The Parliament of the Commonwealth of Australia

House of Representatives
Standing Committee on Community Affairs

HOME BUT NOT ALONE

A Report on the Home and Community Care Program

July 1994

Australian Government Publishing Service
Canberra

ISBN 0644 35157 8

Produced by the Australian Government Publishing Service

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37th Parliament

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TERMS OF REFERENCE

The House of Representatives Standing Committee on Community Affairs is to inquire into and report to the Parliament on:

- The provision of services funded under the Home and Community (HACC) Act (1985) including their costs and their relative efficiency;

- access by the Program's target population to services funded under HACC including the appropriateness of these services, their availability and effectiveness in meeting the Program's objectives;

- gaps in existing service provision; and

- the quality of care provided including the implementation of the HACC National Service Standards and associated quality assurance mechanisms.

ABBREVIATIONS

AAA	Alzheimers' Association of Australia
ABS	Australian Bureau of Statistics
ACA	Aged Care Australia
ACAR	Aged Care Assessment Record
ACAT	Aged Care Assessment Team
ACCNS	Australian Council of Community Nursing Services
ACHA	Australian Community Health Association
ACOSS	Australian Council of Social Service
ACROD	Australian Council for Rehabilitation of the Disabled
ADARDA	Alzheimer's Disease and Related Disorders Association
ADL	Activity of Daily Living
AFAO	Australian Federation of AIDS Organisations
AIHW	Australian Institute of Health and Welfare
ALGA	Australian Local Government Association
ANF	Australian Nursing Federation
APSF	Australian Pensioners and Superannuants Federation
CACP	Community Aged Care Package
CADAC	Campbelltown and District Aboriginal Cooperative
CFA	Consumer Forum for the Aged
CHASP	Community Health Accreditation Standards Project
COPs	Community Options Projects
COTA	Council on the Ageing
CPSF	Combined Pensioners' and Superannuants' Federation of NSW
CRC	Commonwealth Respite for Carers
CSDA	Commonwealth State Disability Agreement
CTO	Community Transport Organisation
DCHS TAS	Department of Community and Health Services (Tas)
DFCS SA	Department for Family and Community Services (SA)
DHCS VIC	Department of Health and Community Services (Vic)
DHHLGCS	Department of Health Housing Local Government and Community Services
DHSH	Department of Human Services and Health
DOCS	Department of Community Services (NSW)
DRG	Diagnosis Related Group

DVA	Department of Veterans' Affairs
ECCQ	Ethnic Communities Council Queensland
EPAC	Economic Planning and Advisory Council
FECCA	Federation of Ethnic Communities Councils of Australia
GAT	Geriatric Assessment Team
HACC	Home and Community Care
HACCAC	HACC Advisory Committee
HCS	Home Care Service of NSW
HDWA	Health Department of Western Australia
IADL	Instrumental Activity of Daily Living
MAV	Municipal Association of Victoria
MRC	Migrant Resources Centre
MS	Multiple Sclerosis
NAPD	National Action Plan for Dementia
NATC	National Accessible Transport Committee
NCOSS	New South Wales Council of Social Service
NESB	Non-English speaking background
OT	Occupational Therapist
QAC	Queensland AIDS Council
RDNS	Royal District Nursing Service
RSL	Returned Services League of Australia
SPRC	Social Policy Research Centre
WACOSS	Western Australian Council of Social Service
TPU	Tasmanian Pensioners Union

RECOMMENDATIONS

CHAPTER 5 - Focus and Targeting

1. The Committee recommends that the Commonwealth Department of Human Services and Health, in consultation with the States and Territories and the HACC community, amend the HACC Program objective and target group to:

   - increase the focus on the need of individuals of all ages with functional disabilities and their carers for support to maintain their independence and quality of life in the community;

   - ensure that the target group encompasses the range of functional disabilities and removes the distinction between groups on the basis of age; and

   - provide a clear statement of eligibility criteria for the HACC Program. **(para 5.12)**

2. The Committee recommends that the Commonwealth Department of Human Services and Health give a high priority to the completion of work on point of intervention to enable clarification of the Program's rationing policy. It is further recommended that this work include an investigation of the impact of the unavailability or withdrawal of services on individuals with lower level needs and on their carers and families. **(para 5.26)**

3. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with State, Territory and local governments and the community, develop priority of access guidelines which state clearly HACC eligibility criteria and the basis for rationing services, to facilitate a consistent and equitable approach to decisions about access to HACC services. **(para 5.27)**

4. The Committee recommends that the Commonwealth Department of Human Services and Health, in consultation with State and Territory governments, develop a marketing strategy for the HACC Program to encompass:

- general information for consumers and potential consumers;

- dissemination strategies, involving appropriate peak organisations, to ensure that general information reaches members of the target group;

- local level marketing strategies;

- appropriate information strategies for people of non-English speaking background and Aboriginal and Torres Strait Islander people, developed in consultation with relevant organisations;

- targeted campaigns, involving appropriate organisations, to provide information to potential referrers; and

- the use of advertised single telephone numbers for HACC services within a region to assist consumers in locating and contacting HACC services. **(para 5.45)**

5. The Committee recommends that, while continuing to develop services to meet already identified needs, such as respite, education and counselling, the Commonwealth Department of Human Services and Health, in consultation with States, Territories and the community, initiate research into the possible size of the target group of carers, service needs of carers and the extent to which carers are able to access needed services under the HACC Program. **(para 5.51)**

6. The Committee recommends that the Commonwealth Department of Human Services and Health, in consultation with States and Territories:

- promote the role of carers in all HACC Program material;

- ensure that promotional material for HACC services clearly identifies carers as members of the HACC target group; and

- continue to support the role of the Carers Association of Australia and State level organisations in assisting and informing carers.**(para 5.53)**

7. The Committee recommends that the HACC Program ensure that guidelines for assessment and for priority of access specify that the needs of carers are legitimate needs and must be taken into account in those processes. **(para 5.56)**

8. The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with States and Territories and in consultation with carers, review existing approaches to respite care including the CRC Program, identify areas of deficiency and develop a range of flexible respite care options to meet the needs of carers and frail elderly people and younger people with disabilities.**(para 5.61)**

9. The Committee recommends that:

- the HACC Program retain the current multiple target group approach;
- the HACC Program liaise closely with the Disability Services Program, at both Commonwealth and State/Territory levels to minimise gaps and to maximise the extent to which HACC services can provide appropriate services to younger people with disabilities;
- the review of the CSDA take into account the relationship between the CSDA and the HACC Program;
- the Commonwealth and the States and Territories investigate fully as a matter of urgency, the reasons for low levels of access to HACC services by younger people with disabilities and develop approaches to service delivery to address those causes; and
- that all HACC training material and publicity stress the place and relevance of younger people with disabilities within the Program and the necessity for service providers to respond to their needs. **(para 5.72)**

10. The Committee recommends that all States and Territories recognise the right of veterans and war widows to access HACC services without discrimination and advise HACC service providers of this right without delay. **(para 5.76)**

CHAPTER 6 - Access by Special Needs Groups

11. The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with States and Territories and in consultation with appropriate organisations including the ECCs, develop and implement a national policy on access to HACC services for people of NESB. The policy should include:

- Evaluation of the adequacy of existing data collection and analysis of the reasons for the current under-utilisation of HACC services by people from NESB;

- Strategies to improve the involvement of NESB groups and individuals in HACC planning processes including representation on regional, State and national advisory structures;

- Improvement of information strategies for people of NESB including information dissemination, appropriate forms of information and appropriate use of language to ensure that information is accessible taking into account issues such as literacy levels in the original language, particularly among older people of non-English speaking backgrounds;

- A clearinghouse to consolidate and coordinate the significant amounts of research being conducted into the needs of people of NESB and ensure that work with broader applicability is available across States;

- Evaluation of existing approaches to service delivery for people of NESB including methods employed in mainstream services to enable the development of more effective approaches; and

- Ensure that people of NESB have access to culturally appropriate assessment through the Regional Community Assessment Agencies recommended in Chapter 9. **(para 6.14)**

12. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with States and Territories and appropriate Aboriginal groups:

- review its data regarding Aboriginal and Torres Strait Islander access and investigate the extent to which HACC services, both mainstream and specific, are meeting Aboriginal and Torres Strait Islander needs;

- ensure that Aboriginal and Torres Strait Islander people are represented in HACC planning processes including representation on regional, State and national advisory structures;

- review the relationship between HACC and other Aboriginal and Torres Strait Islander agencies and Programs; and

- ensure that Aboriginal and Torres Strait Islander people have access to culturally appropriate assessment through the Regional Community Assessment Agencies recommended in Chapter 9. **(para 6.22)**

13. The Committee recommends that all HACC service provider training include material relating to the special needs of people with dementia and approaches to service delivery which address those needs. **(para 6.30)**

14. The Committee recommends that the HACC Program continue to develop the case management model, using, for example, Community Options Projects and that people with dementia be identified clearly as a special needs group for those services. **(para 6.33)**

15. The Committee recommends that the Commonwealth Department of Human Services and Health ensure that the development of innovative and flexible respite care options as recommended in Chapter 5, pay particular regard to the needs of carers of people with dementia and the development of suitable forms of respite for people with dementia. **(para 6.36)**

16. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with State and Territory governments, pilot a user charging system with the following features:

- a simple sliding scale of fees which takes into account the generally low disposable incomes of HACC consumers with discretion to waive fees where consumers are unable to pay;

- the Regional Community Assessment Agency having responsibility for the assessment of the capacity of each consumer to pay for HACC services and possibly for the collection of fees (fees could be paid to the individual service provider for the convenience of the consumer and forwarded to the assessment agency);

- revenue generated from fees to be distributed within the region in line with regional needs based planning as recommended in Chapter 12; and

- an evaluation strategy for the pilot to be implemented to assess the effectiveness of the model in terms of the impact on consumers, any unintended consequences and the cost of assessment for fees and collection compared with the revenue raised. **(para 6.47)**

17. The Committee recommends that the Commonwealth Department of Human Services and Health work with States and Territories to develop and implement nationally consistent definitions of the terms rural, remote and isolated. **(para 6.52)**

18. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with the States and Territories, investigate the effectiveness of various approaches to service delivery in rural areas and, particularly, in remote and isolated areas and develop a rural and remote areas policy which encourages the funding of flexible approaches to service delivery including multiple service outlets with flexibility in the allocation of funds between service types. The policy must address the particular needs of remote and isolated areas. **(para 6.65)**

19. The Committee recommends that, consistent with recommendations in Chapter 10, case management projects be established in rural, remote and isolated areas to ensure full geographic coverage of these areas. It is further recommended that case management projects funded in remote and isolated areas receive funding which recognises the particular difficulties inherent in providing services in sparsely populated remote and isolated areas. **(para 6.70)**

20. The Committee recommends that guidelines for these projects in rural, remote and isolated areas take account of the particular needs of these areas

and allow greater flexibility in terms of target groups and that staffing levels for the projects recognise the greater demands involved in remote and isolated areas where there are few established services. **(para 6.71)**

21. The Committee recommends that the Commonwealth Department of Human Services and Health in consultation with the States and Territories investigate the additional costs of providing community care services in rural, remote and isolated areas in order to develop funding models for these areas which recognise any additional costs identified. **(para 6.73)**

CHAPTER 7 - Improving Continuity Between Health and Community Care

22. The Committee recommends that:

- post acute, palliative care and rehabilitation in the community be funded from the health budget;

- the Commonwealth Department of Human Services and Health develop mechanisms to cost and fund the post hospital component of treatment for acute episodes and terminal conditions and funding for this component should be included in future Medicare Agreements; and

- the implementation of these arrangements give due regard to the practical aspects of service delivery and the recommendations on this matter made below. **(para 7.40)**

23. The Committee recommends that the Commonwealth Department of Human Services and Health encourage the private hospital and health insurance sectors through their relevant peak organisations to adopt standards in relation to early discharge, day surgery and post acute care and to work closely with the proposed Regional Community Assessment Agencies in developing those standards. **(para 7.42)**

24. The Committee recommends that post acute and palliative care and rehabilitation services currently falling within the no growth areas of HACC be provided in the following way using the Regional Community Assessment

Agency as the point of interface between acute care and post acute care and, *subsequently, HACC long term support where required:*

- all public hospitals liaise with the Regional Community Assessment Agencies through discharge planners or community liaison staff;

- the Regional Community Assessment Agency to have the authority to determine in conjunction with discharge planners the type and level of services to be provided and advise the range of providers from which the hospital may purchase those services;

- in the case of consumers who have been receiving HACC services prior to admission to hospital, the Regional Community Assessment Agency is to have the authority to direct the hospital to purchase services where appropriate from the provider which had previously provided those services; and

- the Regional Community Assessment Agency be responsible for ensuring a smooth transition for the consumer from post acute support to long term support where this is required in line with the role recommended for these agencies in Chapter 9 of this report. **(para 7.50)**

CHAPTER 8 - Linkages With Other Programs

25. The Committee recommends that the Commonwealth Department of Human Services and Health in consultation with States and Territories and local government develop and implement improved linkages between the programs at the planning and service delivery level. **(para 8.10)**

26. The Committee recommends that the Commonwealth Department of Human Services and Health define the boundaries and relationships between HACC and other aged care programs to minimise confusion among service providers and consumers, to eliminate gaps in service provision at the boundaries of the programs. It is also recommended that the Commonwealth Department of Human Services and Health promote consistency in administrative requirements between HACC and residential aged care programs, particularly

where organisations are funded to provide services under more than one program. **(para 8.20)**

27. The Committee recommends that the Commonwealth Department of Human Services and Health examine the current provision of home maintenance and modification services to develop an equitable approach across the Program to ensure that members of the target group have access to these services. **(para 8.29)**

28. The Committee recommends that the Department of Housing and Regional Development, ensure that the needs of people with disabilities and frail elderly people are taken into account in future Commonwealth State Housing Agreements. **(para 8.30)**

29. The Committee recommends that the Commonwealth Department of Human Services and Health give consideration to extending HACC services into the area of supported accommodation where these are not currently funded at Federal or State level. **(para 8.34)**

30. The Committee recommends that the Commonwealth Department of Human Services and Health and State and Territory governments examine the material produced by the NATC in order to improve the provision of community transport under the HACC Program and to facilitate the access of HACC consumers to mainstream transport where appropriate. **(para 8.36)**

31. The Committee recommends that the Commonwealth Department of Human Services and Health liaise with the NATC and State transport departments to improve integration in the manner suggested by the NATC and to ensure that adequate safeguards are in place to ensure the appropriate allocation of HACC funds to community transport in line with needs based planning principles. **(para 8.41)**

