, 8 said they did not mind. Around half the respondents in the ACT, Queanbeyan and Goulburn said they would prefer an Indigenous organisation. Twenty-seven people overall (28.1%) said they did not mind whether an Indigenous or non-Indigenous organisation provided their care. An almost equal number (23, 24.0%) said they would prefer a non-Indigenous organisation. One person in this category said: “I don’t trust them [I have a] fear of gossip. I would prefer everything mainstream and everyone get a fair crack.” One person, who said they did not mind whether an Indigenous or non-Indigenous Organisation delivered their care added: “I just care about them doing their job properly.”

7.5: Preferences for aged care residences

Although no one had chosen a residence for older people as their first option, we were still interested in what type of residential care they would choose if necessary. We explained to respondents what their options might be. Half chose “clustering” (explained in Appendix 1. Fifteen of these people were from Tumut (83.3%) and 6 were from Yass (66.7%). Smaller proportions of people in the ACT (38.1%, n=16) and Queanbeyan (41.2%, n=7) chose “clustering.” About a third of people overall chose an Indigenous Aged Care Residence. Eight people (8.2%) said they did not mind and 7 (7.1%) adamantly said “I don’t want this” (Table 39).

Table 38: Order of preference Indigenous or non-Indigenous organisation, by area

Preference	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Indigenous	19	47.5	8	47.1	0	0.0	5	27.8	6	100.0	3	50.0	41	42.7
“Don’t mind”	12	30.0	3	17.6	3	33.3	8	44.4	0	0.0	1	16.7	27	28.1
Non-Indigenous	6	15.0	4	23.5	6	66.7	5	27.8	0	0.0	2	33.3	23	24.0
Other*	3	7.5	2	11.8	0	0.0	0	0.0	0	0.0	0	0.0	5	5.2
Total**	40	100.0	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	96	100.0

*One person said “non-Aboriginal and non-Aboriginal workers”, three said “Don’t want this” and one said “Don’t trust either.”

**Two missing values.

Table 39: Order of preference for Residential Care, by area

Preference	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
“Clustering”	16	38.1	7	41.2	6	66.7	15	83.3	3	50.0	2	33.3	49	50.0
Indigenous	17	40.5	6	35.3	0	0.0	2	11.1	3	50.0	3	50.0	31	31.6
“Don’t mind”	3	7.1	1	5.9	3	33.3	0	0.0	0	0.0	1	16.7	8	8.2
“Don’t want this”	4	9.5	2	11.8	0	0.0	1	5.6	0	0.0	0	0.0	7	7.1
Other*	2	4.8	1	5.9	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1
Total	42	100.0	17	-	9	100.0	18	100.0	6	100.0	6	100.0	98	100.0

*One person said “Don’t know”, one not asked (age less than 45) and one said he wanted an “Aboriginal Hostel.”

Fourteen people made additional comments. The biggest proportion came from those who were adamant that they would not want residential care. One was a carer who said: “I would keep Dad at home whatever.” Another person said: “If Koori people go in to nursing homes, they go downhill. It’s not their way.” Someone who wanted an Indigenous aged care residence pointed out she wanted to be somewhere where the majority of people were Indigenous: “I don’t want to be in the minority again.”

With regard to “clustering” one woman said: “I would prefer to have other Indigenous people there, like old Maori people.” Some people who chose “clustering” had a non-Indigenous partner and wanted somewhere for both Indigenous and non-Indigenous people. One man whose wife was also Indigenous and who chose “clustering” said: “They should mix together, that would be good. As long as we go together.” An unmarried man who stated a preference for “clustering” said:

Multiculturalism is part of Australian life. We’ve been struggling for years against white people, but you get older and realise you can’t punch each other out any more. If this survey helps people like me when we get older, then I can say we haven’t failed. We’ve got to make it better for our kids.

One elder who had recently placed a relative in a nursing home made a lot of suggestions about what Indigenous people needed in a nursing home. She particularly wished for her comments to be included in the report and out of respect for her we have included them verbatim:

In an aged care home, it’s really important to have music, I would like Strauss waltzes. In an aged care residence I wouldn’t eat sugar, chocolate or carbonated drinks. No rock, jazz or country and western. [There should be] time for prayers, time for their spiritual atunement - if the person has these facilities, a prayer room or a quiet room, or a meditation room. A spiritual liaison person could perform this role. In the décor, you need solid colours and perfect pictures. Plain colours.

In this old person’s home my [relative’s] home. they have no activities, they need diversional therapy. Elders need to be called Aunty or Elder so and so. The matron didn’t understand.

In residential care, it’s a question of the food. I never saw what food [relative] is getting. It needs to be healthy and sufficient. Not everyone eats a Western diet. Many Aboriginal people love Chinese food. And the quality of the water. Alternative medicines need to be looked at. It’s a question of preferences. Most people, white and black, are looking towards alternative medicines. A good thing about where [relative] is staying, they understand

that they need less sleep. Things like that. The doctor prescribed her sleeping pills which is ridiculous. In this aged care she's staying in, they let them have a drink with their meal and a drink before they go to sleep.

Stuff for Aboriginal people, in aged care, they need a spiritual person in residence or visiting. There are things that happen, spiritual people experience things differently and only a spiritual person can help them.

Whilst some of this lady's statements would strike a chord with all Indigenous people, some are not necessarily representative of the majority of Indigenous people. Particularly those related to choice of music. Her needs do, however, indicate the heterogeneity of the needs in the Indigenous population.

We have already outlined some problems, such as incontinence and problems with mobility that point to a possible need for Respite Care. Two people referred specifically to a need for this type of care. One was a working woman who was thinking of her future and one was a carer for both her parents.

7.6: Carer preferences

In this section we discuss what cultural, gender and age preferences respondents had for a carer. Before doing so we make mention of another type of carer preference. Naming names, two people said they wanted a friend or family member to care for them. In the process of trying to assist other people we discovered there is a precedent in the ACT for Indigenous family members to care for older family members, on a paid basis.

7.6.i: Cultural background of a carer

Most people did not have a preferred cultural background for a carer (n=53, 55.7%) (Table 40). The gender proportions were similar for all categories. Forty-two people (42.8%) said they would prefer another Indigenous person to care for them. Only three people added comments such as: "I wouldn't want a Gubba (a white person)." One woman said she wanted a non-Aboriginal carer. Some people spoke about the general need for more Aboriginal health workers and many who chose an Indigenous carer said they had done so to improve employment opportunities for their people.

Table 40: Preferred cultural background of carer, by gender of respondent

Preference	Men		Women		Totals	
	n	%	n	%	n	%
“Don’t mind”	19	51.4	34	55.7	53	54.1
Indigenous	15	40.5	27	44.3	42	42.8
Other	3	8.1	0	0.0	3	3.1
Total	37	100.0	61	100.0	98	100.0

We also looked to see whether preferred cultural background of carer differed according to respondents’ age brackets (Table 41). Allowing for the variance of numbers in the cells, no discernible pattern emerged.

Table 41: Preferred cultural background of carer, by age of respondent

Preference	40-49*		50-54		55-59		60-64		65-69		70-74		75+	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Indigenous	10	43.5	10	52.6	9	34.6	5	35.7	2	33.3	4	57.1	2	66.7
Don't mind	12	52.2	8	42.1	17	65.4	9	64.3	4	66.7	2	28.6	1	33.3
Other	1	4.3	1	5.3	0	0.0	0	0.0	0	0.0	1	14.3	0	0.0
Total	23	100.0	19	100.0	26	100.0	14	100.0	6	100.0	7	100.0	3	100.0

*The one respondent in age group 40-44 (answer "don't mind") was aggregated with age group 45-49.

7.6.ii: Gender of a carer for general care

A little more than half the respondents said they did not mind whether a male or female was involved in their general care (cleaning the house or yard). A greater proportion of men (70.3%, n=26) than women (41.0%, n=25) were in this category (Table 42). A larger proportion of women (44.3%, n=27) than men (16.2%, n=6) stated a preference for a female for general care.

Table 42: Preferred gender of carer for general care, by respondent gender

Preference	Men		Women		Totals	
	n	%	n	%	n	%
“Don’t mind”	26	70.3	25	41.0	51	52.0
Female	6	16.2	27	44.3	33	33.7
Male yard, female house	2	5.4	7	11.5	9	9.2
Male	3	8.1	2	3.3	5	5.1
Total	37	100.0	61	-	98	100.0

7.6.iii: Gender of a carer for personal care

Sixty-two respondents (63.3%) had a preference for a female to provide their personal care (which we explained to respondents as a need for help in the shower if, for example, they had a broken leg). A far bigger proportion of women (91.8%, n=56) than men (16.2%, n=6) stated this preference (Table 43). The biggest proportion for men fell into the “don’t mind” category (45.9%, n=17). The other men said they would prefer a male carer (n=13, 35.1%).

Table 43: Preferred gender of carer for personal care, by respondent gender

Gender preference	Men		Women		Totals	
	n	%	n	%	n	%
Female	6	16.2	56	91.8	62	63.3
“Don’t mind”	17	45.9	5	8.2	22	22.4
Male	13	35.1	0	0.0	13	13.3
No disclosure	1	2.7	0	0.0	1	1.0
Total	37	100.0	61	100.0	98	100.0

7.6.iv: Age of a carer

The majority of respondents did not have a preference for the age of a carer (n=51, 52%). Forty (40.8%) stated a preference for a mature aged carer. Another 5 people indicated a preference for a young carer. We looked to see whether age preference might be related to respondent age. Those who preferred a young carer were all between the ages of 45-64. The preference for a mature aged carer (as opposed to “don’t mind”) was stronger amongst respondents in the older age groups (65-75+) (Table 44).

7.7: Service delivery

Many of our respondents made comments about service delivery. Two wanted an Indigenous-specific HACC service. Eight people commented on what was needed to train staff. One woman talked about carers being properly qualified:

We’ve got to think about training and recruitment of staff and their qualifications and credentials. I worry about Mickey Mouse credentials for Aboriginals, they aren’t the same as for white workers in their field.

Other comments were related to the need to teach carers to respect elders, to ensure cross-cultural training for non-Indigenous carers and to make carers aware of issues revolving around confidentiality.

Three people also brought up the importance of educating potential clients. One woman said:

A lot of Aboriginal people are very proud and independent and they’re reluctant to let people, even families, help them. You could overcome this with workshops. If they met other people in the same situation, they’d feel less shamed. Educate them about the Packages, let them know what services white people get already. And ... inform them that the service is confidential.

We pick up on this point about independence since 25 people made direct statements about their independence or implied they wanted to be independent. One woman who was in need of help but who said she was: “helping everyone else” said: “Kooris like to be independent, you’re either independent or a bludger. I’ve always been an independent person.” A man said: “I don’t like to ask, even if I wanted to I wouldn’t. That’s blackfella way, you feel ashamed to ask.”

Table 44: Preferred age of carer, by age of respondent

Preference	40-49*		50-54		55-59		60-64		65-69		70-74		75+	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Young	1	4.4	1	5.3	2	7.7	1	7.1	0	0.0	0	0.0	0	0.0
Mature	7	30.4	9	47.4	8	30.8	5	35.7	5	83.3	4	57.1	2	66.7
“Don’t mind”	15	65.2	9	47.4	15	57.7	7	50.0	1	16.7	3	42.9	1	33.3
“Not too old”	0	0.0	0	0.0	0	0.0	1	7.1	0	0.0	0	0.0	0	0.0
Missing	0	0.0	0	0.0	1	3.8	0	0.0	0	0.0	0	0.0	0	0.0
Total	23	100.0	19	100.0	26	100.0	14	-	6	100.0	7	100.0	3	100.0

*The one respondent in age group 40-44 (answer “don’t mind”) was aggregated with age group 45-49.

Ten people made negative comments about HACC services. To protect confidentiality we do not record here which areas the people who made these comments came from but do try to give a flavour of their concerns. One carer said: “It’s a hassle getting [service] extended. I phoned for four days and spoke to three different people every day.” Another woman said she was:

aware of services, but not the right ones. Like HACC. They don’t ask what we want, we tried to get help [for a family member] but no one contacted us about doing it.”

A man said: “Not the HACC, we don’t get help from them.” A woman who had been receiving HACC services said: “They only turned up every six weeks and I don’t bother with them.”

Making a general comment about service provision, another person said: “I would like to be involved in setting it [a service for Indigenous people] up. I want to know who the Kooris are, and the non-Kooris.” A comment of a similar nature was made by a woman who said she was wary of both: “black and white organisations.” One woman simply said: “The service must be properly run and monitored.”

7.8: Consent for services

Our funding body asked us to identify individuals who were interested in receiving either HACC or a Package. After informing people of the services involved in these types of care we then asked if they wanted to sign a consent form nominating their choice so we could pass on their details to the appropriate body (Appendix 7). We further informed people that before we did this, we would recontact them to ensure that is what they still wished. We were especially vigilant about doing this when people had an immediate problem and wanted us to contact a service agency on their behalf.

A majority of 64.3 per cent of respondents (n=63) signed a consent form saying they would like a “Package.” After stating a preference for this HACC, another 13.3 per cent (n=13) signed a consent form for this service. A minority of respondents 6.1 per cent (n=6) signed a consent form requesting either HACC or a “Package.” The other respondents chose not to sign a consent form, either because they did not want this information documented, or because they did not want any services.

8: Need for information

Prior to commencing the fieldwork, the two interviewers attended a workshop presented by Dr Linda Neuhauser on “The wellness guide” which she along with Professor Len Syme was instrumental in developing (nd). The idea of the book evolved in California after academics and Government agencies realised they were not having a great deal of success in informing the community about the sorts of services they could access. This led them to encourage members of various communities to work together to produce a book which would be more accessible to them. According to Linda Neuhauser the evaluation of “The wellness guide” has proved it to be successful. As she and her co-authors note in a paper on its evaluation, “there is increasing evidence that community participation, a central feature of the ‘new public health’ is a powerful component of the programs that have been successful” (1998:211).

The idea of having something like “A wellness guide” developed by, and for, older Indigenous people led us to incorporate a question on a need for an information booklet in our questionnaire. One respondent we piloted the questionnaire with said: “a lot of elders can’t read, pictures, a video or an audiotape [would be good].” We then added a question about the need for a video in to our questionnaire. The results indicate that nearly all respondents would find a booklet useful and most would also find a video useful (Table 45).

Table 45: Useful information resources

Would information be useful	Video		Booklet	
	n	%	n	%
Yes	79	87.8	94	97.9
No	10	11.1	0.0	0.0
Other	0	0.0	1	1.0
“There’s one already”	0	0.0	1	1.0
Total	90*	—	96*	—

*There are nine missing values on the need for a video largely because this question was added during our piloting. There are also two missing values on the need for a booklet.

Some people offered further comments about their need for an information booklet. A non-Indigenous woman who was present when we interviewed her partner said: “Yes, yes, you don’t really hear, like when the diabetes nurse said you could get a machine [for testing blood sugar levels], I didn’t know about it.” Other people made comments such as: “If they don’t

use big jawbreaker words. If they put it so people understand”; “Yes, a Koori one, because we’re in a fight for equality for Aborigines and Torres Strait Islanders” and:

If it’s in a, you know how gubbas talk, you know, big long words. At the moment I have trouble reading. If it’s in simple English, I’ve done two years of [tertiary studies] but I want something in simple language.

Although some people had said they did not feel the need for a video with a comment such as “Not as much as the booklet. I don’t know whether I’d watch it”, others inferred they would prefer this medium: “Yes definitely, where they can visualise something would be better; “Yes we all prefer watching TV than reading”; “That would be good too, for the older people who can’t read and hide it.” One person had another idea: “Fridge magnets should be put out so that people have [information] at their fingertips.”

We showed the first 34 respondents copies of the *Directory of services for the ageing in the ACT* and *Care options for older persons in the ACT and Queanbeyan* and, if they so wished, we provided them with phone numbers so they could obtain their own copies. After a respondent asked if we could get her copies, we decided it would be better if we obtained these books and handed them out to future respondents. We were kindly given enough copies of *Directory of services for the ageing in the ACT* by the ACT Council on the Aging and *Care options for older persons in the ACT and Queanbeyan* by the ACT Office of the Commonwealth Government of Health and Aged Care to enable us to hand out the books to the remaining respondents. The majority of people we interviewed were not aware of the existence of these books. Even though we were very grateful for them we still believe that an Indigenous specific information book would be of even more benefit. This need is documented below as we record our findings on knowledge of service provision for help in the house, yard, health, shopping, cooking and transport.

Eight respondents talked more fully about a general need for more information sources for Indigenous people. Another, a senior elder, said that people in her position were frequently used as a source of information:

I find that a lot of people like to use me as an information person. It places a strain, it costs money, it’s something you need to be aware of. I have people coming saying ‘can you help me walk the spiritual path’ ... elders are informative sources. It costs money. The paper, the ink. Other elders are doing the same things, it’s an additional task Indigenous people have more

so than non-Indigenous. It's a role they perform, a role they increasingly play.

We included in the questions related to service provision needs, questions about respondents' knowledge of service providers for health, housework yard work, shopping, cooking, access to money and transport. The responses (Tables 46-52) reveal there were large numbers of people, sometimes more than half those interviewed, who were not aware of available services. We do however, apply the same caveat about health service provision that we outlined above (that there was a discrepancy between reports of consultations with medical and health service providers people and help with health problems).

As we went through these questions, we informed people who requested information of some of the services available for older Indigenous people and they indicated their gratitude for the verbal information we gave. One man, for example, said he found the interview itself "Enlightening."

Table 46: Knowledge of service providers for health, by area

Knowledge	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	18	42.8	7	41.2	3	33.3	8	44.4	5	83.3	3	50.0	44*	44.9
Not aware	22	52.4	7	41.2	6	66.7	9	50.0	1	16.7	2	33.3	47	47.9
Enough already	1	2.4	3	17.6	0	0.0	1	5.6	0	0.0	0	0.0	5	5.1
Knows exist but does not know name	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Missing	1	2.4	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
Total	42	100.0	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	98	-

*Specified: HACC (n=23) Winnunga Nimmitjyah Aboriginal Health Service (n=5), Indigenous Health Worker (n=3), Community Nurse (n=3), Occupational Health (n=2), Community Transport (n=2). Another 8 services were mentioned only once.

Table 47: Knowledge of service providers for housework, by area

Knowledge	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	17	40.5	7	41.2	7	77.8	11	61.1	6	100.0	4	66.7	52	53.1
Not aware	19	45.2	5	29.4	2	22.2	5	27.8	0	0.0	1	16.7	32	32.7
Enough already	1	2.4	5	29.4	0	0.0	2	11.1	0	0.0	0	0.0	8	8.2
Knows they exist but does not know name	2	4.8	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	3	3.1
Missing	3	7.1	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1
Total	42	-	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	98	100.0

*Specified: HACC (n=52), Red Cross (n=1), St Vincent De Paul (n=1), White Angels (n=1), Respite Care (n=1).