32. The Committee recommends that the Commonwealth Department of Human Services and Health and the State and Territory governments establish regional pilots aimed at coordinating underutilised HACC transport assets. The pilots should emphasise a regional network of HACC transport services and their connections with suitable mainstream transport capacity. **(para 8.42)**

33. The Committee recommends that the Commonwealth Department of Human Services and Health and appropriate State and Territory departments monitor developments in mainstream transport and highlight the transport needs of HACC consumers to State transport departments to ensure that HACC community transport services are targeted to those members of the target group who are unable to access mainstream services. **(para 8.46)**

34. The Committee recommends that the Commonwealth Department of Human Services and Health conduct an examination of the extent to which HACC community transport services coordinate with both the private sector and with other HACC transport services, to make best use of existing infrastructure. **(para 8.49)**

35. The Committee recommends that the HACC Program trial transport brokerage models to assess the effectiveness and efficiency of the approach. **(para 8.50)**

CHAPTER 9 - Assessment

36. The Committee recommends that undergraduate medical courses and continuing education courses for GPs incorporate material regarding community care programs. **(para 9.14)**

37. The Committee recommends that the Commonwealth Department of Human Services and Health, in consultation with State, Territory and local governments and related programs in aged residential care and disability services, pilot a common agency approach to assessment for community care, aged residential care, post acute care, palliative care and accommodation related disability services. It is recommended that the pilots cover a number of metropolitan and non-metropolitan regions, are jointly funded by the relevant programs and test the following model:

- Adequately resourced and appropriately staffed Regional Community Assessment Agencies to conduct gatekeeping assessments in line with the eligibility criteria of the relevant programs. The agencies must have flexibility in staffing and location(s) and should consist of a core team of staff with the capacity to contract in specialist staff as required

and to contract organisations to conduct assessments on behalf of the agency in certain circumstances, such as in outlying areas of geographically large rural regions;

- Each Regional Community Assessment Agency to be independent of service providers and governments. The agency would be accountable through normal Program channels with administrative details to be negotiated among the programs concerned prior to commencement of the pilot;

- In relation to general HACC services each agency will be responsible only for the assessment of need against the criteria. As described in Chapter 7, the regional assessment agency would have the authority to determine amounts of service for consumers requiring post acute and palliative care services in conjunction with hospital discharge planners. In the case of residential aged care, the regional assessment agency would have the same powers as existing ACATs which would be replaced. For disability services, the agencies would subsume the powers of any existing assessment mechanisms;

- Individual HACC service providers should retain responsibility for deciding on relative need, in line with priority of access guidelines as recommended in Chapter 5, for developing care plans for individual consumers, for ongoing monitoring of consumers and for reassessment and minor adjustments of service levels. Major changes would be referred to the Regional Community Assessment Agency for re-assessment;

- The Regional Community Assessment Agencies should be responsible for follow-up to ensure that referrals are acted upon and to pursue alternatives when HACC agencies are unable to assist;

- The Regional Community Assessment Agencies should be subject to all HACC quality assurance requirements and to additional requirements regarding response time to ensure that the initiative does not lead to delays in assessment and provision of services and is able to respond to emergencies;

- The Regional Community Assessment Agencies should be staffed with recognition of particular needs within the region, such as ethnic populations and dementia, and have the capacity and resources to bring in experts in special need areas such as interpreters or experts in brain injury;

- An avenue of appeal against an assessment, should be established as part of the complaints mechanisms recommended in Chapter 11;

- The pilot projects should incorporate a data collection model consistent with the data required under the draft HACC Program Outcome Indicators to assist in an assessment of the effectiveness of both the role of assessment data in identifying unmet need and of the draft Indicators as a tool for monitoring Program effectiveness; and

- The pilot projects should be run for 12 months concurrently with the other pilots recommended in this report. **(para 9.44)**

38. The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with States, Territories and local government negotiate consistent regional boundaries for these related service delivery areas and based initially on existing area health boundaries. Within the HACC Program consistent regional boundaries should be applied for all regionally based functions. **(para 9.45)**

39. The Committee recommends that the Commonwealth Department of Human Services and Health and relevant State and Territory governments:

- Adopt the common assessment record, with revisions as necessary, as the basic assessment and referral document for the pilot Regional Community Assessment Agencies and the care planning and service delivery record of HACC services in the pilot regions;

- Continue the implementation of the common assessment record and associated training pending the implementation of the recommendations above and evaluation of the pilots; and

- Retain the principle by which basic assessment information and service provision records are held in the consumer's own home and shared, with the agreement of each consumer, between service providers for ongoing use as a care planning and coordination tool following implementation of Regional Community Assessment Agencies, should the recommended pilots support the model. The use of the common record in this way should be made mandatory for projects subject to the agreement of the consumer. **(para 9.56)**

CHAPTER 10 - Service Delivery and Costs

40. The Committee recommends that the HACC Program retain the current diversity of service provider types. It is further recommended that the Commonwealth and the States monitor the costs and effectiveness of service provision by different types of organisations to ensure efficiency and provide appropriate support for service providers. **(para 10.9)**

41. The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with States and Territories examine the relative efficiency and quality of for-profit providers and traditional HACC providers. This will require implementation of a unit cost framework for HACC as recommended later in this Chapter. **(para 10.25)**

42. The Committee recommends that the Commonwealth Department of Human Services and Health investigate any legislative barriers to the participation of the private sector in the provision of HACC services and work with States, Territories, local government, providers and consumers to develop a coherent policy to enable for-profit providers to seek funding to provide HACC services. This recommendation is conditional upon examination of the relative efficiency of these services and the implementation of recommendations regarding mandatory service standards, external complaints mechanisms and accountability for outcomes and outputs. **(para 10.26)**

43. The Committee recommends that the Commonwealth Department of Human Services and Health monitor the outcomes of service delivery models being trialled in States and Territories and continue to encourage innovation in service delivery. **(para 10.32)**

44. The Committee recommends that the Commonwealth Department of Human Services and Health implement flexible approaches to service funding to remove limitations so that an agency may provide a range of services while maintaining adequate accountability standards with a focus on outcomes and outputs. **(para 10.33)**

45. The Committee recommends that the Commonwealth Department of Human Services and Health and the States and Territories actively encourage collocation of services and sharing of administrative resources as the opportunity arises (for example, when funding new projects or when changes in accommodation are required). **(para 10.34)**

46. The Committee recommends that the HACC Program continue to foster improved coordination of service provision at the local level. Mechanisms to achieve this may include increased support for local forums and identification and promotion of best practice in coordination and cooperation. **(para 10.37)**

47. The Committee recommends that the Commonwealth and the States/Territories expand coverage of case management services to ensure that consumers with complex needs in all areas of Australia have access to case management. It is also recommended that these services continue to be targeted to consumers with complex needs. As recommended in Chapter 6, rural and remote areas should be excepted from the requirement that case management is targeted only to high level need consumers. **(para 10.41)**

48. The Committee recommends that the Commonwealth Department of Human Services and Health investigate the industrial and legal issues associated with the purchase of services by case management projects, particularly where those services are provided by an individual. **(para 10.44)**

49. The Committee recommends that the Program proceed with the implementation of a unit costs framework. Once implemented, it is recommended that the framework be utilised to examine the relative efficiency of a range of service delivery models and to identify factors which cause cost variations. **(para 10.53)**

50. The Committee recommends that the Commonwealth Department of Human Services and Health in consultation with State, Territories and local

government and interested organisations, develop a national policy on the reimbursement of volunteer out of pocket expenses and fund projects which involve volunteer input accordingly. **(para 10.59)**

51. The Committee recommends that the Commonwealth Department of Human Services and Health work with State and Territory governments to develop a policy on the funding of volunteer based services which recognises the need for adequate funding of service coordinators to enable appropriate support to be given to volunteers. **(para 10.63)**

52. The Committee recommends that the Commonwealth Department of Human Services and Health and State and Territory governments work with service providers and volunteer agencies to develop a protocol for the conduct of volunteers, guidelines for the types of tasks which volunteers may appropriately carry out and any legal issues, including insurance coverage and public liability, associated with volunteerism in the HACC Program. **(para 10.66)**

CHAPTER 11 - Quality Assurance

53. The Committee recommends that the Commonwealth Department of Human Services and Health review the extent to which the HACC Statement of Rights and Responsibilities has been distributed to service providers and consumers and the extent to which service providers advise consumers of their rights. It is further recommended that the Commonwealth Department of Human Services and Health negotiate with States and Territories to ensure immediate dissemination of this material, where it has not occurred, and to ensure that service providers are aware of their obligation to inform consumers of their rights and to operate their services in accordance with the rights and responsibilities contained in it. **(para 11.11)**

54. The Committee recommends that the Commonwealth Department of Human Services and Health, in consultation with State and Territory governments, local government, consumers and service providers, ensure that HACC consumers have access to independent regionally based complaints mechanisms by building on existing mechanisms to ensure that they have a mandate to investigate complaints in relation to HACC and by establishing

separate mechanisms where suitable institutions do not exist. The independent mechanisms should have the following features:

- they should be completely independent of HACC service providers;
- they should be accessible and non-threatening to consumers, be informal and be well-publicised;
- there should be no requirement that consumers approach the service prior to accessing the independent regionally based mechanism;
- they should have a conciliation and mediation focus but have authority to direct HACC service providers to respond to complaints and to make changes in service provision where necessary;
- they should have the capacity to respond quickly; and
- they should encourage and facilitate the involvement of an advocate (formal or informal) by the consumer. **(para 11.24)**

55. The Committee recommends that the Commonwealth and the States ensure that all HACC service providers have a formal complaints procedure in place, that it is accessible and understandable to the target group and that all consumers are made aware of it, including those who are refused access to a service. **(para 11.25)**

56. The Committee recommends that the Program implement mandatory outcome standards. This implementation should proceed in a staged manner and build on the work already conducted to implement the Guidelines for the HACC Program National Service Standards. The implementation must include continued development and provision of service provider training and take account of the varied nature of HACC service providers and their capacity to implement the standards. **(para 11.42)**

57. The Committee recommends that sanctions, such as transfer of auspice or defunding, for non-compliance be available as a final option. The preferred way of dealing with failure to meet standards is through negotiation and training. **(para 11.43)**

58. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with States and Territories, service providers and consumers, pilot the CHASP model in other States and Territories with the view to implementing it as the service review model and standards monitoring tool across the Program. **(para 11.48)**

59. The Committee recommends that the aggregated results of service reviews form part of the measurement of the performance of the Program as a whole through the HACC Program Outcome Indicators. **(para 11.49)**

60. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with States and Territories, develop a HACC advocacy policy which includes:

- a clear statement of the role and definitions of advocacy to apply under the Program;
- a policy on funding advocacy services and the scope and functions of these services;
- a statement of the right of the consumer to choose and involve an advocate at any stage of their dealings with HACC services, not just in the context of a complaint or dispute; and
- the distinction between advocacy and other services like information, referral and mediation services. **(para 11.55)**

CHAPTER 12 - Service Availability, Planning and Administration

61. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with the States and Territories, develop a new service type under the HACC Program for the provision of medication review and management services. It is further recommended that the Commonwealth Department of Human Services and Health liaise with the Pharmacy Guild of Australia in developing this service type and fully investigate the legal aspects, relationship with existing HACC services, accreditation and training issues. **(para 12.9)**

62. The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with State and Territory governments, investigate the need for additional service types under the HACC Program. This investigation should make use of the input of the regional, State and national advisory structures recommended later in this Chapter. **(para 12.12)**

63. The Committee recommends that the Commonwealth Department of Human Services and Health ensure that State and Territory needs based planning models incorporate effective local and regional planning mechanisms and opportunities for advisory bodies, to be established in line with recommendations later in this Chapter, to have an effective role in strategic planning and needs based planning. **(para 12.25)**

64. The Committee recommends that the Commonwealth Department of Human Services and Health ensure that State and Territory planning models provide for feedback to the community about the contents of State and National Plans and the outcomes of planning processes in which Forums have participated. **(para 12.26)**

65. The Committee recommends that needs based planning models take account of the range of data available including ABS data, local data collections including local government material and data from Regional Community Assessment Agencies. Planning must also take account of existing services which impact on the needs of the target group in each region including those provided under disability programs, other aged care programs, State government health and welfare programs, local government and voluntary projects. **(para 12.27)**

66. The Committee recommends that the Commonwealth Department of Human Services and Health work with State and Territory governments to ensure that effective needs based planning models are in place which include a community development element to assist communities in developing services to meet identified needs or encourages existing large service providers to extend to areas of need. **(para 12.33)**

67. The Committee recommends that the Commonwealth Department of Human Services and Health ensure that HACC data collections are reviewed regularly to confirm their appropriateness and that data is published within one year

of the completion of each collection to ensure its currency and usefulness in the planning framework. It is further recommended that the Commonwealth Department of Human Services and Health continue to work with States, Territories, local government and service providers to ensure the availability of high quality data. **(para 12.37)**

68. The Committee recommends that the Commonwealth Department of Human Services and Health, in conjunction with State and Territory governments, continue the development of community care benchmarks or planning targets which identify an appropriate level of community care services required per head of population. The benchmarks should be based on empirical evidence of the incidence of disability among the population and be capable of being employed at the regional and local levels. **(para 12.41)**

69. The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with State and Territory governments develop a formal role for local government, to be negotiated with the ALGA and the State local government associations, in the HACC planning process. This role should recognise local government as a partner in the planning and delivery of HACC services and acknowledge the significant financial and in-kind contributions of local government to the provision of community care, and should include:

- involvement in broad planning issues including the development of HACC needs-based planning models and State and national strategic plans;

- membership of Regional Forums, State level advisory committees and the national policy advisory committee;

- encouragement of local councils to cooperate on a regional basis in order to facilitate involvement in the proposed regional structure of the HACC Program; and

- a key role in planning at the local and regional level including participation in Commonwealth/State committees responsible for considering priorities and developing funding proposals. **(para 12.49)**

70. The Committee recommends that the Commonwealth Department of Human Services and Health formalise a protocol with States and Territories to ensure that, under normal circumstances, new appointments to State level advisory Committees are confirmed prior to the expiry of terms of existing members. It is further recommended that the Commonwealth Department of Human Services and Health in conjunction with States and Territories, amend the guidelines for the HACCACs to ensure that in the event of unavoidable delays in reconstitution of Committees at the expiry of members' terms, existing members will continue to fill their positions until new appointments are made. **(para 12.55)**

71. The Committee recommends that the Commonwealth Department of Human Services and Health review the guidelines for the HACCACs, in consultation with members of the current Advisory Committees to clarify the role of the Committees and develop protocols for the passing of HACCAC advice to the Commonwealth and State Ministers and for governments to respond to that advice and provide feedback to the Committees. It is further recommended that the Program provide HACCACs with adequate resources to fulfil their role, particularly in terms of community consultation. **(para 12.61)**