Table 48: Knowledge of service providers for help with yard work, by area

Knowledge	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	17	40.5	7	41.2	6	66.7	8	44.4	6	100	1	16.7	45*	45.9
Not aware	20	47.6	9	52.9	3	33.3	9	50.0	0	0.0	4	50.0	45	45.9
Enough already	1	2.4	1	5.9	0	0.0	0	0.0	0	0.0	0	0.0	2	2.0
Knows exist but does not know name	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	1	5.6	0	0.0	0	0.0	1	1.0
Missing	4	9.5	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	4	4.1
Total	42	100.0	17	100.0	9	100.0	18	100.0	6	100.0	6	100.0	98	-

*Specified: HACC (n=36), CDEP (n=5), Land Council (n=1), Munjawa Housing (n=1), “Kids in detention” (n=1) and private service (n=1).

Table 49: Knowledge of service providers for shopping, by area

Knowledge	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	14	33.3	6	35.3	0	0.0	5	27.8	4	66.7	2	33.3	31*	31.6
Not aware	27	64.3	9	52.9	9	100.0	12	66.7	2	33.3	2	33.3	61	62.2
Enough already	0	0.0	2	11.8	0	0.0	1	5.6	0	0.0	0	0.0	3	3.1
Knows exist but does not know name	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Missing	1	2.4	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
Total	42	100.0	17	100.0	9	100.0	18	-	6	100.0	6	100.0	98	-

*Specified HACC (n=23), Community Health (n=3), Community Bus (n=2). Another 7 services were mentioned only once.

Table 50: Knowledge of service providers for cooking, by area

Knowledge	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	20	47.6	7	41.2	2	22.2	5	27.8	3	50.0	3	50.0	40*	40.8
Not aware	19	45.2	10	58.8	7	77.8	12	66.7	3	50.0	1	16.7	52	53.1
Enough already	1	2.4	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	1.0
Knows exist but does not know name	0	0.0	0	0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Needs more of same	0	0.0	0	0.0	0	0.0	1	5.6	0	0.0	0	0.0	1	1.0
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Missing	2	4.8	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	2	2.0
Total	42	100.0	17	100.0	9	100.0	18	100.0	6	100.0	6	-	98	-

*Specified: Meals on Wheels (n=29) and HACC (n=10). Another 3 services were mentioned only once.

Table 51: Knowledge of service providers for accessing money, by area

Knowledge	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	5	11.9	2	11.8	0	0.0	4	22.2	0	0.0	1	16.7	12*	12.2
Not aware	33	78.6	15	88.2	9	100.0	14	77.8	6	100.0	3	50.0	80	81.6
Knows exist but does not know name	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
“Wouldn’t use”	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7	1	1.0
Missing	4	9.5	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	4	4.1
Total	42	100.0	17	100.0	9	100.0	18	100.0	6	100.0	6	-	98	-

*Specified: Centrelink (n=6), HACC (n=2) and Winnunga Nimmitjyah Aboriginal Health Service (n=1). Other services were mentioned only once.

Table 52: Knowledge of service providers for transport, by area

Knowledge	ACT		Queanbeyan		Yass		Tumut		Brungle		Goulburn		Totals	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	12	28.6	4	23.5	1	11.1	6	33.3	1	16.7	3	50.0	26*	26.5
Not aware	26	61.9	11	64.7	6	66.7	12	66.7	1	16.7	2	33.3	58	59.2
Enough already	1	2.4	2	11.8	0	0.0	0	0.0	0	0.0	1	16.7	4	4.1
Needs more of same	0	0.0	0	0.0	0	0.0	0	0.0	4	66.7	0	0.0	4	4.1
“Wouldn’t use”	0	0.0	0	0.0	2	22.2	0	0.0	0	0.0	0	0.0	2	2.01
Missing	3	7.1	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	3	3.1
Total	42	100.0	17	100.0	9	100.0	18	100.0	6	-	6	100.0	98	100.0

*Specified: HACC (n=7), Winnunga Nimmityjah Aboriginal Health Service (n=4), taxi vouchers (n=3), Community transport/bus (n=3), Community Care (n=3), Land Council (n=2), Gagan Gulwan (n=2) and CDEP (n=2). Nine other services were mentioned only once.

9: Need for advocacy

We have interwoven throughout this report, thirteen instances where the interviewers acted as advocates on the behalf of a respondent. In addition, the news of our interviews spread to a family living well outside the Region. We were contacted by members of this family who said they might move to the ACT if there were services for older Indigenous people here. We arranged to meet them for an interview but they were unable to make the appointment. They later contacted us and we spent a great deal of time trying to organise better services in their own town.

As well as the respondent who identified a specific need for an Aboriginal Unit in housing, another three respondents said an advocacy service for Indigenous people was required: the first to help “people filling in forms”, the second to give financial advice and the third believed there was a need for a comprehensive advocacy service.

10: Personal reflections

Before concluding this report we offer some personal reflections from the two interviewees.

Ros Brown

Although I jumped at the opportunity to participate in research that would be beneficial to the health of my people, I was wary of the intentions of the ACT Office of the Commonwealth Department of Health and Aged Care. This is because of numerous research projects commissioned by other departments that do not produce a positive outcome. In the words of Puggy Hunter, Chairperson of the National Aboriginal Community Controlled Health Organisation (NACCHO):

Everybody feels a bit sad and sorry for the status of Aboriginal health, and ... it's like a trophy that you pull down once a year and polish it up and then you put it back in a glass cabinet ... because you don't want to do nothing with it but you own it

(1999).

For many years I have been concerned about the high morbidity and mortality rate of Aboriginal people. I have not only been aware of this by studying statistics but also by my constant attendance at the funerals of family members and close friends. This anomaly is the reason I have been involved in the research.

Although I am still an active member of my community, as fate would have it I have somehow managed to step out of the oppressive bubble that contains Indigenous Australia. Looking in from the outside has shocked me and put a whole new perspective on Aboriginal health. This has strengthened my commitment to participate in the struggle to improve Indigenous well being.

Because I have mainly had contact with my own community, this project gave me the opportunity to meet people from other Aboriginal communities. As with the Ngun(n)awal people they too have graciously accepted us into their homes and shared their thoughts. Of particular interest is the compassionate nature in which they expressed concern for non-Indigenous people, who also suffer from inequity, and live in circumstances beyond their control.

During my time as co-researcher in this project I have had the pleasure of meeting Phyll Dance, Gabriele Bammer and Bev Sibthorpe. As an Indigenous woman unfamiliar with the complexities of being a researcher, I have gained an understanding of, and appreciate, the commitment of my peers. It has also been with their guidance that I now have a greater understanding of the importance of epidemiological research. I wish to let it be known that if the end product of this research is dealt with “like a trophy” in no way do I hold my fellow members of the research team responsible.

In conclusion I must stress that the funerals are still occurring at an exceptional and increasing rate, so is the poverty. Because of this, at times I have been experiencing bouts of depression during my time as a researcher. But I also realised that I was not the only one who was being affected. The high percentage of deaths and the extremity of poverty have touched and distressed my colleague Phyll Dance. She has been introduced to circumstances that she had little knowledge of. This introduction into the disturbing plight of Indigenous people, and the fact that she has had her own share of family health problems, has at times been very daunting for her as well. I thank her for the patience and professionalism she has shown which has helped me to carry on during this time.

I salute all respondents who participated in this research project.

Phyll Dance

I embarked on this research knowing little more about Indigenous people than I had read in the newspapers, or seen on the television. I did know about the lower age of mortality, and the significant health problems experienced by many Indigenous people. But somehow, I did not associate these problems with Canberra, the “middle class city.” I was eager to take on the challenge of working in an area that was new to me, but I was not prepared for the problems I found and the distress of many of the people we interviewed.

Soon after she joined the research team Ros told me she would take me into the Indigenous world. She proved to be an excellent guide and I learned more from her and the people we interviewed than the reading I did to prepare me for the research. It would not have been possible for us to have interviewed so many people, to have asked the research questions or written this report in a culturally appropriate way, without the depth of knowledge Ros has for her people. She brought this knowledge to the research and generously shared it with her

fellow researchers. Ros did this because of her passion for improving the health of her people.

It was with some trepidation that I first went to interview the research participants. I was under the misapprehension that as a white person I would experience racism. What I did encounter in the vast majority of respondents was warmth, a generosity of spirit and hopes for reconciliation. I had expected to feel like an outsider, this was rarely the case. When people talked about past and present injustices perpetrated by white people, I did not feel they were blaming me. Nor did I feel that, in general, there was blame attributed to the whole of white society. So often respondents expressed the hope that this research would help white people too.

Even people who at first were a little shy of me, lost some of that shyness when Ros told them I was a nurse. I believe this was important to them, and also important for the research since most people talked very openly of their health problems. As indicated above, many also asked for nursing advice.

I now offer a few of the memories of the research process which are not encapsulated in the report. For example, a couple we were interviewing at home and who generously shared their table with us as the husband told stories of his youth and how he and his now wife had to sit in different parts of the cinema because he was darker skinned than she was. And still the racism persists with the stares as he shops at his local shopping centre. For the first time, I heard the accounts of the devastating impact of being Stolen. I asked some of the people who talked of these hardships if it would make a difference to them if the Prime Minister did say "Sorry." Futile though I know this to be, I will make my voice even louder to implore the Prime Minister to say "Sorry" to those many people of the Stolen Generations. I also heard people talking of the loss of their children, some had died of overdoses or other drug-related illnesses.

In addition to Ros hearing these problems, she experienced grief as she went to the funerals. She also had a great deal of family and cultural responsibilities as well as her own studies to continue. I commend her for the professional way she was still able to give her all to this research. There were lots of tears throughout the research process and they continued as we

read a draft of this report and were reminded of the terrible state of Indigenous health in general, as well as the plight of many of the people we interviewed.

But, there were plenty of good times too. One woman whom I have seen several times after the interview has always ended these meetings with a kiss and a “Love you Phyll.” Ros would also tell me of people who said they had “clicked” with me. This warmth has meant a great deal to me and has helped me through the difficult task of dealing with the problems we encountered. I also remember the laughter when I used one of the Ngun(n)awal words that Ros had taught me, or when I fell off a chair in someone’s back yard. The fun I had with Agnes and Hilary (two of our Reference Group members) on our trip to the South Coast. And going out to the bush early one morning to pick “old man weed” whilst being regaled with stories about the traditional ways of the Ngun(n)awal people.

There was also the satisfaction of leaving respondents with more knowledge about service provision than they had before and of achieving something immediate when we intervened on a respondent’s behalf. But there was also frustration when I was contacting a service and discovered that sometimes I could only get action by announcing that I was Doctor Dance from the ANU. It was then that I realised how difficult it must be for other people. I recall one man, on whose behalf I advocated, who told me that he would not use a particular service again because of the way he had been treated in the past: “It’s because I’m an Aboriginal, they think I’m a bludger.”

Like Ros, I am aware of the gap between research and action. It was, however, with great hope that we participated in a forum organised by our funding body on the research we had undertaken on illegal drug use amongst young Indigenous people. Several service providers came to this Forum in February. They were told by the ACT Office of the Commonwealth Department of Health and Aged Care that there would be a report of the meeting, as well as another meeting of community elders. Several months elapsed between the meeting and the distribution of the report. And service providers are still asking when the meeting of community elders will be. Because of our involvement and the fact that we were in out the field continuing our meetings, Ros and I have been attributed with some personal and professional blame. That too has been difficult to deal with.

Despite the problems, the distress that I witnessed in Ros, and my personal distress, I am privileged to have been able to take part in this research and to have gained an understanding of the lives of Indigenous people living in the ACT and Region. I thank the ACT Office of the Commonwealth Department of Health Care for providing me with this opportunity. I also thank Gabriele and Bev for asking me to join the research team. I am indebted to Ros for everything she has taught me and I am greatly appreciative of the warmth and hospitality extended by her family. I shall always warmly remember the people we interviewed.

11: Conclusion

Before agreeing to be interviewed, most respondents asked us for further information about the end results of our research. They had great hope that their input would lead to improved health and living conditions for older Indigenous and non-Indigenous people in general, as well as hopeful that the research could make a difference to their own lives. Only one indicated scepticism about the research: “You reckon things like this will do any good?”

In addition to our funding body, other Government agencies and service providers, this report will be distributed to the people we interviewed. With them in mind we conclude the report by saying that we trust we have done justice to the needs they expressed to us and we sincerely hope that we have been able to impart to those who will fund and deliver their care, some of the depth of feeling we had for them.

References

- Aboriginal Hostels Limited. 1997-98. *Annual Report*. Canberra, Aboriginal Hostels Limited.
- Australian Bureau of Statistics. 1995. *National Aboriginal and Torres Strait Islander Survey 1994: Detailed Findings*, Cat. No. 4190.0. Canberra, Australian Bureau of Statistics.
- Australian Bureau of Statistics. 1998. *Experimental projections of the Aboriginal and Torres Strait Islander population, 30 June 1996 to 30 June 2006. Catalogue No 3231.0*. Canberra. Australian Government Publishing Service.
- ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care. 1999. *Care options for older persons in the ACT and Queanbeyan*. Canberra, ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care.
- Australian Institute of Health and Welfare (AIHW). 1999. *Residential aged care facilities in Australia, 1998: a statistical overview. AIHW cat no 14*. Canberra, AIHW and Department of Health and Family Services (Aged Care Statistics Series).
- Commonwealth Department of Health and Aged Care. 1998. *Aged care – make the choices that are right for you*. Canberra, Commonwealth Department of Health and Aged Care.
- Commonwealth Department of Health and Aged Care. 1999. *Aged care in Australia*. Canberra, Commonwealth Department of Health and Aged Care.
- Commonwealth Department of Health and Aged Care. nd. Department of Health and Aged Care, Australian Capital Territory, Aged Care Planning Advisory Committee Report, 1999-2001. Canberra, Commonwealth Department of Health and Aged Care.
- Commonwealth Department of Health and Family Services. 1998a. *Staying at home – a new \$280m package for older Australians. Information sheet No 1*. Canberra, Commonwealth Department of Health and Family Services.
- Commonwealth Department of Health and Family Services. 1998b. *Staying at home: care and support for older Australians*. Canberra, Commonwealth Department of Health and Family Services.
- Commonwealth Department of Human Services and Health. 1996. National Drug Strategy Household Survey: *Urban Aboriginal and Torres Strait Islander Peoples Supplement, 1994*. Canberra, Department of Health and Family Services.
- Council on the Ageing (ACT). 1998. *Directory of services for the ageing in the ACT*. Canberra, Council on the Ageing (ACT).
- Cunningham, J and Y Paradies. 2000. *Mortality of Aboriginal and Torres Strait Islander Australians, 1997*. Canberra, Australian Bureau of Statistics.
- Dance, P. R Brown and G Bammer. 2000. *“They’ll just read about us in storybooks”: estimations of the number of young indigenous people using illegal drugs in the ACT and Region*. Canberra, NCEPH.

- House of Representatives Standing Committee on Family and Community Affairs. 2000. *Health is life: report on the inquiry into Indigenous health*. Canberra. The Parliament of the Commonwealth of Australia.
- Hunter, P. 1999. Keynote presentation: Community control and primary health care for Indigenous health. *5th National Rural Health Conference*. Adelaide 14-17 March.
- McConnell, J. 1998. *Aborigines and Torres Strait Islander people in the ACT*. Canberra, ACT Department of Health and Community Care.
- McLennan, W and R Madden. 1999. *The health and welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. Canberra, Australian Bureau of Statistics.
- Madden, R. 1995. *National Aboriginal and Torres Strait Islander survey, 1994*. Canberra, Australian Bureau of Statistics.
- Mannix, J. Political context. In I Stein (ed). 1999. *Aged care: a contemporary view*. Canberra, Royal College of Nursing:1-14.
- National Drug Strategy, Commonwealth Department of Human Services and Health. 1996. *National Drug Strategy Household Survey. Survey Report, 1995*. Canberra, Australian Government Publishing Service.
- Neuhauser, L. M Schwab, SL Syme, M Bieber and S King Obarski. 1998. Community participation in health promotion: evaluation of the California wellness guide. *Health Promotion International*, 13:211-21.
- Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation. 1995. *They might have to drag me like a bullock. The Tilpi Pampa Tjutaku Project*. Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation.
- Ngun(n)awal Community. 2000. *Ngun(n)awal Community Care Pamphlet*. Yass.
- Norušis, MJ. 1998. *Guide to data analysis*. New Jersey, Prentice-Hall Inc.
- Ring, I. 1995. An open letter to the President of the Public Health Association. *Australian Journal of Public Health*, 18:228-30.
- Stein, I. D Jackson and J Mannix. Safe housing and health. In I Stein (ed). 1999. *Aged care: a contemporary view*. Canberra, Royal College of Nursing:29-39.
- Richards, L. 1990. Software for soft data: computing and qualitative analysis. In J Daly and E Willis (eds) *Social Sciences and Health Research. The report of a workshop on the contribution of the social sciences to health research*. Ballarat. Public Health Association of Australia:86-92.
- Tripp, M. 1997. Aboriginal and Torres Strait Islander aged care. *Aboriginal and Islander Health Worker Journal*, 21:11-15.
- University of California, Berkeley. nd *The wellness guide*. Berkeley, University of California
- World Health Organisation. 1986. Ottawa Charter For Health Promotion. *Canadian Journal of Public Health*, 77:426-30.

Appendix 1: Background information on aged care services

Australia's aged care system

Australia's aged care system operates on all three levels of Government (Commonwealth, State/Territory and Local Government) (Commonwealth Department of Health and Aged Care, 1999). The system consists of "two main forms of care delivery: residential and community care [which] operate in a broader system of health delivery, income support and community services. Together, these systems offer older people a broad range of services and support, depending on their needs and circumstances" (Commonwealth Department of Health and Aged Care, 1999:1). There is a mixture of services providing aged care including the private, religious and charitable sectors, and Local and State/Territory Government providers (Commonwealth Department of Health and Aged Care, 1999).

Older Australians (or their carers) in need of services and support may contact ACATs. These teams can be contacted either directly or through a local doctor or hospital to "provide **free** information, advice and help [for those people] ... who find it difficult to manage at home without assistance" (ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care, 1999:6). These multidisciplinary teams, jointly funded by the Commonwealth and State/Territory Governments, are composed of professionals such as geriatricians, social workers and nurses. In addition to providing advice about available services, ACATs are trained to assess the suitability of clients' needs for residential or community care. If a client's dependency increases, ACAT's are also responsible for assessing the need for a higher level of care. Government funding for aged care is related to the level of dependency determined by ACATs, the higher the level of dependency, the higher the level of funding (Commonwealth Department of Health and Aged Care, 1999). Recipients of both residential and community care also make a financial contribution to the cost of their care with the Government regulating the maximum charges for service.

Generally, the Commonwealth Government allocates 100 aged care places per 1000 people aged 70 or more. The allocation ratio for Indigenous aged care places is usually 100 per 1000 people aged 50 or more. As a rule, for both Indigenous and non-Indigenous people, 40 of the 100 places are for high level care, 50 for low level care and the remaining 10 places consist of community care packages. These 3 types of placements are more fully described below.