72. The Committee recommends that the role of State level HACCACs encompass the existing role but have a much stronger emphasis on consideration of policy issues. HACCACs should take a proactive approach and advise governments of areas where existing policy is lacking, where implementation is not proceeding effectively and where issues arising in the HACC community require a policy response on behalf of governments. In addition, HACCACs should be included in the consultation process for all major new policy initiatives. **(para 12.62)**

73. The Committee recommends that the Commonwealth Department of Human Services and Health ensure that the membership of HACCACs is representative of the communities they serve and includes a high level of consumer representation and people who are able to advocate for special needs groups. **(para 12.63)**

74. The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with States and Territories ensure the establishment and maintenance of regional HACC Forums in all States and

Territories to advise on regional service needs, broad priorities for funding, consumer views and service delivery issues. It is further recommended that the advice of the Forums be forwarded to governments through the State HACCACs and that the Commonwealth Department of Human Services and Health ensure that mechanisms exist for feedback from governments to the Regional Forums. **(para 12.69)**

75. The Committee recommends that Regional Forums have a sufficiently flexible and informal structure to enable the Forums to be accessible to consumers. While this would include formal consumer representatives on the Forums, it should extend to informal consultative activities where consumers may feel more able to participate. **(para 12.70)**

76. The Committee recommends that the Commonwealth Department of Human Services and Health establish a National HACC Advisory Council comprising the national peak organisations representing consumers and providers of HACC services. The Council should meet annually and have the capacity for special meetings to examine major policy initiatives as is currently the case. The role of the Council will be to:

- participate in the development of the National Strategic Plan, although the final decisions about the Plan will be made by governments;
- advise on community concerns and areas in which HACC performance requires improvement;
- have access to Program data, including the results of the monitoring of the HACC Program Outcome Indicators when they are implemented, to enable analysis and advice on the program's performance; and
- provide a two-way communication link between governments and the community in relation to the HACC Program. **(para 12.72)**

77. The Committee recommends that prior to any change to streamline administration, the Commonwealth Department of Human Services and Health evaluate the success of the strategic planning processes discussed earlier in this Chapter in terms of the level of cooperation by State and Territory governments, the extent of the match between nationally agreed

objectives and State/Territory Triennial Plans and outcomes reported in State/Territory Business Reports. **(para 12.83)**

78. The Committee recommends that the Commonwealth Department of Human Services and Health negotiate revised accountability measures with State and Territory governments to improve the capacity of the Program to measure the extent to which it achieves its objectives and ensure that HACC funds are applied to further HACC objectives. These arrangements are to include:

- Continuation of existing accountability for expenditure of HACC funds;
- A more focused approach to data collections in line with the data requirements of the HACC Program Outcome Indicators when finalised;
- Timely provision of other information required within the Outcome Indicators framework including unit cost information and aggregated results of standards monitoring; and
- A commitment by States and Territories to the timely provision of data to allow publication of data within one year of its collection. **(para 12.84)**

79. The Committee recommends, that subject to favourable findings from this evaluation and the implementation of accountability measures recommended, the Commonwealth Department of Human Services and Health and State and Territory governments implement the following streamlined administrative processes through revised HACC Agreements:

- Continued Commonwealth responsibility for the development, coordination and implementation of policy and strategic directions, initiation of innovative service models on an unmatched basis, initiation of research and development activities to advance Program objectives, data analysis and publication, national promotional activities, national financial monitoring;

- State and Territory governments to be responsible for the day to day administration of the Program, including funding decisions to be made at regional level with Commonwealth and State Ministers and Members advised simultaneously;

- Joint agreement to the quantum of funds to be available to the Program in each State and Territory; and

- Continued joint responsibilities at a broad strategic level, including: joint agreement to national and State level strategic plans; joint agreement to policy initiatives and major program tools like needs based planning models, standards monitoring mechanisms and service agreements; joint participation in advisory structures; and joint involvement in program evaluation activities. **(para 12.85)**

80. The Committee recommends that the Commonwealth Department of Human Services and Health monitor regionalisation initiatives which affect the Program and negotiate with States and Territories to ensure that this occurs in a coordinated way to promote the consistency discussed above. **(para 12.89)**

81. *The Committee recommends that the Commonwealth Department of Human* Services and Health, in conjunction with State and Territory governments, pilot a regional administration approach to the provision of HACC services. The pilot regions must involve the selection of common regions both by the Commonwealth and State departments responsible for the HACC Program and related Programs. The Committee considers that State Health Regions may be the appropriate basis for the pilot regions, as they are well established in most States and have close links between HACC and the acute health sector. In order to test the total package of initiatives recommended in this report, the regions for these pilots should be the same as those for the Regional Community Assessment Agencies. It is recommended that the pilots have the following features:

- Commonwealth and State/Territory officers responsible for the HACC Program working in close partnership;

- A strong role for Regional HACC Forums in advising on priorities and examining the effectiveness of the Program;

- A regional funding allocation, developed on the basis of the priorities identified in the State Strategic Plan, with authority to distribute funds delegated to State government officers in the Region or to a regional community board;

- Commonwealth and State officers to attend key meetings of the Regional Forums in an ex officio capacity;

- Local government representatives to have a formal role in the Regional Forum, in needs-based planning and in the development of funding priorities; and

- A strategy for the formal evaluation of the Pilot. **(para 12.90)**

CHAPTER 1

ESTABLISHMENT OF THE INQUIRY

INTRODUCTION

1.1 On 23 June 1993, the then Minister for Housing, Local Government and Community Services, the Hon Brian Howe MP, wrote to the Chairman, Mr Allan Morris MP, referring an inquiry to the Committee. The specific terms of reference were for the Committee to inquire into and report to the Parliament on were:

- The provision of services funded under the Home and Community Care (HACC) Act (1985) including their costs and relative efficiency;

- Access by the Program's target population to services funded under HACC including the appropriateness of these services, their availability and effectiveness in meeting the Program's objectives;

- Gaps in existing service provision; and

- The quality of care provided including the implementation of the HACC National Service Standards and associated quality assurance mechanisms.

CONDUCT OF THE INQUIRY

1.2 The Inquiry was advertised in the major metropolitan newspapers in July 1993. In addition, letters inviting submissions were sent to State Premiers, Territory Chief Ministers, State and Territory Ministers responsible for the HACC Program and organisations likely to have an interest in the Inquiry.

1.3 In response, almost 400 submissions were received from consumers and providers of HACC services, community organisations, academics, health care

providers, local government bodies, State and Territory governments and the Commonwealth.

1.4 To assist in its investigations, the Committee held public hearings in all capital cities, except Darwin, as well as in Campbelltown, the Blue Mountains, Newcastle and Launceston. These hearings generated over 3,000 pages of evidence.

1.5 Inspections were conducted at Vitalcall in Sydney, Nyampa Aboriginal community in NSW and HACC services funded at Broken Hill. A public meeting of interested persons was also held in Broken Hill.

1.6 In February 1994, the Committee released a discussion/options paper which consolidated the major issues raised in submissions and evidence received and proposed a range of options for reform of the HACC Program. The paper formed the basis for Public Forums held in Sydney, Melbourne, Brisbane and Adelaide. The Committee also received written responses to the paper from a number of individuals and organisations.

1.7 The final part of the consultation process consisted of meetings between the Chairman and representatives of peak welfare organisations who attended the public forums in an invited capacity.

PRELIMINARY OBSERVATIONS

1.8 The HACC Program was established in 1985 through the consolidation of existing programs which provided home nursing, home help, delivered meals and paramedical services predominantly to elderly people. The introduction of the HACC Program brought these services together under one umbrella and changed the target group for community care services to include the frail elderly and younger people with disabilities who would otherwise be at risk of premature or inappropriate admission to residential care and the carers of these groups. It also broadened the range of services which could be provided in order to develop a comprehensive system of community care for the target group.

1.9 There is a very high level of support for the HACC Program in the community. The Program is perceived as providing a range of valuable services

which are critical to the capacity of members of the target group to remain in their own homes in the community.

1.10 The HACC Program operates in a dynamic environment which is quite different from that which existed at its inception in 1985. Due to the nature of its target group, HACC is influenced by a range of other programs and by changes in population characteristics and community expectations. In particular, policy in aged care, disability programs and the acute health sector have significant implications for the HACC Program.

1.11 Perhaps the major challenge for community care in Australia into the next century will be the changing nature of the Australian population. The population is projected to age significantly over the next 20 to 50 years, placing greater demands on the range of aged care services including community care. Community expectations are also changing. There is no longer an expectation that frail elderly people will be admitted to residential care. Nor is residential or institutional care considered an appropriate response to the needs of younger people with disabilities. The availability of informal carers is also an area of change due to increasing workforce participation by women, who comprise the majority of carers.

1.12 Concerns have been expressed that the Program is not funded adequately to meet existing levels of need for community care. In order to meet these challenges the HACC Program will need: a planning strategy which is responsive to changes in the size of the target group; an effective and efficient method of service delivery; and clear objective, eligibility criteria and focus.

1.13 There have been three major reviews of the HACC Program since its inception in 1985: the First Triennial Review of the HACC Program (1988); a review by the House of Representatives Standing Committee on Finance and Public Administration which reviewed the findings of an efficiency audit by the Auditor-General in 1987-88 and produced the report "There's No Place Like Home" (1989); and a review of the administration and structure of the Program as part of the Special Premiers' Conference process in 1991.

1.14 In addition to these specific reviews, the HACC Program was considered by Stages 1 and 2 of the Mid-Term Review of Aged Care (1991 and 1993) in which issues about HACC in relation to elderly Australians were canvassed.

1.15 Since its inception, and in some instances as a result of these reviews, the HACC Program has developed on a number of fronts. There has been some streamlining of administration with clarification of the roles of the Commonwealth and the States and Territories and agreement that joint Commonwealth and State/Territory approval is no longer required for certain funding decisions in relation to existing projects. The community has greater access to the policy and decision making process through advisory structures. The Program has increased its consumer focus with the development of a quality assurance and consumer rights strategy. Planning for new services is moving towards a more needs based approach and the Program is endeavouring to achieve greater equity within and between regions and States.

1.16 Concerns remain, however, about the extent to which the Program has succeeded in some of these areas. Administration of the Program, for example, is still perceived as costly and inefficient with duplication between the roles of the Commonwealth and the States and Territories. The area of planning and advisory structures is also the subject of significant concerns in the community.

1.17 The Committee is aware of a number of reviews currently underway which relate to the HACC Program. At the national level the Commonwealth initiated the Commonwealth/State Review of the Efficiency and Effectiveness of the Home and Community Care Program. Reviews have also been undertaken in NSW and Victoria to consider the way in which HACC services in those States are funded and delivered.

1.18 This Inquiry complements these reviews and takes a broader perspective on the HACC Program. The Committee has examined the Program in terms of its effectiveness, the appropriateness and quality of the services provided, access to services by the target group, administration of the Program and the approach taken to planning HACC services.

1.19 Throughout the report, the Committee focuses on the needs of members of the HACC target groups and the need for the Program to be responsive to the needs of consumers and the changing environment in which it operates, to provide easy access to services by members of the target group and to ensure high quality and more cost-efficient services.

1.20 The report begins with a description of the history of the HACC Program, the reasons for its introduction and its impact on community care in Australia. It also examines the structure of the HACC Program today, taking into account the roles of the participants in the Program, the objectives and target group of the Program and the services it provides. Further background is provided in a description of the policy and social context in which the HACC Program operates.

1.21 During its investigations, the Committee heard concerns about fragmentation of HACC services and difficulties faced by consumers in gaining access to services. The Committee has examined these issues and made a number of recommendations about facilitating access through improved coordination, changed assessment processes, clarification of the target group and Program objective and attention to special needs groups.

1.22 The community and governments have expressed concern about the lack of linkages between HACC and related programs. The Committee has examined these linkages and made recommendations for their improvement. The interface between community care and the acute health sector is particularly critical to the HACC Program and its consumers and has been examined in more detail.

1.23 The report discusses the way in which HACC services are delivered, the quality of those services and the rights of consumers. The Committee has suggested ways to overcome the perceived rigid approach to the delivery and funding of HACC services, to ensure high quality services and to assist consumers in asserting their rights and pursuing any complaints they may have about the services they receive.

1.24 The report also addresses the planning and administration of the HACC Program and the role of advisory structures. The Committee has recommended a number of ways in which planning can be enhanced and administration streamlined. There are also recommendations intended to give a greater focus to the role of the HACC Advisory Committees and associated regional forums.

1.25 In its concluding Chapter, the Committee brings together the recommendations it has made throughout the report and describes the system of community care which would result from the implementation of its recommendations.

CHAPTER 2

HISTORY OF THE HOME AND COMMUNITY CARE PROGRAM

COMMUNITY CARE BEFORE HACC

2.1 Until 1985, when the Home and Community Care (HACC) Act was introduced, community care in Australia was provided through four separate Programs under the following legislation:

- the Home Nursing Subsidy Act 1957;
- the States Grants (Home Care) Act 1969;
- the States Grants (Paramedical Services) Act 1969; and
- the Delivered Meals Subsidy Act 1970.

2.2 It became apparent during the 1970s and early 1980s that community care was not meeting the needs of frail elderly people and younger people with disabilities and the carers of these groups.

2.3 The then Commonwealth Department of Health, Housing, Local Government and Community Services, now the Commonwealth Department of Human Services and Health, stated in its submission to this Inquiry that:

> "These pre-existing services, funded under the States Grants Acts, created artificial barriers which restricted the ability to respond to individuals needs." (DHSH: Volumes of submissions p 234)

2.4 A number of reports and inquiries in the early 1980s identified restrictions on the capacity of the community care programs available at that time

to respond to the needs of the population. Important among these were:

- 'In A Home Or At Home: Accommodation And Home Care For The Aged' (the McLeay Report - House of Representatives Standing Committee on Expenditure, 1982); and

- 'Older People at Home' (Department of Social Security and Australian Council on the Ageing, 1985).

2.5 The McLeay Report highlighted the dominance of expenditure on residential care for the frail aged compared with amounts provided for home care services. Also stressed was the incapacity of community care services to respond to individual needs due to the legislative limitations under which they were provided. The Report made recommendations designed to redress this imbalance and to improve the flexibility of community care. The main recommendation about community care, referred to as 'extended care' in the report, was that:

> "The following strategy be implemented:
>
> - an Extended Care Program be introduced to replace the States Grants (Home Care) Act 1969, the States Grants (Paramedical Services) Act 1969, the Home Nursing Subsidy Scheme and the Delivered Meals Subsidy;
>
> - the Extended Care Program include an Attendant Care Allowance to replace the Domiciliary Nursing Care Benefit and the Personal Care Subsidy;
>
> - the range of services to be funded be decided in consultation with the States to encourage a diversity of services to meet local need;
>
> - resources be distributed so as to achieve a basic provision in all areas rather than solely in response to submissions for funding; and
>
> - the extended care Program be funded through a grant without matching conditions."[1]

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1 House of Representatives Standing Committee on Expenditure, "In A Home Or At Home: Accommodation And Home Care For The Aged", Parliamentary Paper No. 283 of 1982, pp ix-x.

2.6 The Home and Community Care Program, when introduced, did not comply with all the recommendations, but did reflect many of the key aspects of the McLeay Report.

2.7 It was, therefore, against a background of fragmented, limited and loosely targeted services that the HACC Program was introduced. The Act brought the range of community care services for the aged together under a single umbrella for the first time, introduced a more specific focus to community care and expanded the target group of these services to include younger people with disabilities. It also recognised and provided support for the first time to those who care for frail elderly people and younger people with disabilities.

2.8 When introducing the HACC Act in 1985, the Commonwealth Minister responsible for the Program, Senator the Hon Don Grimes, stated that he expected that the HACC Program would lead to vast improvements in the provision of community care in Australia. Senator Grimes said:

> "The Home and Community Care Program signals a new approach to the planning of community services in Australia, an approach which will hold out the possibility of achieving a more caring and equitable society. Services which are appropriately planned, distributed and financed provide an essential complement to other social policies in achieving social equity and needed support to ensure that our society functions properly."[2]

IMPACT OF HACC PROGRAM

2.9 This Inquiry has provided the opportunity to examine the extent to which the HACC Program has fulfilled this vision and to measure its impact on the lives of the frail elderly, younger people with disabilities and carers in Australia.

2.10 It is clear from the submissions and evidence given to the Committee that the HACC Program has had a significant and generally positive impact on the provision of community care in Australia in that:

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2 Australia, Senate 1985, *Debates*, vol. S 111, p 2126.

- the range of community care services has expanded substantially to include day care centres and other forms of respite care, transport, community options, information, referral and advocacy services, support groups for carers and services for special needs groups;

- funding levels for community care have increased significantly since the start of the HACC Program with combined Commonwealth and State/Territory expenditure increasing from an estimated $152.221 million in 1984-85 (the base year for the Program) to an estimated $564.496 million in 1992-93; and

- there have been substantial improvements in coordination and integration of community care services.

2.11 In purely numerical terms it is apparent that HACC services have developed substantially since the introduction of the Program. The increase in funding levels and in the range of service types available has meant that large numbers of consumers are now able to access HACC services. The Commonwealth estimates that around 215 000 people use HACC services in a month. (DHSH: Volumes of Submissions, p 268)

2.12 The impact of the introduction of the HACC Program has, however, varied between States and Territories. Some have been more committed to the growth of the Program than others and there has been significant variation in the way in which new service types have been implemented and the emphasis given to various service types.

2.13 Appendix 4, Table 1, for example, shows significant variations in the percentage of funds allocated to the various service types under HACC. Some States such as the ACT have allocated a greater proportion of funds to services like respite care which did not exist prior to the inception of the Program. Others have continued to focus on more traditional services like home nursing and home help, which are of course critical to the HACC objective, and together made up almost 70% of total HACC expenditure in Tasmania in 1992-93 compared with the national average of just under 54%. Without making judgements about the relative value of the various service types, the Committee notes that the wide differences between States and Territories do raise issues of equity.

2.14 The amount of growth allocated to the HACC Program has also contributed to the variability of its impact on community care between States and Territories. Appendix 4, Tables 2 and 3, demonstrate the differences in growth factors, which are largely determined by States and Territories, with some States taking greater advantage of the growth available in each year than others. This has led to significant per capita differences in funding levels and, hence, to an inequitable distribution of HACC resources between States.

2.15 These variations are highlighted simply to give an indication of some of the variations in the way in which HACC has been implemented by different States and Territories. This variability, while it may justified in some instances, raises questions about equity and about the extent to which consumers in each State and Territory have benefited from the introduction of the Program.

2.16 The evidence presented to this Committee indicates that while there is very strong support for the Program in most sectors of the community, there is considerable scope for improvement in the structure and delivery of community care in Australia. This report focuses on the key areas of concern and makes recommendations for change to improve the capacity of the HACC Program to fulfil its purpose and objectives.

CHAPTER 3

CURRENT STRUCTURE AND PHILOSOPHY OF THE PROGRAM

THE HACC PROGRAM

3.1 The Home and Community Care Program is a jointly funded and administered Commonwealth and State/Territory initiative to provide basic maintenance and support services to members of the HACC target groups. The relative financial contribution of the Commonwealth government and the States and Territories is determined on the basis of an established ratio. The ratio in each State and Territory is historically based and includes any additional funds incorporated in the Commonwealth or State Territory share since the original ratios were established at the inception of the Program. Nationally, the Commonwealth contribution is approximately 60% while the States and Territories contribute around 40%. The State/Territory share of Program funding incorporates any funds contributed by local government and community organisations.

3.2 Growth in HACC funding is determined annually. The level of growth to apply in each State or Territory is determined primarily in the State/Territory budget context. Each State and Territory proposes a level of growth and seeks the Commonwealth matching contribution in line with the ratio for that State or Territory. Under the terms of the bilateral agreements which govern the operation of the Program, all parties are required to maintain their level of effort.

3.3 Services are provided by State government, local government, community and religious and charitable organisations.

PROGRAM OBJECTIVE

3.4 The philosophy of the HACC Program is underpinned by the stated objective of the Program which is:

> "To enhance the quality of life of the frail aged and younger people with disabilities and their carers, by providing high quality and cost-effective care in the community, so that appropriate services are provided according to the assessed need of the individual, and inappropriate admission to residential care avoided." (DHSH: Volumes of submissions p 242)

3.5 According to the Commonwealth Department of Human Services and Health, the HACC Program aims to achieve this objective by:

> ". providing a comprehensive and integrated range of basic support services for frail aged people and people of any age with a disability, and their carers;
>
> . helping these people to be more independent at home and in the community, thereby avoiding their inappropriate admission to long term residential care and enhancing their quality of life; and
>
> . providing a greater range of services and more flexible service provision to ensure that services respond to the needs of users." (DHSH: Volumes of submissions p 242)

TARGET GROUP

3.6 The target population for the HACC Program is defined in the Schedule to the Home and Community Care Act 1985, at Clause 6, in the following terms:

> "6. The Program shall be directed towards assisting-
>
> (a) persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the Program, are at risk of premature or inappropriate long term residential care, including-

(i) frail or at-risk aged persons, being elderly persons with moderate or severe disabilities;

(ii) younger disabled persons, being persons with moderate or severe disabilities; and

(iii) such other classes of persons as are agreed upon by the Commonwealth Minister and the State Ministers; and

(b) the carers of those persons."[1]

SERVICE TYPES

3.7 The HACC Program funds the provision of a range of services which may be required by members of the target group in order to continue to live in the community. The service types, specified in the HACC Program National Guidelines, are:

- **Allied health services**: Services, including physiotherapy, podiatry, speech therapy and occupational therapy, to assist members of the target group to maintain their independence and mobility.

- **Assessment services**: Services which provide a centralised point for the evaluation of potential consumer needs and referral to needed services.

- **Community nursing**: Services providing nursing care to members of the target group to improve or maintain health or wellbeing. They are not intended to meet intensive health care needs.

- **Coordination**: This service type is designed to ensure the integration and coordination of services in the community. It is intended to complement the coordination undertaken by individual service providers. It may include services to improve access by all target groups, community monitoring systems to facilitate emergency or other services and coordination of a number of services such as transport services, volunteers or respite carers.

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1 *Home and Community Care Act (1985)*

- **Education and training**: These services promote the development of training for service providers and consumers including support for in-service training for service providers including volunteers and support for the training of carers.

- **Food services**: Services to assist those who, due to frailty or disability, are unable to prepare meals or maintain adequate nutrition. Food services include provision of meals at home (including the well known 'meals on wheels' services) or at a community centre, nutritional advice, cooking lessons and food buying services.

- **Home help (including personal care)**: These services assist with household tasks and self care. Services may include house cleaning; washing and ironing; assistance with shopping; transport to personal appointments; general support like paying bills, assisting with telephone calls; personal care (eg. bathing, toileting, dressing and feeding); personal grooming; and provision and laundering of linen.

- **Home maintenance and modification**: These services assist members of the target group to maintain their own homes, gardens and yards to ensure safety and provide an adequate level of security. Assistance may include: essential repairs and maintenance, such as changing light bulbs, carpentry and painting; referral and advice on maintenance and modification matters; modifications such as installation of ramps, bathroom modifications or non-slip flooring; and maintenance of gardens.

- **Information**: Information services are intended to increase public awareness of community care services.

- **Respite care**: This service assists carers of frail aged people and younger people with a disability to maintain the caring role by providing a short term substitute for usual care arrangements. Respite can be provided in the consumer's own home, the respite carer's home, day care facilities or at venues used by the general community accompanied by the respite service's staff.

- **Transport services**: These services assist members of the HACC target group by providing essential transport. These services are often provided in

conjunction with other HACC services. For example, mini bus services to take people to and from day respite facilities where other suitable transport is not available.

- **Community options projects:** These services use a case management or brokerage approach to provide a package of care to meet the assessed needs of individual clients. A case manager with a flexible budget is assigned to each consumer and coordinates the provision of services to that individual. The capacity of the case manager to purchase services for the consumer allows access to a range of services which is not limited to those available from the HACC Program.[2]

ROLES OF PARTICIPANTS IN THE PROGRAM

3.8 The HACC Program operates as a partnership between the major participants in community care in Australia. These include governments, service providers, consumers and carers.

Governments

3.9 The Schedule to the Home and Community Care Act 1985 forms the basis of bilateral Agreements between the Commonwealth and each State and Territory. These Agreements specify the way in which the Program will operate, the roles of governments, the funding mechanism and the scope of the Program. In general terms, the Commonwealth is responsible for maintaining a national perspective in the Program and for a range of financial matters while the States and Territories are responsible for the day to day administration of the Program.

3.10 The Commonwealth and State/Territory governments have joint responsibility for some aspects of the Program:

- The quantum of funds to be made available for the Program each year in each State and Territory is jointly agreed by the Commonwealth Minister and each State and Territory Minister;

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2 "Home and Community Care Program - National Guidelines", AGPS, 1989, p 5.

- The rate of cost-supplementation in each State and Territory each year is jointly agreed between Commonwealth and State/Territory Ministers;

- Commonwealth and State/Territory officers participate in the Joint Officers Group (known as the Joint Officers Committee in Victoria) in each State and Territory which develops specific funding proposals for consideration by Ministers;

- All new projects funded under the HACC Program and significant variations to levels of funding of existing projects are subject to joint approval by Commonwealth and State/Territory Ministers. Recommendations for project approvals, variations or revocations are developed by the Joint Officers Group for consideration by Ministers;

- Commonwealth and State/Territory Ministers jointly announce project approvals and variations;

- Membership of HACC Advisory Committees, which advise Commonwealth and State/Territory Ministers on Program development priorities and planning strategies is approved jointly by Commonwealth and State/Territory Ministers; and

- State and Territory Strategic Plans are jointly agreed by the Commonwealth and the State/Territory.

3.11 The major responsibilities of the Commonwealth in the HACC Program are set out below:

- The Commonwealth is responsible for the coordination of national policy development under the HACC Program. As part of this role, the Commonwealth commissions and funds research to develop policy;

- The Commonwealth is involved in all levels of the HACC planning process, including the development of the national and State/Territory strategic plans, and in the development of needs-based planning methodologies in each State and Territory and in work to develop benchmarks for the Program;

- The Commonwealth maintains and develops, in consultation with State and Territory governments, the national data collections for the HACC Program and provides the systems and analysis of the data collected;

- The Commonwealth is responsible for financial assistance to the States and Territories for the provision of community care in line with the HACC Agreements, monitoring expenditure of HACC funds and maintenance of national data systems and data relating to HACC expenditure; and

- While States and Territories are responsible for the day to day management of the Program, the Commonwealth participates with the States/Territories in some aspects. For example, the implementation and evaluation of national policy initiatives and review of HACC funded projects include Commonwealth HACC officers.

3.12 Under the terms of the HACC Agreements, the States and Territories are responsible for the day to day administration of the Program and are the primary point of contact for service providers. States and Territories also contribute with the Commonwealth to national policy development.

3.13 The day to day management responsibilities of State and Territory governments include:

- making payments to funded organisations;

- provision of project support;

- financial management within the State or Territory, including accountability to the Commonwealth for Commonwealth funds;

- development of State/Territory level publicity and information and dissemination of State/Territory and national level material;

- implementation and monitoring of agreed policy; and

- needs based planning, including secretariat support for HACC Advisory Committees.

3.14 According to the Commonwealth Department of Human Services and Health, local government plays an important role in the planning, development and delivery of HACC services (DHSH: Volumes of submissions, p 245). Local government also provides funding for HACC services and this is recognised as part of the State government contribution to the Program. As local government is not a party to the HACC Agreements, it is not bound by those agreements and has not been given the formal role in the Program it has sought from time to time.

3.15 In Victoria, the local government role in service provision, planning and financial contribution has been particularly strong and local government has been accorded a more formal role than in other States and Territories. The Municipal Association of Victoria is represented on the Joint Officers Committee and is involved in decisions on priorities and the development of recommendations for funding.

Service Providers

3.16 Service providers are the front line of the HACC Program. They are responsible for providing the services, implementing HACC policy, promoting the services they provide, assessing potential consumers, making referrals to other services, feeding back data to governments and accounting to governments for HACC funds. There are four major groups of HACC service providers. These groups and the proportion of HACC funds which were directed to each in 1992-93 are:

. State/Territory government - 40%;

. community organisations - 35.9%;

. local government - 19.9%; and

. religious and charitable organisations - 4.2%.

3.17 HACC service providers are diverse in nature, ranging across the small community organisation providing a single service type, large community organisations like the Silver Chain Nursing Association which provides services across a number of regions in WA, large State and Territory government bodies like the Home Care Service of NSW, local government providers and some private

providers. This presents real challenges to the HACC Program in terms of developing appropriate accountability, standards, policy implementation and training which take account of this diversity.

3.18 The responsibilities of service providers to consumers of their services are spelled out in detail in the HACC Program Statement of Rights and Responsibilities.[3]

Consumers and Carers

3.19 Under the multiple target group approach of the HACC Program there are three distinct groups of consumers: frail elderly people; younger people with disabilities; and the carers of members of these groups.