Residential aged care

Since the *Aged Care Act, 1997*, there has been a single Residential Aged Care Sector with two main types of aged care: high level (nursing home) and low level (“hostel”). Some aged care facilities do, however, offer a continuum from high to low level of care. Residential aged care is financed and regulated by the Commonwealth Government. With some funding from the Commonwealth Government, a few residential aged care facilities are operated by State and Local Governments. Residential aged care is, however, largely in the hands of the non-government religious, charitable and private sectors. Residents are charged accommodation fees and, depending on their needs, for nursing care, personal care, meals and laundry. There may be additional fees depending on a resident’s income (Commonwealth Department of Health and Aged Care, 1999).

Low care facilities

In addition to providing accommodation and support services (for example, cleaning, laundry and meals), low level care facilities provide personal care services such as “help with dressing, eating, toileting, bathing and moving around.” Occasional nursing care and other health services, such as physiotherapy and podiatry, may also be provided (Commonwealth Department of Health and Aged Care, 1999). Residents living in a low care facility are encouraged to “lead independent lives within the facilities’ supportive environment [where they] regard their room as their home and may furnish them with their belongings” (ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care, 1999:17). Clients living in these facilities would have been initially assessed as having a Resident Classification Scale of 5 to 7, but rather than transferring a resident to a facility providing high level care, some low level nursing homes do cater for clients as their level of dependency increases (Koodiaroff, S. Nurse Educator specialising in the care of older people, ACT Community Care. 1999, pers comm, 19 October). There are 15 low care facilities in Canberra and one in Queanbeyan.

High care facilities

As well as the range of services offered by low level care facilities, high care facilities provide for frailer older people who have been assessed as having a Resident Classification Scale of 1 to 4 (Koodiaroff, S. Nurse Educator specialising in the care of older people, ACT Community Care. 1999, pers comm, 19 October). These people often require continuous nursing care delivered by Registered Nurses who staff high care facilities. These facilities usually consist of a mixture of four-bed, two bed and single rooms with shared lounge/dining

area and bathrooms. The ACT has eight high care facilities as well as a 22 bedded Aged Care Unit at The Canberra Hospital. This unit caters for the needs of older people with “complex care needs, who have an acute medical illness [who need] rehabilitation [and] people with confusion who become acutely ill” (ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care:6).

Residential aged care facilities for people from Culturally and Linguistically Diverse Backgrounds

In an effort to cater for the variety of cultures found within the aged Australian population, and to help prevent the isolation felt when an aged person does not have the company of those from the same ethnic background, some aged-care facilities are making special arrangements in the form of culturally appropriate food and activities to support groups of residents from similar “ethnic origins.” There are three residences in Canberra providing care for specific ethnic groups (Croatian, Greek and Italian) (ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care, 1999).

The Community Visitors Program aims to provide support to lonely and isolated residents in facilities who can benefit from contact with a volunteer. This scheme includes residents having contacts with volunteers from their own ethnic background (Commonwealth Department of Health and Aged Care, 1999).

Community aged care

The Commonwealth Aged Care Act , 1997 recognised a need for older people to stay in their homes as long as possible. Recently, the Commonwealth Government announced a new \$280 million package to “strengthen community support and recognition for older Australians” (Commonwealth Department of Health and Family Services, 1998a:1). Along with State/Territory Governments, the Commonwealth Government funds and administers community aged care. Some State, Territory or Local Governments do, however, directly provide some services (Commonwealth Department of Health and Aged Care, 1999). Community aged care may be provided in a variety of ways. Some are outlined below.

Community Aged Care Packages

CACPs were designed for older people who can be looked after in their own homes but whose dependency qualifies them for entry into at least low level care. CACPs allow an older person or their carer to deal only with one service provider who arranges all their care. CACPs include services such as simple home maintenance, supervision (but not administration) of medicines, simple wound management, assistance with hygiene, provision of meals (through services such as Meals on Wheels) and transport to medical appointments. Hours of contact with a carer increase as the level of dependence increases (Stein et al:1999).

CACPs are funded by the Commonwealth Government. The maximum fee for pensioners is around \$1600 a year for services which cost the Commonwealth Government around \$11 000 to provide (Commonwealth Department of Health and Aged Care, 1999). CACPs were designed specifically for older people who can be looked after in their own homes but whose dependency qualifies them for entry into at least low level care. Care may be provided from up to 3 days a week to daily. The number of contact hours depends on client needs. Rather than a client having to deal with several service providers, CACPs simplify matters since they allow an older person or their carer to deal only with one service provider who arranges all their care (Koodiaroff, S. Nurse Educator specialising in the care of older people, ACT Community Care. 1999, pers comm, 19 October).

The initiation of CACPs has enabled some older people to stay in their homes rather than being placed in an aged care facility. Five hundred new CACPs were provided in the last financial year (Commonwealth Department of Health and Family Services, 1998a). CACPs include services such as simple home maintenance, supervision (but not administration) of medicines, simple wound management, assistance with hygiene, provision of meals (through services such as Meals on Wheels) and transport to medical appointments. Hours of contact with a carer increase as the level of dependence increases (Stein et al:1999).

Experience with provision of Indigenous aged care in NSW has led to a revision of the generally used model of 10 CACP places per 1000 older Indigenous people. Since this generates enough money to employ a full time co-ordinator, service providers in NSW now operate on a model of 30 CACPs for mainstream services and 60 low level care facilities **or** CACPs per 1000 older Indigenous people (Swain, R. Indigenous Development Officer, Commonwealth Department of Health and Aged Care. 1999, pers comm, 18 October).

Extended Aged Care at Home Packages

There is a pilot program in operation to test the feasibility and cost-effectiveness of providing high level care to people in their own homes through the provision of EACH Packages. These Packages are suitable for frailer older people who wish to stay in their own home (Koodiaroff, S. Nurse Educator specialising in the care of older people, ACT Community Care. 1999, pers comm, 19 October). The pilot has expanded to 10 services, including services in the ACT (Commonwealth Department of Health and Aged Care, 1999). In addition to services provided in CACPs, EACH packages provide for **administration** of medicines, complex wound management, nursing and medical care and legal documentation (Stein et al:1999). Five service providers deliver community packages in the ACT.

Home and Community Care

In response to reports of inappropriate admissions to nursing homes because of a lack of home care services, the HACC program was introduced in the 1980s (Mannix, 1999). The Commonwealth Government provides 60 per cent of the funding and, sometimes with financial contributions from Local Governments, State Governments provide the remaining 40 per cent of funding to community agencies which provide services to enable older people to stay at home. Services provided by HACC include community nursing, as well as some other health services, personal care, Meals on Wheels, help with shopping, home help (such as cooking, cleaning, washing, ironing or banking) home modification and maintenance, transport and community based respite care (Commonwealth Department of Health and Family Services, 1998b).

In order to qualify for HACC it is necessary for a potential recipient to demonstrate some form of disability, including, but not exclusively, being a frail older person. HACC may be provided on a temporary or occasional basis and HACC services may be a broker for other one-off services, such as garden maintenance (Koodiaroff, S. Nurse Educator specialising in the care of older people, ACT Community Care. 1999, pers comm, 19 October).

Respite Care

This service provides respite care options for carers of an older person. This can be provided in the carer's home, a Residential Aged Care Facility or a Day Care Centre (ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care). Respite care is available at three of the ACT's high care facilities and at all of the low care facilities. This care can be provided for up to 63 days each financial year.

Community Options

Community Options is an ACT-based service which provides co-ordinated assistance for people with complex special needs, including the frail aged and people with dementia. This organisation also provides assistance to carers. Community Options particularly caters for people from non-English speaking cultures (Council on the Ageing [ACT], 1998).

Safe at Home Initiative

The Safe at Home Initiative includes funding of easy to operate communication aids, such as personal safety, personal medical alert and care management systems (Commonwealth Department of Health and Aged Care, 1999).

Community Liaison Advisory Safety Project

The Community Liaison Advisory Safety Project aims to identify problems and help older people reduce risks in and around the home. Officers from the Australian Federal Police, the Fire Brigade and the Ambulance Service will visit an aged person's home and give advice in crime prevention, improved security, fire safety and personal safety.

Day Therapy Centres

Day Therapy Centres offer a range of services such as physiotherapy, occupational therapy and podiatry. Most charge a small fee, and most are located at residential care facilities (Commonwealth Department of Health and Aged Care, 1999).

Assistance with Care and Housing for the Aged

The aim of the recently initiated Assistance with Care and Housing for the Aged (ACHA) is to connect housing and community care for frail older people whose circumstances (such as low income, insecure housing or homelessness) put them at risk of being placed prematurely in residential aged care facilities. The Commonwealth Government funds organisations to provide paid workers and/or volunteers to link clients to appropriate mainstream housing

and/or care service. These services are mostly located in inner city areas where there may be frail elderly people living in insecure accommodation (Commonwealth Department of Health and Aged Care, 1999).

In the ACT, ACHA workers operate from Northside, Southside and Woden Community Services (ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care, 1999).

Multi Purpose Services

Multi Purpose Services (MPS) are funded jointly by the Commonwealth and State/Territory Governments. to provide “more flexible, co-ordinated and cost-effective” health and aged care services to people living in rural and remote regions (Tripp, 1997:13). They are targeted for communities of less than 5000 people (Jackson, M. Director of Planning and Access, Commonwealth Department of Health and Aged Care. 1999, pers comm, 21 September). The ACT does not fit into the criteria for funding.

Carers

Carers who are looking after older people “in need of constant personal care or supervision [and who are] at home for six months or more” may be eligible for a *Carers Payment*. If the older person has been assessed as needing high level care, carers may be eligible for a *Domiciliary Nursing Care Benefit* (Commonwealth Department of Health and Family Services 1998b:15-16). The Carers Association of the ACT “offers guidance, counselling, information and support to caregivers.” Information is provided in the form of a Carer Support Kit. A kit is designed specifically for Indigenous carers (ACT Office of the Commonwealth Department of Health and Aged Care and ACT Health and Community Care, 1999:12).