3.20 Carers are in the unique position of having a dual role in relation to the HACC Program. While they are legitimate consumers of HACC services, they are also a critical part of the support networks which enable frail elderly people and younger people with disabilities to remain in the community.

3.21 Consumers of HACC services, including carers, have an important role to play in ensuring the quality of HACC services. Feedback from consumers about the quality of services is essential to allow service providers and funding bodies to make assessments about the effectiveness of the Program as a whole and about individual services. Consumer participation in the operation and management of HACC services and in the HACC Program's advisory structures is critical to ensuring a consumer focused approach in the Program.

3.22 The HACC Program Statement of Rights and Responsibilities sets out the following rights and responsibilities of consumers of HACC services:

"The key rights which affect consumers of HACC services... are:

1) the right to respect for their individual human worth, dignity and privacy

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[3] "HACC Program Statement of Rights and Responsibilities", AGPS, 1992.

2) the right to be assessed for access to services without discrimination

3) the right to be informed about available services

4) the right to choose from available alternatives

5) the right to pursue any complaint about service provision without retribution

6) the right to involve an advocate of their choice.

... Consistent with their status as members of Australian society, HACC consumers have a responsibility:

1) to respect the human worth and dignity of the service provider staff and other consumers

2) for the results of any decisions they make

3) to play their part in helping the service provider to provide them with services."[4]

3.23 The Committee has noted that there is a lack of understanding of consumer rights among HACC consumers and service providers. The extent of implementation and knowledge of the Statement of Rights and Responsibilities varies significantly between States and Territories. This issue is discussed in greater detail in Chapter 11.

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4 ibid.

CHAPTER 4

POLICY AND SOCIAL CONTEXT

4.1 The HACC Program operates within the wider social and policy context of aged care, disability support and health policies, the expectations of society about care for these groups and demographic characteristics of Australian society. This context is dynamic and the HACC Program today operates in an environment substantially different from that which existed at the inception of the Program. In any examination of HACC, it is necessary to consider the current environment, the impact it has on the Program and the capacity of HACC to respond to it.

AGED CARE POLICIES

4.2 Aged care services are much more diverse in 1994 than was the case in 1985 when HACC was introduced. In 1985 the range of Commonwealth funded aged care services encompassed nursing homes, hostels and limited community care. The focus of aged care services was, as noted in the McLeay Report, primarily on institutional care.[1] The balance of aged care services has moved progressively away from the dominance of nursing home care to an increasing emphasis on less restrictive options like hostel and community care. Nursing home care has been targeted increasingly toward those with higher level needs. There is also a greater focus on the needs of consumers and on offering consumers greater choice in their care.

4.3 Residential aged care has undergone significant change in the last decade. The Mid-Term Review of Aged Care noted major areas of progress in the provision of residential aged care from 1985 to 1990. These included: significant improvement in needs-based planning; the introduction of planning ratios for

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1 House of Representatives Standing Committee on Expenditure, op cit.

nursing homes and hostels[2]; a shift in the balance between nursing home and hostel places (from 67 and 33 respectively per 1 000 people 70 and over to 59 nursing home places and 36 hostel places[3]); the establishment of Geriatric Assessment Teams (GATS) to assess the eligibility of potential nursing home residents; an increased focus on quality of care and residents' rights; and changes to recurrent funding to address issues of equity, access and affordability.[4] GATs were subsequently renamed Aged Care Assessment Teams (ACATs) with an expanded role of assessing eligibility for hostels in addition to nursing homes.

4.4 Along with these developments, new approaches to the delivery of aged care services have been put in place. The 1993-94 Program Performance Statements for the Health, Housing, Local Government and Community Services Portfolio give an indication of the range of services, apart from nursing homes, hostels and HACC services, provided through the Aged and Community Care Program. These include Community Aged Care Packages which provide hostel level care to frail elderly people in their own homes; multi-purpose services to provide a range of coordinated aged care and health services in rural areas under a single auspice; day therapy centres; Aged Care Assessment Teams (ACATs); and Transition Care Projects to assist frail elderly people discharged from hospital to avoid residential care through the use of ACATs to arrange and purchase community support services.[5]

4.5 The Commonwealth has also introduced a small program to provide additional respite care in the community through the Commonwealth Respite for Carers (CRC) Program. This Program funds the development of flexible respite care services to support carers and builds on existing HACC funded services in many instances. It is funded and administered solely by the Commonwealth.

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2 The current planning targets, or benchmarks for residential care are: 40 nursing home beds; 52.5 hostel beds; and 7.5 Community Aged Care Packages per 1 000 population aged 70 and over.

3 The ratio at 30 June 1993 had shifted further to 54 nursing home places and 39 hostel places. (Budget Related Paper No 7.8A, "Program Performance Statements 1993-94, Health, Housing, Local Government and Community Services Portfolio", p 281).

4 Department of Health, Housing and Community Services, "Aged Care Reform Strategy Mid-Term Review 1990-91: Report", AGPS, 1991, pp 3-5.

5 Budget Related Paper No 7.8A, "Program Performance Statements 1993-94, Health, Housing, Local Government and Community Services Portfolio", AGPS, 1993, pp 231-88.

4.6 It is clear that the aged care environment is complex. While the range of services has provided greater choice for elderly Australians, it has led to some confusion among consumers and providers of services about what services are available and how to gain access to them.

DISABILITY PROGRAMS

4.7 There is a significant interface between the HACC Program and other services for younger people with disabilities.

4.8 The HACC target group has a substantial overlap with those of both employment services for younger people with disabilities funded and administered by the Commonwealth through the Disability Services Program and accommodation related services provided by the States and Territories under the Commonwealth/State Disability Agreement (CSDA).

4.9 The relationship between these programs does not appear to be clearly defined, resulting in duplication and in gaps between the programs.

4.10 The Commonwealth Department of Human Services and Health notes:

> "The boundaries between HACC and Disability Services Programs are not always precise. Younger people with disabilities access services under both Programs." (DHSH: Volumes of submissions, p 252)

4.11 The most important developments in disability support policies from the perspective of the HACC Program have been moves away from institutional care and, more recently, the implementation of the Commonwealth/State Disability Agreement. Concerns about the impact of these changes on the HACC Program are evident.

4.12 The Council on the Ageing (Australia) notes in its submission that there is a perception that younger people with disabilities may be gaining access to a greater share of the HACC dollar at the expense of the elderly. COTA (Australia) goes on to say that this perception and resulting tension is regrettable as it reflects

inadequate funding levels rather than any inherent conflict (COTA (Australia): Volumes of submissions, p 206). The Commonwealth also notes anecdotal evidence of the impact of disability policies on HACC:

> "There has been some anecdotal evidence that moves to deinstitutionalise people with disabilities may have led to greater pressure on HACC services. In addition the transfer of responsibility for the provision of services under the Commonwealth/State Disability Agreement (CSDA) to the State and Territories has led to concerns about the criteria being adopted by individual States and Territories in their administration of in-home support services..."(DHSH: Volumes of submissions, p 252)

4.13 The impact of the implementation of the CSDA is not yet apparent, but there are some disparate views evident. Despite the concerns noted by the Commonwealth, some States see the advent of the CSDA as an opportunity to bring about enhanced links and cooperation between the programs.

ACUTE HEALTH CARE

4.14 The acute health system is an important part of the environment in which the HACC Program operates. The interactions in this area are complex, particularly for the elderly and their carers, involving the hospital sector, general practitioners, ACATs, community care services, residential care and rehabilitation.

4.15 The most significant point of interface between HACC and acute health is the provision of post acute and palliative care. Services to people requiring post acute or palliative care were among those designated 'no growth' areas under HACC at the inception of the Program. The no growth restrictions mean that funding for these services has been maintained, in real terms, at the levels which existed at that time.

4.16 There is a widespread perception that changes in the acute health sector and the lack of alternative funding sources for post acute and palliative care have placed increased pressure on the HACC Program to provide these services. Hospitals have focused increasingly on throughput leading to reduced lengths of stay in hospital and greater use of day surgery and it is likely that the introduction of

casemix funding will see a continuation of this emphasis. The Australian Institute of Health and Welfare (AIHW) notes a number of important changes in the patterns of hospital usage over the last decade. In "Australia's Health 1994" the AIHW notes:

> "The average time spent in acute hospitals by admitted patients declined by 28% from 6.9 to 5.0 days between 1982-83 and 1991-92. The rapidity of the decline in length of stay has also increased, from 1.9% per year from 1982-83 to 1984-85, to 2.9% per year over the next four years to 1988-89, then to 5.5% per year over the years from 1989-1990 to 1991-92."[6]

4.17 The AIHW goes on to suggest that the reasons for the change in average length of stay are attributable to a range of factors, which include advances in antibiotics and anaesthetics, less invasive surgical techniques and fewer patients requiring nursing home care being cared for in acute hospitals. It is also noted that the increasing use of same-day treatments has accelerated the decline in length of stay.[7]

4.18 While there is little empirical evidence of any change over time in the level of usage of post acute and palliative care under HACC, there is consistent anecdotal evidence. The Australian Council of Community Nursing Services (ACCNS), for example, stated:

> "As a result of ongoing cost containment problems in hospitals leading to early discharge, significant increases in day surgery procedures and the desire of the terminally ill to be cared for at home, the number of elderly people requiring home nursing care is increasing without a significant shift of resources from hospitals to the community to care for them." (ACCNS: Volumes of submissions, p 23)

4.19 Changing health care policies clearly have impacted upon the HACC Program. While it is difficult to measure the extent of this impact, the anecdotal evidence for its existence is strong.

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6 Australian Institute of Health and Welfare, "Australia's Health 1994: the Fourth Biennial Health Report of the Australian Institute of Health and Welfare", AGPS, Canberra, 1994, p 162.

7 ibid.

CARERS

4.20 The critical role of carers and their legitimate place in the HACC target group is acknowledged by governments and the community. The Carers Association of Australia stated in relation to the importance of carers:

> "Carers are fundamental to, and represent the cornerstone of community care." (Carers Association of Australia Inc: Volumes of submissions, p 418)

4.21 The Association further noted the need for governments to recognise the contribution of carers and to support carers:

> "However, we feel that caring needs to be a choice and that therefore, any policies which seek to encourage care in the community need to be implemented in conjunction with a corresponding increase in community resources." (Carers Association of Australia Inc: Volumes of submissions, p 418)

4.22 The Commonwealth Department of Human Services and Health acknowledged that:

> "A great innovation of the HACC legislation was the increased emphasis on carers. The establishment of HACC recognised that effective support to the frail in the community necessitates support for their carers. The explicit recognition of carers as a target group distinguishes Australia as a leader in community care." (DHSH: Transcript of evidence, pp 545-546)

4.23 Supporting the interdependence of HACC and carers, the Economic Planning Advisory Council (EPAC) Background Paper 'Australia's Ageing Society' notes, among a range of challenges identified for HACC, some issues relating to the importance of carers in maintaining the elderly in the community. While the EPAC comments specifically relate to carers of frail elderly people, they also apply to the carers of younger people with disabilities. The challenges noted include: the availability of volunteer carers; the movement of traditional carers into the workforce; the level of involvement which should be expected from the aged in caring for spouses and relatives; the appropriateness of shifting the balance of care

to the community; and the level of financial responsibility the elderly should take for their own care.[8]

4.24 It is clear that community care is reliant upon the efforts of carers and that governments must take account of the relationship between carers and community care. Community care policies must facilitate continued support for carers and must be cognisant of any projected changes in the availability of carers.

POPULATION PROJECTIONS

4.25 Submissions and evidence to this Inquiry have revealed serious concerns among service provider and consumer groups about the capacity of the HACC Program to respond to the predicted increases in Australia's aged population. It is argued that the Program is unable to meet existing demand and that current levels of growth will not be sufficient to enable it to do so in the face of increased need for community care services.

4.26 The Australian Pensioners' and Superannuants' Federation (APSF), for example, drawing on data from the Mid-Term Review of Aged Care, concludes that only half of the estimated number of severely handicapped people over 70 living in the community receive home help and one-fifth receive home nursing. APSF goes on to express concern about falling rates of growth in HACC funding. (APSF: Volumes of submissions, pp 49-50)

4.27 The Commonwealth Department of Human Services and Health, in its submission, estimates that, based on the Australian Bureau of Statistics (ABS) 1988 Survey of Disabled and Aged Persons, the potential HACC target group is between 576 100 (severely disabled persons living in the community) and 1 166 000 (moderately and severely disabled persons living in the community). The submission goes on to note that an estimated 215 000 people receive HACC services in a month. The Department further states that the target group of carers of people with a severe handicap was estimated in 1993 at 348 000. An estimated 117 000 HACC consumers have a carer who would benefit indirectly from the provision of HACC services (DHSH: Volumes of Submissions, pp 267-269). Even the more conservative

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8 Clare, R and Tulpule, A, "Australia's Ageing Society" Background Paper No 37, Economic Planning and Advisory Council, AGPS, 1994, pp 86-87.

estimate of the potential target group for HACC services indicates a significant undersupply of HACC services. Nor do these estimates take into account the size of the target group in the no growth areas of HACC. It should be kept in mind, however, that it is unlikely that all those who fall within the ABS definitions of severe or moderate disability require or desire HACC services.

4.28 EPAC makes some important points in relation to the care needs of the elderly and the challenges for the HACC Program. The paper foreshadows a significant ageing of the population over the next 60 years. For example, it projects that the ratio of the young and the old to the working age population, or the dependency ratio, will continue the existing downward trend (due to low fertility rates) until around 2011 and then rise steadily from the current level of approximately 50 per 100 people of working age to over 53 per 100 by 2021 and to over 60 per 100 by 2051 for the majority of projections.[9] The number of people aged over 65 in Australia will rise, according to the projections in the paper, from around 11% of the total population, in 1991 to over 13% in 2011, 19% in 2031 and 22% of the population, by 2051. The increase in population among those aged 80 years and over is still more significant with the proportion of the population in this age group likely to increase from 2.2% in 1991 to 3.5% in 2011 and to at least treble by 2051.[10]

4.29 It is clear then that governments must ensure that the HACC Program, along with other programs providing assistance to the aged, is in a position to respond to the changes ahead over the next fifty to sixty years. The EPAC paper points out that it is likely that community care and hostel care will be subjected to continued, and possibly increased, emphasis and that HACC will confront a number of challenges as the population ages.[11]

4.30 This Inquiry has examined the HACC Program in the context of the policy and social circumstances of Australia and the impact these are likely to have on the provision of community care in the future. This report endeavours to create a picture of a community care system able to respond to the challenges into the next century.

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9 ibid, p 14.

10 ibid, pp 18-20.

11 ibid, pp 86-87.

CHAPTER 5

FOCUS AND TARGETING

5.1 Submissions to the Inquiry from some consumer and service provider organisations indicate that the community questions the existing focus of the HACC Program and the way HACC services are targeted. Concerns about the focus of the Program relate to the Program objective and definition of the target group and to the Program's rationing policy, which requires that services be provided to those with greatest relative need. Access to HACC services by members of the target groups has also been raised with the Committee.

PROGRAM OBJECTIVE AND TARGET GROUP

5.2 Consistent questions have been raised regarding the continuing appropriateness of the existing HACC Program objective and associated target group definition. The major point of contention is the focus on prevention of premature or inappropriate admission to residential care. The primary basis for the concerns is that, in the view of some service providers and consumer groups, most younger people with disabilities and frail elderly people in the community are not at risk of premature institutionalisation but are at risk of neglect and poor quality of life in the community. Where these people have carers, it is not residential facilities, but carers who take responsibility for maintaining the person, preventing neglect and ensuring quality of life.

5.3 A further issue in terms of the target group definition is the lack of clarity about who is included in that group. It is apparent that there is an inconsistent approach among HACC service providers regarding the eligibility for HACC services of groups including people with psychiatric disabilities, acquired brain injuries, HIV/AIDS and people living in various forms of supported accommodation.

5.4 It has been suggested that the HACC objective and target group should be redefined to give a greater focus on supporting independence and quality of life for people with disabilities of all ages and their carers, rather than prevention of admission to residential care. The redefinition should also remove artificial distinctions on the basis of age and avoid the exclusion of individuals who, on the criterion of functional disability would appear to be eligible for HACC services. The Alzheimer's Association of SA, for example, stated, in relation to the Program objective:

> "The present focus on risk of institutionalisation is a narrow one... What is more important is for the quality of life to be enhanced at any stage and for individuals and families to be supported in their individualised choices, which may include institutionalisation."[1]

5.5 ACROD also expressed support for a broader, more community focused Program objective:

> "It fits more closely with both government policy and community philosophy that support for people to live in the community is the most desired accommodation objective.
>
> It is also a more realistic option for younger people with disabilities given that institutionalisation as such is not an available, or in most cases desirable, option. Support to remain living in the community is also the preferred option of most older people with disabilities."[2]

5.6 The Committee has received evidence from a number of organisations that the existing approach to eligibility for HACC services has led to members of some of the groups noted earlier missing out on HACC services. For example, the Queensland AIDS Council (QAC), in its submission, reported on the response of the Queensland Office of the Commonwealth department responsible for HACC, to inquiries about the eligibility of people with HIV/AIDS for HACC services:

> "The writer was told that HIV positive people were generally not frail, older people; nor did they have multiple disabilities and thus were not able to access HACC funded services. Further as there were programs

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1 Ms F Gunner, President, Alzheimer's Association (SA) Inc, Correspondence in response to HACC Options/Discussion Paper, 7 April 1994.

2 Ms S Taylor, Deputy Executive Director, ACROD, Correspondence in response to HACC Options/Discussion Paper, 11 April 1994.

specific to the AIDS area funded to provide the same services... people living with HIV/AIDS were not within the target groups."(QAC: Volumes of submissions, p 1807)

5.7 The submission from the Australian Federation of AIDS Organisations (AFAO) indicates, however, that in some States there is an acceptance that people with HIV/AIDS are eligible for HACC services, but that difficulties arise in terms of the priority allocated to the group and lack of service provider training (AFAO: Volumes of submissions, pp 187-188).

5.8 The same inconsistencies occur in relation to the other groups noted above, causing great difficulties for consumers, carers, advocates and service providers.

5.9 The question of the HACC objective and target group was canvassed at the Public Forums conducted by the Committee. There was widespread support for the notion of broadening the HACC objective and target group on the basis that it would be a more positive objective which focuses on achievement rather than avoidance. Comments in support of a broader objective and target group included the following:

- A positive objective which encourages community living, fosters self-esteem, removes guilt for those receiving services who are not 'at risk' and includes people who need support for quality of life;

- Reduces boundaries and gaps for consumers, carers and providers and offers an easier transition for ageing people with disabilities and ageing carers;

- Provides an opportunity for increased choice and flexibility for consumers, improved coordination, increased eligibility for and equitable access to HACC services; and

- Better reflects the needs and preferences of younger people with disabilities, for whom residential care is neither available nor appropriate, and the needs and preferences of older people.

5.10 There were also some words of caution at the Forums. In particular, it was pointed out that in a program where resources are already insufficient to meet needs, a broader target group definition and objective would serve to increase

the pressure on HACC services. The Commonwealth Department of Human Services and Health also noted in its additional submission to the Inquiry that:

> "The Department acknowledges that the objectives of the Program as they relate to younger people with disabilities, need further development to make them more appropriate for that group... If the Program's objectives were changed to reduce or eliminate the focus on avoiding residential care in favour of an emphasis on need for community care, there would be no guarantees that frail aged people would continue to receive the level of services they required."[3]

5.11 While the Committee acknowledges the concerns of the Department, the weight of evidence indicates that the existing objective and target group are outdated and no longer reflect the environment in which HACC operates or the profile of those in the community who require community support. The planning and distribution of HACC resources is canvassed in Chapter 12 and the need to define priority of access is covered later in this Chapter.

5.12 **The Committee recommends that the Commonwealth Department of Human Services and Health, in consultation with the States and Territories and the HACC community, amend the HACC Program objective and target group to:**

- **increase the focus on the need of individuals of all ages with functional disabilities and their carers for support to maintain their independence and quality of life in the community;**

- **ensure that the target group encompasses the range of functional disabilities and removes the distinction between groups on the basis of age; and**

- **provide a clear statement of eligibility criteria for the HACC Program.**

5.13 A further concern noted at the Public Forums was that older people and their carers may not identify with the term 'functional disability'. Most elderly people see themselves as ageing and needing support as a result, but not as having disabilities. This concern should be addressed by the way HACC services are presented to the elderly, to their carers and to other sections of the target group.

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[3] Department of Human Services and Health, "HACC Options/Discussion Paper: Response From The Department of Human Services and Health", Additional Submission.

SERVICE RATIONING AND PRIORITY OF ACCESS

5.14 There is serious concern in the community that the requirement, under paragraph 5(1)(a) of the Schedule to the HACC Act, that services are directed to those with greatest relative need ignores the potential benefits of early intervention. The following evidence to the Inquiry indicates that the direction of services to those with the greatest relative need has led to an increasing focus on individuals with complex care needs. Many have questioned the appropriateness of this situation where large amounts of resources are concentrated in providing services to relatively few clients while large numbers of people with lower level needs are denied access. It is apparent, however, that in some instances providers are attempting to assist larger numbers of clients and may be providing such low levels of service that the effectiveness of this support must be questioned.

5.15 NCOSS, in its submission, discussed the impact of prioritisation of need and placed the process in the context of resources:

> "Providers reported a growing and often overwhelming strain on their resources and consumers are alarmed about the reduction or loss of their services... Prioritisation for service does not reduce need, it simply passes it on through 'hierarchies of service delivery'. That is, responsibility passes from the largest most powerful service provider to the community managed service providers, and when their (already inadequate) resources are insufficient, to consumers and families."(NCOSS: Volumes of submissions, p 1160)

5.16 The Combined Pensioners' and Superannuants' Federation of NSW states its concerns about the increasingly high need focus of the HACC Program in the following terms:

> "There is... a widespread and growing concern regarding a tightening of eligibility criteria, which has two major effects; it reduces existing services and precludes services for potential clients."(CPSF: Volumes of submissions, pp 1629-1630)

5.17 The Australian Council of Community Nursing in its submission stressed that the current targeting approach in HACC raises equity questions and noted that early intervention support is also essential. ACCNS went on to state:

"Many clients are being referred to home nursing services who require between twenty and thirty hours home nursing care a week. The intermittent nature of home nursing care means that many other support services must be provided between the nurses' visits. There comes a point when the resources required to care for a person with this level of nursing need would be more appropriately provided in an institution."(ACCNS: Volumes of submissions, pp 22-23)

5.18 The difficulties encountered in relation to the focus on high level needs, while not confined to NSW, are clearly illustrated by the Home Care Service of NSW (HCS). The Committee heard consistently of problems arising from the policy of the HCS, the major service provider in that State, whereby preference is given to those consumers who require personal care services (such as bathing and dressing) over consumers with lower level needs. The consumers in the latter group are generally those who require assistance with what have been called the 'traditional' services of the HCS, including housework, shopping and gardening.

5.19 The HCS, itself, recognises the difficulties arising from rationing and explained the dilemma faced by service providers in the following terms:

"... in the process of reassessing people, we have taken the approach that our role is to provide a service to the people who are most in danger of being institutionalised. To a certain degree, that is a judgment... Now it does not make a lot of sense to somebody who is 74 who has been having the service for nine years, when we suddenly say to them, `There is now no longer any space for you to have service'. But on the outside of the service seeking help are people who can demonstrate they have far greater needs than some other people who are on the inside of the service. Our critics would say it is very hard to establish whether two hours of service a month is less valuable than when somebody is receiving 30 hours a week, and I would have to agree that there are problems about that. I would have to say that Home Care, along with all other HACC service providers, looks towards a system where some more clearly understood rules about the rationing could take place."(HCS: Transcript of evidence, pp 136-137)

5.20 The tensions arising from the necessity to ration services seem to be exacerbated by the lack of any firm guidance from the HACC Program as to how to determine greatest need. The decision as to what constitutes greatest need is left largely to the individual service provider. There are great variations around Australia in the way this requirement is implemented. Not all service providers have interpreted 'greatest relative need' as meaning most complex needs. Nor is the

requirement to assist those with greatest relative need implemented consistently by service providers. The Committee has heard of many instances where service providers attempt to assist larger numbers of consumers by limiting the amount of service provided to each. In some instances the amount of service is so low that the effectiveness of providing the service is doubtful. In Tasmania, for example, Family Based Respite Care said:

> "For example, a person receiving home help for an hour a week or half an hour a fortnight, which is happening and is ludicrous...".(Family Based Respite Care: Transcript of evidence, p 1223)

5.21 The Tasmanian Consumer Forum for the Aged and the Tasmanian Pensioners Union also commented on the levels of service provided:

> "Home help; most of our people would be lucky if they got an hour a week. Basically, I would say 50 per cent of them would be on half an hour a week - maybe more than 50 per cent."(Tasmanian CFA and TPU: Transcript of evidence, p 1261)

5.22 Similar instances have been raised in other States and Territories.

5.23 The governments responsible for the HACC Program have also recognised the concerns about rationing HACC services on the basis of greatest relative need. The Commonwealth Department of Human Services and Health told the Committee:

> "In that regard we are looking at letting a consultancy which looks at the point of intervention with the client, the level of intervention, the gains for a client through that, the levels of cost to the Program associated with it and balancing the issue. We have identified it as a key issue."(DHSH: Transcript of evidence, p 561)

5.24 Resourcing of the HACC Program is discussed in Chapter 12 in the context of needs based planning. However, it must be acknowledged that the HACC Program is unlikely, in the immediate future, to be able to respond fully to the level of need for community care. It is essential, therefore, that these issues about rationing policy and the point of intervention are resolved.

5.25 The resolution of these issues will require the Program to: take decisions about what constitutes greatest need, particularly in terms of the most

appropriate point of intervention; develop and implement priority of access guidelines to assist service providers in making decisions about the relative need of individual consumers; and an effective assessment mechanism to ensure that the needs of each potential consumer are correctly identified and that there is a means of documenting needs which are not being met. Assessment is discussed in detail in Chapter 9. Despite the weight of the anecdotal evidence about difficulties arising from existing rationing policies in the HACC Program and the lack of any firm policy on either priority of access or early intervention, it is impossible to make decisions about a change in focus in the absence of a complete investigation of the benefits of various points of intervention.

5.26 **The Committee recommends, therefore, that the Commonwealth Department of Human Services and Health give a high priority to the completion of work on point of intervention to enable clarification of the Program's rationing policy. It is further recommended that this work include an investigation of the impact of the unavailability or withdrawal of services on individuals with lower level needs and on their carers and families.**

5.27 **The Committee further recommends that the Commonwealth Department of Human Services and Health, in conjunction with State, Territory and local governments and the community, develop priority of access guidelines which state clearly HACC eligibility criteria and the basis for rationing services, to facilitate a consistent and equitable approach to decisions about access to HACC services.**

ACCESS BY THE TARGET GROUP

5.28 Consideration of access to HACC services by members of the target group falls into two categories. First there is the question of the extent to which the target group as a whole is able to access HACC services. Secondly, there are specific issues which need to be taken into account in relation to particular parts of the target group, including carers and younger people with disabilities.

General Access Issues

5.29 Access to HACC services by the target group depends upon a number of factors including service awareness among potential consumers and carers, the level of knowledge among service providers regarding eligibility for HACC services, service provider attitudes to various consumer groups and the availability of services. As noted earlier in this Chapter and discussed further in Chapter 12, the availability of sufficient HACC services to meet demand is an issue of serious concern in the HACC community. This discussion of general access issues seeks to address the challenges faced by consumers and referrers in identifying and making contact with HACC services. These concerns are relevant regardless of resourcing levels.

5.30 The Committee canvassed the concept of a HACC identity with many witnesses. There is widespread agreement that there is no clearly identifiable entity known as HACC and that consumers, carers and referrers have difficulty in identifying and gaining access to the range of community services.

5.31 While many service providers and government officials agree that there is a lack of HACC identity and that this leads to problems for consumers, some considered that marketing of HACC services and cooperation of local service providers have largely overcome this problem. The ACT Housing and Community Services Bureau, for example, said:

> "I believe that since 1986, HACC has been a very high profile service in the ACT. The service providers that we are dealing with identify very strongly with it and I believe that there has been quite a degree of marketing of the program within the ACT. My view is that there is a real identity of the program not only among the providers of the service but also among the users of the service."(ACT Housing and Community Service Bureau: Transcript of evidence, p 3060)

5.32 The Committee accepts that governments and service providers have made serious efforts to address the access problems arising from an apparent lack of HACC identity. Nevertheless, consumer organisations in particular perceive a continuing lack of HACC identity or visibility in the community and consequent barriers to access. A consumer group in South Australia, for example, said in relation to the existence of HACC as an entity:

"No it does not exist. All that exists is domiciliary care, Meals on Wheels, district nursing et cetera. But HACC does not exist except for the... people in the know."(Council of Pensioners and Retired Persons Associations Inc: Transcript of evidence, p 1911)

5.33 The ACT Consumer Forum for the Aged supported this view:

"My impression would be that the client community out there does not know... There has been a lot of publicity in regard to HACC in recent years, but people still tend to look at it in terms of the individual service that they need at the time, as you say, whether it be Meals on Wheels, a bit of home help or whatever."(ACT CFA: Transcript of evidence, p 3099)

5.34 While a definite identity for HACC is not essential if the Program is seen merely as a funding umbrella, it is critical if the potential of HACC to provide integrated and accessible support services to the community is to be realised. From the consumer perspective, the funding source is irrelevant. It is, however, essential that they can identify the services which can assist them to remain in the community.