Services for aged Indigenous peoples

The Commonwealth Department of Health and Aged Care has stipulated that health strategies for Indigenous peoples are a priority and thus aims to improve their access to culturally appropriate and high quality health (Commonwealth Department of Health and Aged Care, 1999). In accordance with this philosophy, some aged care places are earmarked for Indigenous peoples and some strategies have been implemented specifically for Indigenous peoples (Commonwealth Department of Health and Aged Care, 1999). An example of this is

a Dementia Training Package for Indigenous Communities (Commonwealth Department of Health and Aged Care, 1999).

Mainstream aged care services for Indigenous peoples

Mainstream aged care services for Indigenous peoples are funded under the *Aged Care Act, 1997*. There are 29 mainstream aged care services for Indigenous peoples in Australia (Ragless, K. ACT Office of the Commonwealth Department of Health and Aged Care. 1999. pers comm, 12 October). None are in the ACT.

Flexibly funded Indigenous aged care services

Flexibly funded Aboriginal aged care services are financed under the Aboriginal Aged Care Strategy. Since 1994, ten million dollars a year has been allocated by the Commonwealth government to the Aboriginal Aged Care Strategy. Currently, there is funding for 25 services and the funding is almost fully committed. There is no provision for capital funding (ie building costs) under this Strategy (Jackson, M. Director of Planning and Access, Commonwealth Department of Health and Aged Care. 1999. pers comm, 21 September). Aged care services under the Aboriginal Aged Care Strategy do not fall under the Aged Care Act of 1997. Rather than using the Resident Classification Scale, flexibly funded services use an average subsidy for each care place. Though there are flexible services in some urban areas, funding is aimed mainly at remote and rural communities (Ragless, K. ACT Office of the Commonwealth Department of Health and Aged Care. 1999. pers comm, 12 October).

There are no flexibly funded services in the ACT and since the Aboriginal Aged Care Strategy is largely directed to Indigenous people living in remote and rural areas, it is unlikely that ACT applications for funding from the Aboriginal Aged Care Strategy would be successful.

Aboriginal Hostels Limited

Aboriginal Hostels Limited (AHL) was founded in 1972 when it was wholly owned by the Commonwealth Government. AHL is still being funded through the Commonwealth Government via ATSIC. Some funding is also obtained from a variety of other sources and the maintenance of existing Hostels, as well as the building of new ones, must come through this funding. AHL provides low-cost temporary accommodation to Indigenous peoples through a national network of 135 hostels. Additionally, AHL supports government programs

in a variety of areas, including aged care (Aboriginal Hostels Limited, 1997-98). There are no Aboriginal Hostels in the ACT.

“Clustering”

According to discussions held with Matthew Jackson (Director of Planning and Access, Commonwealth Department of Health and Aged Care), it has recently been proposed that Indigenous and non-Indigenous people work with an existing provider of aged care to “cluster” Indigenous people together in the same facility.

Appendix 2: Meetings with service providers

Rose Mumbler Village, Nowra

Along with Agnes Shea and Hilary Crawford, two of our Reference Group members, Phyll Dance made a visit to Rose Mumbler Village at Nowra. This facility is a non-government organisation which was developed specifically for Indigenous people, by Indigenous people. Rose Mumbler opened its doors to its first clients nine years ago when it was set up to provide services appropriate for Indigenous people needing low level care. Inevitably, with the passing of time, many of these clients now require a higher level of care. Rhelma Slabb, the General Manager of Rose Mumbler, was amongst several Indigenous people who, during our preliminary discussions, highlighted the need to consider the potential for a client's increasing disability over time. Rhelma told of the distress experienced when residents could no longer be cared for at Rose Mumbler and had to move to a facility providing high level care. She said: "Be sure you have a second stage for people to move on to as their need for a higher level of care increases." At the ATSIC Regional Council Meeting in Mollymook, which we attended the day after our visit to Rose Mumbler, we were told of an Indigenous aged care facility at Kempsey which does provide for clients needing both low and high level care.

Rose Mumbler Village consists of 21 private units, including two double rooms. Each room has an en-suite. One group room is provided for both recreation and dining purposes. This spacious room has as its focal point a large (safely enclosed) burning fire. One of the most impressive features of Rose Mumbler is the well laid out and expansive garden area, largely planted with native plants. The atmosphere at Rose Mumbler is very informal. For example, the staff do not wear uniforms and residents are allowed to smoke on the premises. Whilst alcohol use is not permitted, there is a vehicle which takes clients for outings, including outings to local "pubs."

In addition to Commonwealth funding, and the tariff paid by residents, there is some funding from Aboriginal Hostels. This organisation provides \$17.50 a week for each Indigenous person's food. (Aboriginal Hostel Owned Hostels do provide more resident-funding than this.) The General Manager lives on the premises and both Indigenous and non-Indigenous people staff the facility. These staff are mostly Personal Care Workers, but there are also Assistant Nurses and Enrolled Nurses on staff. Male staff provide personal care for male clients and female staff provide personal care for female clients. A Registered Nurse visits once a week to perform more complex nursing care and a physician, who is always on call,

visits Rose Mumbler fortnightly. We were told of the need for other service providers, such as podiatrists and dentists, to attend Rose Mumbler and Rhelma Slabb also brought an important point to our attention when she told us of the need for clients to see counsellors: “There are counsellors for everything else, the elderly need counsellors too, to cope with the problems of being elderly.”

Rhelma Slabb also advised us that “Anything under a twenty bed nursing home won’t be viable. You need to have people there to make it pay.” Currently, there are only eight Indigenous people at Rose Mumbler (the remaining places are filled by non-Indigenous people). We were told that other nursing homes may charge residents 85.7 per cent of their pension, but Rose Mumbler only charges a tariff of 65 per cent.

Whilst there are many important lessons to be learned from the visit to Rose Mumbler Village, we have been informed that capital funding (for a purpose built facility) is very competitive (Jackson, M Director of Planning and Access, Commonwealth Department of Health and Aged Care. 1999, pers comm, 21 September). We should not, therefore, be building up unrealistic hopes in the people we interview of obtaining funding for such a facility in the ACT.

Low care facilities

Two of the 15 low care facilities in Canberra (The Goodwin Retirement Village in Farrer and George Forbes House in Queanbeyan) were visited by Ros Brown and Phyll Dance. Each of these residences provides clients with their own rooms with en-suite, and each has a large communal dining and recreation area.

Goodwin Aged Care Services

During the visit to the Goodwin Retirement Village, Ros Brown and Phyll Dance met with Suzanne Grey, who co-ordinates the Goodwin Outreach Program. This Program has placements for 86 clients and at the time of our visit there were 80 people on the waiting list. Two CACPs are allocated for either Indigenous people, or for people from a Non-English Speaking Background. If clients from either of these backgrounds access the service, then carers from their own cultural background can be allocated to them. Training for carers consists of a mandatory First Aid Certificate, orientation with other carers and on-going education on relevant topics.

Nugun(n)awal Community Care, Yass

Nugun(n)awal Community Care is a Community Options Project and operates as a brokering service for Indigenous people within HACC Guidelines. Yass, Queanbeyan, Bungendore and Braidwood are covered by this service. The staff are all Indigenous. In addition to the administrator, the service also employs a Service Co-ordinator and a Care Co-ordinator / Case Manager. The services brokered for are available to disabled and aged Indigenous people in need of help in the house or garden or who need assistance with “everyday tasks, personal hygiene, household duties, shopping, banking and getting to medical appointments” (Ngun(n)awal Community Care Pamphlet, 2000). For this service, aged is considered to be 45 and over.

According to Eric Bell, the Administrator of Nugun(n)awal Community Care, the Age and Disability Department in NSW funds this service which was set up 12 months ago. This service sends out a Case Manager to assess people who are commonly referred via Hospital services. One Case Manager provides services for all areas. Following assessment, Nugun(n)awal Community Care then contacts mainstream service providers to supply the care. They do not employ anyone directly to deliver care, but they buy services from mainstream service providers, such as HACC, to provide services. They will also facilitate contact with domiciliary nurses. Eric Bell said “We try and get Home Care Service to employ Aboriginal people but we can’t hire anyone ... when we started, Queanbeyan did not have many Aboriginal workers and not many Aboriginal clients. We suggested Aboriginal workers and that increased Aboriginal clients.”

The Yass Nugun(n)awal Community Care works mainly with HACC and Community Health. With regard to payment for services Eric Bell said: “We’d like to say there’s a minimum fee, but often [clients] don’t have the money. If they need home and yard care, it’s not means tested. The Case Manager has to assess everyone.”

Goulburn Community Care Centre

Dudley Duncan is the Senior Aboriginal Health Education Officer at Goulburn Community Care Centre. According to Dudley he is employed by the Southern Area Health Service. Goulburn, Queanbeyan, Yass, Young and Cooma are covered by this service.

Tumut Community Care

Coral Bulger is the Senior Aboriginal Health Education Officer at Tumut Community Care. Coral said she is employed by the Greater Murray Area Health Service. Coral works at the Tumut Community Care Centre and the area she provides health care service to are Tumbarumba Shire, Tumut Shire and Gundagai Shire.

Appendix 3: The questionnaire

Date:

Time started:

Time finished:

Length of interview:

Venue:

Interviewers: (signature)

..... (signature)

Name/s of respondent/s: Potential client

..... Carer

If carer interviewed:

Relationship to potential client:

Address:

If this is not usual address, also record usual address:

Phone number/s

Before the interview begins, we would like to remind you that you do not have to answer any questions that you do not want to answer. As we said, some of these questions might be of a personal nature but we would also like to let you know that Phyll is a Registered Nurse. If at any time, you would prefer that only one of us was here whilst you answer any questions, please tell us and the other one of us will leave the room. If you would like someone else here while we do the interview, that's fine too. If at any time, you don't understand a question, please say so and we'll try to put it a better way so that you have a clearer understanding.

1. Gender:

1. Male
2. Female

2. Respondent:

1. Potential client
2. Carer
3. Client and carer
4. Service provider

If carer or service provider, rather than potential client is being interviewed, frame questions appropriately, eg use of third person

If you don't mind, we'll start with some general questions about the food you eat.

3. Do you eat something every day?

1. Yes
2. No

4. What do you usually eat?

5. Do you need help, or do you think you may need help in the future, with:

Kinds of help	<u><i>Family, friends</i></u> If getting help now, relationship, period	<u><i>Family, friends</i></u> If getting help, is this help enough?	<u>Family, friends</u> Freq¹	<u>Services</u> If getting help now from services: name services, how services heard of, do they have to pay, if so how much, likes/dislikes	<u>Services</u> If getting help, is this help enough?	<u><i>Services</i></u> Freq¹	Where appropriate, is there anyone who could help if help was needed (specify, friends, relatives, knowledge of aged care, community care etc)?
House (<i>specify, type, now future</i>)							
Yard (<i>specify, type, now, future</i>)							

¹ = Frequency: 1=always, 2= sometimes, 3=no help, but needed, 4= Not needed, 5= May need help in future.

Kinds of help	<u><i>Family, friends</i></u> If getting help now, relationship, period	<u><i>Family, friends</i></u> If getting help, is this help enough?	<u>Family, friends</u> Freq ¹	<u>Services</u> If getting help now from services: name services, how services heard of, do they have to pay, if so how much, likes/dislikes	<u>Services</u> If getting help, is this help enough?	<u>Services</u> Freq ¹	Where appropriate, is there anyone who could help if help was needed (specify, friends, relatives, knowledge of aged care, community care etc)?
Health problems (<i>specify, type, now, future</i>)							
Shopping (<i>specify, type, now, future</i>)							

¹ = Frequency: 1=always, 2= sometimes, 3=no help, but needed, 4= Not needed, 5= May need help in future.

Kinds of help	<u><i>Family, friends</i></u> If getting help now, relationship, period	<u><i>Family, friends</i></u> If getting help, is this help enough?	<u>Family, friends</u> Freq¹	<u>Services</u> If getting help now from services: name services, how services heard of, do they have to pay, if so how much, likes/dislikes	<u>Services</u> If getting help, is this help enough?	<u><i>Services</i></u> Freq¹	Where appropriate, is there anyone who could help if help was needed (specify, friends, relatives, knowledge of aged care, community care etc)?
Cooking (<i>specify, type, now future</i>)							
Pension cheque/money (<i>specify, type, now, future</i>)							

¹ = Frequency: 1=always, 2= sometimes, 3=no help, but needed, 4= Not needed, 5= May need help in future.

Kinds of help	<u><i>Family, friends</i></u> If getting help now, relationship, period	<u><i>Family, friends</i></u> If getting help, is this help enough?	<u>Family, friends</u> Freq¹	<u>Services</u> If getting help now from services: name services, how services heard of, do they have to pay, if so how much, likes/dislikes	<u>Services</u> If getting help, is this help enough?	<u><i>Services</i></u> Freq¹	Where appropriate, is there anyone who could help if help was needed (specify, friends, relatives, knowledge of aged care, community care etc)?
Transport (<i>specify, type, now future</i>)							
Other (<i>specify, type, now, future</i>)							

¹ = Frequency: 1=always, 2= sometimes, 3=no help, but needed, 4= Not needed, 5= May need help in future.

6. Would you mind if we wrote down the type of housing you are living in?

1. Separate house
2. Semi-detached row or terrace
3. Flat, unit or apartment
4. Other (*specify*)
5. Does not want documented

7. Have you got:

Hot water 1. Yes
 2. No

Cold water 1. Yes
 2. No

Garbage removal 1. Yes
 2. No

Electricity 1. Yes
 2. No

Phone 1. Yes
 2. No

8. Are you satisfied with the housing you have at the moment (*if not, prompts, what would respondent like, eg larger house, smaller house, Indigenous-specific housing, now, future, is there difficulty with stairs, bathroom, toilet, could assistance in the house, such as CACPs or HACC assistance, make it a more suitable place to live*)?

9. To help us decide the type of care you might need, could we now ask you these questions and we'll include the answers later on this assessment scale (*show instrument, if respondent agrees, fill in RCS at end of interview and document level of care below*)?

RCS LEVEL

10. Are you able to get about without someone assisting you?

1. Yes
2. No (*specify*)

11. Do you find that sometimes you don't quite make it to the toilet on time?

1. Yes (*specify*)
2. No

Where appropriate:

12. Does the person you care for sometimes go wandering?

1. Yes (*specify*)
2. No
3. NA

Where appropriate:

13. Does the person you care for sometimes get aggressive towards you or anyone else?

1. Yes (*specify*)
2. No
3. NA

14. Do you need any help at night, such as someone helping you go to the toilet?

1. Yes (*specify*)
2. No

15. How many times have you consulted the following for **your own health** in the **last 12 months**?

	None	1 or 2	3 -5	>5
Family doctor or another general practitioner	0	1	2	3
Hospital doctor (<i>eg as an outpatient or in casualty if yes, specify reason/s</i>)	0	1	2	3
Hospital doctor, <i>as an inpatient (if yes, specify reason/s, length of time)</i>	0	1	2	3
Specialist doctor	0	1	2	3
Allied health professional (eg optician, dentist, physiotherapist, podiatrist, dietician, counsellor, etc)	0	1	2	3
“Alternative” health practitioner (eg chiropractor, naturopath, acupuncturist, herbalist etc (<i>specify</i>))	0	1	2	3
Other (<i>specify</i>)	0	1	2	3

16. Are you currently using any medications (*if yes, fill in as below, may need to ask respondent to show us what medications they are using and to also provide them with any feedback they request*)?

Medication name	How long have you used this medication			Was it prescribed by a health practitioner			
	≤ 6 months	> 6 months	NA	Yes	No	P & ¹ Non-P	NA
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4

¹ Equals both prescribed and non-prescribed.

Document any comments on prescribed drug use, eg whether drugs have been taken as prescribed.

17. Would you mind telling us about any other drugs you are using?

Drug name	How long have you used this drug			Freq	Route	Comments
	≤ 6 months	> 6 months	NA			
Alcohol	1	2	3			
Tobacco	1	2	3			
Marijuana	1	2	3			
Over the counter(<i>specify</i>)	1	2	3			
	1	2	3			
	1	2	3			
	1	2	3			
	1	2	3			
Other (<i>specify</i>)	1	2	3			
	1	2	3			
	1	2	3			
	1	2	3			
	1	2	3			

If respondent is in need of any care:

18. If you were to need any care now, or in the future, which of the following sorts of care would appeal to you most (*firstly, rank Community or Residential care in order of preference, then, what types of care respondent would prefer in each category, ask why they would prefer this type of care*)?

COMMUNITY CARE:

HACC

CACPs/EACH with Aboriginal organisation

CACPs/EACH with a non-Aboriginal organisation and Indigenous workers

Other

AGED RESIDENTIAL CARE:

Aboriginal aged care residence

Residential services for both Aboriginal and non-Aboriginal people where there is some sort of special care provided for Aboriginal people

Other

Would you find an information booklet about services for older Indigenous people useful?

Would you find a video about services for older Indigenous people useful?

Where appropriate:

19. Do you have a preference for the gender of a carer for general care?

1. Male
2. Female
3. Don't mind
4. NA
5. No disclosure

20. Do you have a preference for the gender of a carer for personal care?

1. Male
2. Female
3. Don't mind
4. NA
5. No disclosure

21. Do you have a preference for the age of a carer?

1. Yes (specify)
2. No

22. Do you have a preference for the cultural background of a carer?

1. Yes (specify)
2. No

Now, if you don't mind, we'll move on to some more general questions about you.

23. Could you please tell us which of these age brackets you fit into?

1. 45-49
2. 50-54
3. 55-59
4. 60-64
5. 65-69
6. 70-74
7. 75+
8. No disclosure

24. Are you

1. Single
2. Married/*De facto*
3. Separated/Divorced
4. Widowed
5. No disclosure

25. Is anyone, financially or, in any other way, dependent on you (*where appropriate, prompts, number of people dependent, their relationship, amount of money involved, type of dependency*)?

26. Who else lives here with you?

Living situation	Y/N/NA ¹	Length of time	Number	All the time/ Visiting ²	Comments
<u>Alone</u>					
<u>Relatives</u>					
• Partner					
• Child/ren					
•					
• Other (<i>specify</i>)					
<u>Non-family</u>					
• Friend/s					
•					
• Other (<i>specify</i>)					
<i>Total</i>	-	-		-	-

¹ Throughout: 1 = Yes, 2 = No, and, unless otherwise specified, 3 = NA.

² All the time = 1, sometimes = 2.

27. How many different places, apart from holiday places, have you lived in during the past 12 months?

1. Only current home
2. 1 other place
3. 2-5 other places
4. 6-10 other places
5. > 10 other places
6. No disclosure

28. Do you practice any religion?

1. Traditional
2. Catholic
3. Anglican
4. Uniting Church
5. Presbyterian
6. Baptist
7. No religion
8. Other (*specify*)
9. No disclosure

29. Could you tell us which community you belong to?

1. Ngun(n)awal
2. Other (*specify*)

30. At what age did you leave school?

1. No schooling
2. < 15
3. 15
4. 16
5. 17
6. 18
7. ≥19
8. No disclosure

31. Have you done any courses or training programs since you left school?

1. Yes
2. No
3. No disclosure

If yes:

32. Could you give us a few more details please?

Type	Y/N/NA	Codes ¹
Trade certificate		
Professional certificate		
Undergraduate diploma		
Undergraduate degree		
Postgraduate diploma		
Postgraduate degree		
Other (<i>specify</i>)		

¹ None = 1, uncompleted =2, deferred = 3 current = 4, completed 5, no disclosure = 6.