5.35 The possibility that a single point of entry may resolve some of the difficulties in accessing HACC services has been suggested by a number of witnesses, including the Victorian HACC Advisory Committee (HACCAC) which said:

"Another suggestion with regard to administrative rationality which gets a lot of support on the ground is the idea of a one stop shop, not so much reducing the numbers of service providers because everybody wants to continue their own service. People get very enthusiastic about the idea of one place that people could come to."(HACCAC VIC: Transcript of evidence, p 808)

5.36 This view is supported by the South East Regional HACC Forum, which said:

"And as things have grown, we have seen that co-locating services and having the ability to tailor things to the client gives them a much better package of service, I guess. It gives them a better option for going to a service and saying, `This is what we want', and we try and work around the guidelines."(South East Regional HACC Forum: Transcript of evidence, p 3163)

5.37 If there is no person or organisation in the community which consumers, carers and referrers can identify as the place to approach to get community care services, the capacity of the community to access services is impaired. The Committee considers that the implementation of assessment agencies as recommended in Chapter 9, will achieve a single point of entry to the Program while addressing the equally important question of streamlining the assessment process.

5.38 A single point of entry, while more visible than the current approach does not resolve the problems fully. There is also limited awareness of the Program among potential key referrers such as general practitioners. Individuals who may benefit from HACC services may not be aware of the Program or the services it offers. The HACC Program appears to lack an organised and effective marketing strategy.

5.39 Evidence presented to the Inquiry indicates, for example, that the Commonwealth produces a large amount of material such as brochures and pamphlets and distributes this to State governments for dissemination in the community. The performance of the States in this regard is variable. The Committee found, for example, that the distribution of consumer rights brochures varied considerably with some witnesses being aware of them and others, even large organisations, not having seen them. The Australian Pensioners' and Superannuants' Federation noted that:

> "In fact, we try our best to get those kinds of things out to our affiliates and encourage them to get them out to the branches, but sometimes it is so hard to get them... we find that not very much actually does reach the consumers. It is very hard to get information."(APSF: Transcript of evidence, p 96)

5.40 A local government employee in NSW expressed a similar concern:

> "... I do not think they are readily available in the general community. With a lot of those things people see it as a lot of gloss - government glossies... They need a brochure to say, 'Here are HACC's services' - basically what it is about - 'If you need it, here is a number to contact'. They can then put it where it is readily available."(Camden Council: Transcript of evidence, p 428)

5.41 Effective distribution of available material for consumers is certainly important. It does not, however, provide the full solution. General material distributed in this way may not be perceived by potential HACC consumers as relevant to them particularly if it arrives at a time when they are managing well and do not require assistance. It is essential, therefore, that information about the HACC Program is also targeted at possible referrers. There are a range of potential referrers of HACC consumers including general practitioners, pharmacists, community health centres, social workers and hospital based professionals. It is essential that governments ensure that referrers are well informed about the Program and are encouraged to participate.

5.42 The Committee is particularly concerned that general practitioners are not more involved in facilitating access by their patients to the HACC Program. Many witnesses spoke of the importance of and difficulties in informing and involving GPs. The witness from the Social Policy Research Centre (SPRC), University of New South Wales, for example, said:

> "We found in the work that we have done with clients - and one of our projects has been following clients up over a three-year period, so we go there fairly regularly - that they have regular contact with a general practitioner, at least once a fortnight and frequently much more often... When asked where they would go for information on services they said, almost to a person, 'We will for to the general practitioner'... But when they go there, it is not available. We found a lot of evidence of lack of use of services."(SPRC: Transcript of evidence, p 224)

5.43 There is no evidence that the HACC Program has utilised appropriate organisations to improve the knowledge base of referrers. The recently commenced Divisions of General Practice, the Pharmacy Guild, the Australian Community Health Association, the Royal Australian College of General Practitioners and other professional agencies provide avenues for the Program to target information to appropriate points.

5.44 The Committee has been told that there is a reluctance among service providers to publicise their services as they have insufficient resources to meet existing needs. While the Committee accepts the difficulties faced by service providers in this regard, the approach of keeping demand down by not promoting services has undesirable consequences. First, it has the effect of hiding unmet need in the community by not encouraging those who need services to come forward and

ask for them. Secondly, it means that HACC services are going to those consumers who know or are able to find out that HACC services exist, rather than those who most need assistance, according to whatever criteria are adopted by the Program for determining priority of access. The Committee considers it essential that HACC services are publicised and that the target group and potential referrers are aware of the availability and role of HACC services.

5.45 It is clear that information dissemination in the HACC Program is ad hoc and has limited impact on the community. **The Committee recommends that the Commonwealth Department of Human Services and Health, in consultation with State and Territory governments, develop a marketing strategy for the HACC Program to encompass:**

- **general information for consumers and potential consumers;**
- **dissemination strategies, involving appropriate peak organisations, to ensure that general information reaches members of the target group;**
- **local level marketing strategies;**
- **appropriate information strategies for people of non-English speaking background and Aboriginal and Torres Strait Islander people, developed in consultation with relevant organisations;**
- **targeted campaigns, involving appropriate organisations, to provide information to potential referrers; and**
- **the use of advertised single telephone numbers for HACC services within a region to assist consumers in locating and contacting HACC services.**

Carers

5.46 The Committee has received a number of submissions and heard from several witnesses concerned about the availability of support for carers. Issues raised in relation to access to HACC services by carers include the general access issues already discussed, along with a range of issues more specific to carers.

5.47 The role of carers in allowing younger people with disabilities and frail elderly people to live and participate in the community can not be underestimated. The significance of this role was canvassed in Chapters 3 and 4. Carers have serious concerns about their access to services. These relate to the availability of services, assessment, knowledge of carer needs, the level of carer awareness of services and the willingness of carers to accept support.

5.48 It is clear that services provided under the HACC Program can give significant levels of support to carers. Support for carers falls into two categories: those services which assist the person cared for, such as delivered meals or community nursing, and are of indirect benefit to carers; and services which are provided directly to carers, such as education and counselling. Other services like respite care are of direct benefit to the carer but also have a direct impact on the person with a disability or frail elderly person. This dual impact can present challenges to the Program and to service providers in situations where the needs and preferences of the carer are at variance with those of the person cared for.

5.49 The Carers Association of Australia pointed out in its submission to the Inquiry:

> "It is important to distinguish between services that assist carers in their practical roles such as home help and community nursing and those which are directed to enhancing carers' knowledge and skills and improving their access to services, such as information, education and training and coordination of care.
>
> Apart from the Carers Support Kit, respite care is the only service directly provided to carers."(Carers Association of Australia: Volumes of submissions, p 419)

5.50 Knowledge of carer needs and indeed the size of the potential target group of carers is critical to ensuring access to services by carers. The Carers Association of Australia proposed that:

> "It is vital that some research of carers as consumers of HACC services be undertaken in order to establish how they feel about current service provision and what additional services might also be appropriate to their needs." (Carers Association of Australia: Volumes of submissions, p 419)

5.51 This view was supported by participants in the Public Forums who, in general, agree that although in recent years there has been significant consultation with carers, there is a need for more formal research on which to base funding and service provision decisions. It was argued strongly at the Forums that the need for research must not, however, delay action to meet already identified needs such as increased levels and flexibility of respite care. **The Committee recommends that, while continuing to develop services to meet already identified needs, such as respite, education and counselling, the Commonwealth Department of Human Services and Health, in consultation with States, Territories and the community, initiate research into the possible size of the target group of carers, service needs of carers and the extent to which carers are able to access needed services under the HACC Program.**

5.52 Major barriers to access by carers are the lack of knowledge among carers of support services available, the fact that many carers do not identify themselves as carers and, commonly, a reluctance among carers to accept assistance. A number of relatively recent developments may begin to impact upon these constraints. The formation of carers associations, for example, is a fairly recent development (the Carers Association of Australia was formed in January 1993) which provides carers with a point of contact and identification and can raise the public profile of carers in the community. The Commonwealth has produced a carers kit to provide specific information to carers about carer issues and services available to carers. The kit is distributed through the Carers Associations.

5.53 The Committee considers that the HACC Program needs to build on these positive developments. **The Committee recommends, accordingly, that the Commonwealth Department of Human Services and Health, in consultation with States and Territories:**

- **promote the role of carers in all HACC Program material;**
- **ensure that promotional material for HACC services clearly identifies carers as members of the HACC target group; and**
- **continue to support the role of the Carers Association of Australia and State level organisations in assisting and informing carers.**

5.54 The assessment process can also be problematic for carers. The Carers Association of Australia said:

> "There are many reported instances of this shift towards crisis care leading to diminishing services for carers.
>
> For example, some carers caring for a person with high needs report that precedence will be given to another person with high care needs who does not have a carer, thus increasing the pressure on the carer. As one carer said 'you have to crack up before they will help'."(Carers Association of Australia: Volumes of submissions, p 419)

5.55 The Committee is concerned that the needs of carers should not be discounted in decisions about access to services.

5.56 **The Committee recommends that the HACC Program ensure that guidelines for assessment and for priority of access specify that the needs of carers are legitimate needs and must be taken into account in those processes.**

5.57 Access to adequate respite care is critical to carers. Respite is consistently identified as the single most important service for carers. The concerns which carers have expressed to the Committee in relation to respite include the amount of respite available, the range of respite services and lack of flexibility. It is clear that carers need adequate respite care and that care must be provided in a variety of forms, including centre-based and home-based, and that the hours of the respite must be flexible. Other aspects of respite which concern carers are the need for crisis or emergency respite, residential respite to allow the carer a holiday and long term solutions, particularly for younger people with disabilities, when carers are no longer able to manage or after the death of the carer.

5.58 The introduction of the Commonwealth Respite for Carers (CRC) Program will increase the supply of respite care services and provide the opportunity to develop more flexible respite care approaches and to test these approaches.

5.59 Typical comments from carer groups and others include:

> "The feedback we are getting from carers is that they want more respite, but they also want the respite that is there to be more flexible. I think we need to look into new forms of respite which are not currently available... There is not much respite available for people to

come into the carer's home which seems to be the preferred method of respite. Day care respite is very popular but you do not have the alternative with that of weekend or overnight, and that is something which is in big demand in that kind of context."(Carers Association of Australia: Transcripts of evidence, p 2500)

"Crisis Respite Care as a regional initiative... is an excellent and flexible concept. HACC should extend this concept to other regions as it would greatly benefit carers..."(Queensland Council of Carers: Volumes of submissions, p 429)

"That brokerage models for the provision of respite care be more widely distributed."(The Carers Association of NSW: Volumes of submissions, p 427)

"These continuing needs are... adequately funded, independent respite brokerage services."(Alice Springs District HACC Forum: Volumes of submissions, p 469)

"... we are constantly getting input from parents and carers of young people who are really at their wits' end. They do not really know what they are going to do with their child, especially during working hours, Monday to Friday. There is no option currently under the HACC program that meets this big area of need, this gap in service."
(Macarthur Community Care Forum: Transcript of evidence, p 486)

5.60 The NSW Government recognises these concerns, recommending in its submission greater flexibility in the use of day care centres for overnight respite and the conduct of a study to develop and pilot innovative models of service delivery to meet the special needs of carers (NSW Government: Volumes of submissions, p 1666).

5.61 **The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with States and Territories and in consultation with carers, review existing approaches to respite care including the CRC Program, identify areas of deficiency and develop a range of flexible respite care options to meet the needs of carers and frail elderly people and younger people with disabilities.**

Access by Younger People with Disabilities

5.62 Access to HACC services by younger people with disabilities is an area of significant contention in the HACC Program. HACC User Characteristics data from 1990 show that some 20% of HACC clients are aged under 65 years. This does not compare favourably with ABS data which show that 60% of the population with moderate to severe handicaps are aged under 65.[4] Resolution of this problem has been canvassed without success over a number of years through mechanisms including the Special Premiers' Conference which proposed, but did not take decisions about, splitting the HACC Program and aligning community care for younger people with disabilities with the Disability Services Program.

5.63 A number of reasons for the imbalance have been suggested to the Committee, most of which relate to a perception that the HACC Program is biased toward the elderly and the difficulty in providing appropriate support for the different needs of frail elderly people and younger people with disabilities through the same service structure.

5.64 The perceived aged care orientation of HACC services and its effect on access by younger people with disabilities has been raised with the Committee on many occasions by organisations representing younger people with disabilities. ACROD, for example, stated quite clearly that:

> "... I think part of the reason why they have not been able to access them up until now is that when HACC was developed it was based on a lot of aged care services that had tremendous pressures put on them and probably very little understanding of what a younger person with a disability needs."(ACROD: Transcript of evidence, p 2485)

5.65 A group representing people with physical disabilities said:

> "One of our centres, in just the last few weeks was told very directly that a person with MS that it was attempting to get extended home help for was not eligible for it - that it was for frail and elderly people. Our staff spend quite a deal of time negotiating with the local government providers to try and get them to accept that these people

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[4] Department of Health Housing and Community Services, "Service Development and Evaluation Report No. 3: HACC User Characteristics Survey 1990", AGPS, 1992, pp 9-10.

are eligible and then to actually get a service to these people."(MS Society of Victoria: Transcript of evidence, p 947)

5.66 As younger people with disabilities clearly are part of the HACC target group, it is of serious concern to the Committee that evidence such as this shows that some service providers do not recognise their eligibility.