33. Could you please tell us your current employment status?

Employment status	Y/N/ND ¹	Time	If working/pension, type
<u>Not employed:</u>			NA
• Unemployed			
• Home duties			NA
• Pensioner			
• Volunteer			
• Other (<i>specify</i>)			
<u>Employed</u>			
• Employed part time paid			
• Employed full time paid			
• Employed casually			
• Other (<i>specify</i>)			

¹ No disclosure = 3.

34. About how much money do you obtain from (*as above*) a week (*if necessary, show card with range of amounts*)?

Source	Amount
<u>Employment</u>	
<u>Unemployment</u>	
• Unemployment benefits	
• Pension	
<u>Other</u> (<i>specify, including any household income</i>)	
<i>Total</i>	

35. Do you have any children, your own children, grandchildren, or other family members you've reared?

..... (Number)

If yes

36. What is the age range of these children?

..... *youngest* - *eldest*

RECOMMENDATIONS FOLLOWING NEEDS ANALYSIS. DISCUSS WITH RESPONDENT WITH, IF NECESSARY, REFERENCE TO “CARE OPTIONS FOR OLDER PERSONS IN THE ACT AND QUEANBEYAN.” DOCUMENT BELOW.

REITERATE THAT INTERVIEW DOES NOT MEAN PROVISION OF SERVICES BUT ASK RESPONDENT HOW THEY WOULD FEEL ABOUT US GIVING THEIR DETAILS TO ACT OFFICE OF COMMONWEALTH DEPARTMENT OF HEALTH AND AGED CARE. DOCUMENT BELOW. NB, IF CLIENT WISHES INTERVIEWERS TO GIVE THEIR NAME, CONSENT FORM MUST BE SIGNED.

NB, IF CLIENT WISHES INTERVIEWERS TO GIVE THEIR NAMES TO OTHER AGENCIES, DOCUMENT BELOW, CONSENT FORM MUST BE SIGNED.

We're now coming to the end of the interview but we would like to ask you some questions about any older Indigenous people you know of who might need any health or community services over the next 5 years. We would be interested in talking to other people in the ACT, or Queanbeyan or in the NSW Region. We would also like to know if there's anyone who might move to the ACT if there were appropriate services for Indigenous people.

37. Do you have any friends or relatives aged 45 or over living **outside** of the ACT or Queanbeyan?

If yes:

38. Which town/s do they live in?

39. If there were appropriate health or community services for Indigenous people in the ACT, do you think they might move here for services?

40. Is there any other older Indigenous person you know who might be in need of health or community care and who might be willing to be interviewed?

Yes *n flyers given*

No

41. Has anyone else interviewed you about your health in the past 12 months (*if so, specify who, when*)?

42. Would you mind telling us how you heard about this survey?

Finally, while we are here, we would like to ask you if there is anyone living in the ACT or Region that you are concerned about who is using illegal drugs. We do not need the name of this person it is just that we need more of an understanding of the drug problem in the Indigenous community so that we can advise the Government about funding projects.

Are any of the children you've reared, or any other family members using drugs (*specify what drugs are being used, number of people using*)?

Could you give an estimate of how many young Indigenous people in Canberra and Region use illegal drugs (*ask respondent to specify what drugs*)?

*Are there any questions you'd like to ask, comments you'd like to make, anything you think we should have asked and haven't (**document below**)?*

INTERVIEW FEE AND RECEIPT

THANK YOU VERY MUCH

Appendix 4: The Resident Classification Scale

The weightings that apply to each question on the Resident Classification Scale are:

Question	Response Weighting			
	A	B	C	D
1. Communication	0.00	0.28	0.36	0.83
2. Mobility	0.00	1.19	1.54	1.82
3. Meals and Drinks	0.00	0.67	0.75	2.65
4. Personal Hygiene	0.00	5.34	14.17	14.61
5. Toileting	0.00	5.98	10.65	13.70
6. Bladder Management	0.00	2.22	3.82	4.19
7. Bowel Movement	0.00	3.32	5.72	6.30
8. Understanding and Undertaking Living Activities	0.00	0.79	1.11	3.40
9. Problem Wandering or Intrusive Behaviour	0.00	0.80	1.58	4.00
10. Verbally Disruptive or Noise	0.00	1.19	1.75	4.60
11. Physically Aggressive	0.00	2.34	2.69	3.05
12. Emotional Dependence	0.00	0.28	1.50	3.84
13. Danger to Self or Others	0.00	1.11	1.54	1.98
14. Other Behaviour	0.00	0.91	1082	2.61
15. Social and Human Needs - Resident	0.00	0.95	1.98	3.01
16. Social and Human Needs – Families and Friends	0.00	0.28	0.55	0.91
17. Medication	0.00	0.79	8.55	11.40
18. Technical & Complex Nursing Procedures	0.00	1.54	5.54	11.16
19. Therapy	0.00	3.64	6.10	7.01
20. Other Services	0.00	0.71	1.46	2.93

The range of points for each category is:

Greater than 81.01 points	Classification Level 1
69.61 to 81.00 points	Classification Level 2
56.01 to 69.60 points	Classification Level 3
50.01 to 56.00 points	Classification Level 4
39.81 to 50.00 points	Classification Level 5
28.91 to 39.80 points	Classification Level 6
10.61 to 28.90 points	Classification Level 7
0 to 10.60 points	Classification Level 8

(Aged and Community Care Division, Commonwealth Department of Health and Family Services, 1997:5-6).

Appendix 5: The flyer

**ARE YOU A KOORI AGED 45 OR MORE?
DO YOU KNOW SOMEONE WHO IS 45 OR OLDER WHO NEEDS HEALTH OR
COMMUNITY SERVICES?**

**ARE YOU TAKING CARE OF A RELATIVE WHO IS
45 OR OLDER?**

**DO YOU HAVE RELATIVES 45 OR OLDER LIVING
OUTSIDE OF THE ACT AND WANT THEM
TO COME TO LIVE IN THE ACT?**

**IF SO WOULD YOU BE WILLING TO BE INTERVIEWED BY AN
INDIGENOUS RESEARCHER AND A NON-INDIGENOUS RESEARCHER
FROM THE AUSTRALIAN NATIONAL UNIVERSITY?**

THEN PLEASE RING ANY OF THE NUMBERS BELOW

(REVERSE CHARGES WILL BE ACCEPTED)

\$20.00 interview fee will be paid

Ros Brown and Phyll Dance at work 62492145

Phyll Dance mobile: 0414 976278

PTO-for full details=

Researchers from the National Centre for Epidemiology and Population Health at the Australian National University have been funded by the ACT Office of the Commonwealth Department of Health and Aged Care to conduct a health and community needs analysis of older indigenous people in the ACT and Region. We would like to interview:

- ❖ Indigenous people aged 45 or more who are in need of health or community services;
- ❖ Carers of Indigenous people aged 45 or more who are in need of health or community services;
- ❖ Indigenous people who would, if there were appropriate services, bring relatives aged 45 or more in need of health or community services to live in the ACT.

Whilst the information we obtain will help the ACT Office of the Commonwealth Department of Health and Aged Care to provide services for older Indigenous people, the researchers can not ensure the provision of services to people they interview.

The interviews will last one to two hours and we will be asking questions about health status, current use of health and community services and a need for health or community services. All information will be completely confidential.

Interviews will be conducted by an Indigenous researcher Ros Brown, and a non-Indigenous researcher Phyll Dance. We will be conducting interviews over the next few months. If you would like to be interviewed please contact us on any of the following numbers (you may, if you wish, reverse charges):

Ros Brown and Phyll Dance at work 62492145
Phyll Dance mobile: 0414 976278

Appendix 6: Consent for interview form

I understand that this interview is being conducted by Ros Brown and Phyll Dance from the National Centre for Epidemiology and Population Health into a needs analysis of older Indigenous people. I have been informed that Gabriele Bammer and Bev Sibthorpe are also on the research team. I am aware that the research has been funded by the ACT Office of the Commonwealth Department of Health and Aged Care. I understand that the research is being guided by a Reference Group consisting of five Indigenous people: Mrs Hilary Crawford; Ms Flo Grant; Mr Bill Humes; Ms Audrey Kinnear; Mrs Agnes Shea, and representatives from The ACT Office of the Commonwealth Department of Health and the ACT Department of Health and Community Care.

I have been told that I will be asked questions about health status, use of health and community services, and my need for health or community services. I have been informed that some of these questions might be of a sensitive nature and that I can refuse to answer any questions or reply to them as briefly or fully as I choose.

I have been told that although the information I give will help the ACT Office of the Commonwealth Department of Health and Aged Care provide services for older Indigenous people, the researchers can not ensure the provision of services to me.

I realise that the interview will take one to two hours to complete and that I can take a break or stop the interview at any time. I know that I can ask any questions related to the interview now, or at any time during the interview, and that as long as they do not involve breach of another person's confidentiality, they will be answered. I am satisfied that no information about me will be given to anyone else unless I decide that I am in need of any assistance and would like my name to be given to service providers. If so I will provide my written consent on a separate form.

The results of the study will be published in a report. The report will be written in such a way that individuals can not be identified.

I agree to be interviewed

Signature

Appendix 7: Consent for referral to other services form

I am willing for details of my needs to be forwarded to (specify appropriate department/s):

Signature



THE AUSTRALIAN
NATIONAL UNIVERSITY