5.67 The appropriateness of existing HACC services for younger people with disabilities is a further area of concern. Once again, many disability groups consider that services which have developed in a program framework with an aged care orientation are not sufficiently responsive to the needs of younger people with disabilities. ACROD expressed the following view on the appropriateness of HACC services for this group:

> "We mentioned in our submission that Meals on Wheels really is not an appropriate service for a younger person with a disability who has a job... Perhaps the whole thing of the HACC service is that it is not flexible enough to assist the young person with a disability who really just needs help to get out of bed in the morning, get dressed, get off to work."(ACROD: Transcript of evidence, p 2486)

5.68 A Victorian advocacy group funded under the Disability Services Program compared HACC services to attendant care services funded specifically for younger people with disabilities and expressed fundamental concerns about the operation of HACC services from the perspective of younger people with disabilities:

> "Within HACC services, HACC consumers do not have that flexibility and that control to select their own attendants. Therefore there are occasions when they have people coming into their own homes who they do not know... and there is not that continuity of service." (Attendant Care Coalition: Transcript of evidence, p 779)

5.69 Despite the reservations expressed about the capacity of the HACC Program to meet the needs of younger people with disabilities there is not a high level of support, in the evidence before this Committee, for a split between the aged care and disability components of the HACC target groups. ACROD for example, while noting that services could better meet the needs of younger people with disabilities, was reluctant to support the split due to concerns that younger people with disabilities and their carers would lose out, as they are currently receiving a low proportion of HACC resources, and that it would, in relation to some service

types, involve setting up different services and separate administrations to do the same thing. (ACROD: Transcript of evidence, p 2486)

5.70 The Western Australian government in supporting the existing structure said:

> "A suggestion which has been sometimes put forward is that the Program should be split in order to resolve tension over the way funds are divided between different target groups. The Western Australian Government opposes such a move... Problems would arise because of the significant overlaps in service provided to the different target groups. A new source of administrative duplication would be created."(HDWA: Transcript of evidence, p 2062)

5.71 At the Public Forums, the general consensus was that the Program should not be split along target group lines but that ways be found to deal with the problems within the existing structures. In fact, as discussed above, the majority view supported broadening of the target group rather than breaking it up further.

5.72 **The Committee therefore recommends that:**

- **the HACC Program retain the current multiple target group approach;**
- **the HACC Program liaise closely with the Disability Services Program, at both Commonwealth and State/Territory levels to minimise gaps and to maximise the extent to which HACC services can provide appropriate services to younger people with disabilities;**
- **the review of the CSDA take into account the relationship between the CSDA and the HACC Program;**
- **the Commonwealth and the States and Territories investigate fully as a matter of urgency, the reasons for low levels of access to HACC services by younger people with disabilities and develop approaches to service delivery to address those causes; and**
- **that all HACC training material and publicity stress the place and relevance of younger people with disabilities within the Program and the necessity for service providers to respond to their needs.**

Access by Veterans and War Widows

5.73 The Committee heard evidence from the Department of Veterans Affairs (DVA), expressing concern about the access of veterans and war widows to HACC services.

5.74 DVA raised concerns, in its submission, that veterans and war widows may be excluded from HACC services because there is an incorrect belief that DVA is able to provide in home support to this group. DVA pointed out that it has no mandate to provide home support services, as the Veterans' Home Support Program and its funding was subsumed into the HACC Program in 1988. (DVA: Volumes of submissions, pp 398-400). Officers of DVA said on the issue of access:

> "In brief, the point we are making is that veterans ought to be treated as part of the Australian community. They should not be excluded merely because they are regarded as veterans or war widows. They should have the opportunity to access those services."(DVA: Transcript of evidence, p 2467)

5.75 This view was supported by the Commonwealth Department of Human Services and Health which noted concerns that difficulties had been experienced by this group in relation to equitable access to services. The Commonwealth Department of Human Services and Health said in its submission:

> "The Commonwealth has sought to persuade all States and Territories to circulate to HACC service providers a letter clearly setting out the rights of frail older and disabled veterans to access services on a non-discriminatory basis. States and Territories have been very slow to forward this letter to service providers, and in some cases have minimised the obligations of providers."(DHSH: Volumes of submissions, p 279)

5.76 **The Committee recommends that all States and Territories recognise the right of veterans and war widows to access HACC services without discrimination and advise HACC service providers of this right without delay.**

CHAPTER 6

ACCESS BY SPECIAL NEEDS GROUPS

6.1 The HACC Program recognises that, within the target population there are groups which find it more difficult than others to access appropriate community care services. The HACC Program National Guidelines identify the following groups as having special needs:

- people from a non-English speaking background;
- Aborigines and Torres Strait Islanders;
- persons suffering from Alzheimer's disease and related disorders;
- financially disadvantaged persons; and
- members of the target group living in remote or isolated areas.

6.2 The National Guidelines go on to state that HACC only provides specific services for these groups where an existing service cannot meet the needs, although where special circumstances exist, HACC may fund services aimed specifically at these groups.[1]

6.3 It is apparent that the Program has made efforts to meet the needs of these groups, with significant numbers of specific services funded. However, organisations representing special needs groups, while acknowledging the efforts of the HACC Program to provide appropriate services, make it clear that there is still a long way to go before their needs are met adequately.

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[1] "Home and Community Care Program - National Guidelines", AGPS, 1989, p 4.

PEOPLE OF NON-ENGLISH SPEAKING BACKGROUNDS

6.4 People of non-English speaking background (NESB) are under-represented among HACC consumers. The Commonwealth Department of Human Services and Health acknowledges:

> "Statistics indicate that people of NESB have lower access to HACC funded services. The ABS Survey of Disability and Ageing conducted in 1988 indicated that approximately 16% of people over 65 with moderate or severe disability were born in NESB countries... The HACC User Characteristics Data Collection identified approximately 10% of consumers as coming from a non-English speaking background. The reasons for this are unclear, although differences in family structure and cultural expectations may be relevant." (DHSH: Volumes of submissions, pp 277-278)

6.5 The Program has numerous initiatives in place and has conducted research into various aspects of community care for people of NESB. Some examples of these initiatives include ethno-specific services, multicultural services, case management services, training for mainstream providers and the provision of advocacy and access services for NESB groups.

6.6 The Committee has heard from a number of groups representing non-English speaking background consumers and service providers. The HACC Program is seen by NESB groups as being, generally, a positive development for their constituencies. The Ethnic Communities Council of SA, for example said:

> "I must say, in 1985 when HACC was established we welcomed it very much. We found it very useful to help with ethnic aged problems." (ECC of SA: Transcript of evidence, p 1923)

6.7 This view was supported by the Federation of Ethnic Communities Councils of Australia (FECCA):

> "We affirm to the subcommittee our support of the HACC program and its overriding focus. It is a particularly important program to ethnic communities, which show a very strong preference for community care over institutionalised care."(FECCA: Transcript of evidence, p 325)

6.8 These groups agree, however, that NESB consumers experience difficulties in accessing services and in getting appropriate support. In general, they

do not suggest that these difficulties arise from the sources suggested by the Commonwealth Department of Human Services and Health: rather they suggest that access problems for people of NESB arise from the structure and operation of the Program. Evidence available to the Committee suggests that the HACC Program has an inconsistent approach to the provision of services for people of NESB. These inconsistencies cover areas including representation of NESB people in planning processes, the cultural sensitivity of the assessment process, information provision, ethno-specific service provision and monitoring of access. Issues relating to the assessment process are canvassed in Chapter 9.

6.9 FECCA, on behalf of its State Councils, expressed concern about NESB involvement in planning in HACC:

> "In all of the HACC state advisory committees there is, for example, no ethnic representation, which is of concern... All our state councils believe it is imperative that there be more active involvement in the planning process."(FECCA: Transcript of evidence, p 326)

6.10 In a similar vein, a Victorian Migrant Resources Centre said:

> "In the new northern region HACC advisory committee, for example, the MRC has been excluded, and that makes it very difficult for us to be able to represent issues about non-English speaking people."(Preston/Reservoir MRC: Transcript of evidence, p 675)

6.11 While there may be people of non-English speaking backgrounds represented on Advisory Committees at various times, the Committee is concerned that there is no specific policy of ensuring NESB representation on the Committees.

6.12 The provision of information to people of NESB is also of concern to the Committee. It is apparent that while the HACC Program produces various brochures and pamphlets in a range of languages there is no coordinated information strategy for people of NESB. The Preston/Reservoir MRC said in relation to information strategies:

> "It should actually be done at that community level, rather than having things come from the top down. It is fine if they are translated, but sometimes the language is so highbrow that people still cannot use it- and that is if they get hold of it... Information is always crucial."(Preston/Reservoir MRC: Transcript of evidence, p 686)

6.13 The way in which services are provided is also an area of concern for people of NESB. There are many different approaches taken in the delivery of services for this group including ethno-specific services, use of case management models, multicultural services and efforts to make mainstream services sensitive and responsive. The views of NESB witnesses around Australia vary depending on service provision approaches in each State or region. FECCA, taking a national perspective, pointed out that:

> "... the information we do have from the limited data that is collected suggests an under-utilisation which is a concern. That is clear evidence that the service is not meeting the communities needs. At the same time, the funded ethno-specific or multicultural services have very long waiting lists. The resources that are allocated to ethno-specific or multicultural services are significantly less than what the population warrants... Cultural and linguistic factors need to be taken into account when delivering services to either the aged or the disabled. Quite often, those issues are not taken into account by mainstream service providers."(FECCA: Transcript of evidence, p 327)

6.14 **The Committee recommends that the Commonwealth Department of Human Services and Health in conjunction with States and Territories and in consultation with appropriate organisations including the ECCs, develop and implement a national policy on access to HACC services for people of NESB. The policy should include:**

- **Evaluation of the adequacy of existing data collection and analysis of the reasons for the current under-utilisation of HACC services by people from NESB;**

- **Strategies to improve the involvement of NESB groups and individuals in HACC planning processes including representation on regional, State and national advisory structures;**

- **Improvement of information strategies for people of NESB including information dissemination, appropriate forms of information and appropriate use of language to ensure that information is accessible taking into account issues such as literacy levels in the original language, particularly among older people of non-English speaking backgrounds;**

- **A clearinghouse to consolidate and coordinate the significant amounts of research being conducted into the needs of people of NESB and ensure that work with broader applicability is available across States;**

- **Evaluation of existing approaches to service delivery for people of NESB including methods employed in mainstream services to enable the development of more effective approaches; and**

- **Ensure that people of NESB have access to culturally appropriate assessment through the Regional Community Assessment Agencies recommended in Chapter 9.**

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

6.15 The Commonwealth Department of Human Services and Health considers that access by Aboriginal and Torres Strait Islander people is satisfactory. In its submission, the Department stated:

> "Strategies to target Aboriginal and Torres Strait Islander people have been successful in the Program. The HACC User Characteristics Data Collection, showed that some 2.4% of HACC consumers were Aboriginal or Torres Strait Islander people, compared with 1.5% in the general population."(DHSH: Volumes of submissions, p 278)

6.16 The Committee has received very little information from Aboriginal and Torres Strait Islander groups in the course of the Inquiry. Despite the apparently favourable comparison between the representation of Aboriginal and Torres Strait Islander people among HACC consumers compared with the general population, those groups which have approached the Committee are not satisfied that the HACC Program is responding adequately to the needs of this group.

6.17 The figures provided by the Commonwealth Department of Human Services and Health require further examination before it can be concluded that the Program is satisfying the requirements of this group. First, it must be noted that the HACC User Characteristics Survey 1990 raises some doubts about the accuracy of the figure of 2.4% quoted by the Commonwealth Department of Human Services and Health. That publication cautions that it is likely that Aboriginal and Torres Strait Islander clients were over-reported due to sampling factors, including oversampling

of this group in NSW, a proportion of duplicate data in the Northern Territory and a high percentage of unknown data in Western Australia.[2] Even taking account of the sampling errors, however, it is not likely that Aboriginal and Torres Strait Islander people are significantly under-represented in the HACC Program.

6.18 The second issue is that the Commonwealth Department of Human Services and Health has compared the participation of this group in the HACC Program with its representation in the general population and not with its representation among the HACC target group. There is a paucity of available information about the incidence of disability in this group. Published data from the 1988 Survey of Disability and Ageing does not include information on the incidence of disability among this group. Initial publications from the 1993 Survey, similarly, do not refer to Aboriginal and Torres Strait Islander disability or handicap rates.

6.19 Leaving aside the lack of quantitative data, there was concern expressed by the small number of Aboriginal groups which gave evidence to the Inquiry about the appropriateness of HACC services for Aboriginal people. An Aboriginal organisation in NSW told the Committee of its experience in running a HACC funded service for the first time and the potential conflict between the interests of government and the Program and those of the Aboriginal community in the area:

> "... it was also in the agency's own interest to meet some accountability of performance requirement in the departmental side of the world, rather than one that was responsive to the difficulties of this community and the diversity of this community... They had a Program and they found an agency, namely CADAC, to get it going. There was a very supportive push to get it going. The difficulty we are having is that we are struggling with the emergence of something while we are still finding out about what it means and what the strings attached may be." (Campbelltown and District Aboriginal Cooperative: Transcript of evidence, p 409)

6.20 The same organisation commented on the capacity of the HACC Program, or any Program which is focused on a particular target group, to be responsive to Aboriginal needs:

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[2] Department of Health, Housing, Local Government and Community Services, "Service Development and Evaluation Report No. 3, HACC User Characteristics Survey 1990", AGPS, Canberra, 1992, p 42.

"So, in focusing a particular program, it in a way contributes to the marginalisation or the continuing fragmentation of our society's fundamental values of being as one, together... if an activity is focused in today's terms to a particular group, it is segregating that group from the social whole, the togetherness of us. It is the way we think; it is an alien concept to Western thinking."(CADAC: Transcript of evidence, pp 403-404)

6.21 Another Aboriginal service provider reported to the Committee difficulties in interaction with mainstream service providers:

"I find that mainstream services cannot interact with Aboriginal services. We can always say that Aboriginal services will not interact with mainstream but it also goes the other way... Sometimes when you approach an Aboriginal organisation, you might feel that you are getting a really blank response. This could be true, but you have to keep on trying to get that interaction. Finally, you will get a better and a more relaxed response."(Gilgai Aboriginal Day Care Centre: Transcript of evidence, p 2615)

6.22 While this evidence is limited and does not come from a wide range of Aboriginal organisations, the Committee considers that it does prompt some questions about the extent to which the HACC Program is responding to the needs of Aboriginal and Torres Strait Islander people. **The Committee recommends therefore that the Commonwealth Department of Human Services and Health, in conjunction with States and Territories and appropriate Aboriginal groups:**

- **review its data regarding Aboriginal and Torres Strait Islander access and investigate the extent to which HACC services, both mainstream and specific, are meeting Aboriginal and Torres Strait Islander needs;**

- **ensure that Aboriginal and Torres Strait Islander people are represented in HACC planning processes including representation on regional, State and national advisory structures;**

- **review the relationship between HACC and other Aboriginal and Torres Strait Islander agencies and Programs; and**

- **ensure that Aboriginal and Torres Strait Islander people have access to culturally appropriate assessment through the Regional Community Assessment Agencies recommended in Chapter 9.**

DEMENTIA

6.23 People with Alzheimer's disease and related disorders are an identified special needs group under the HACC Program. The Commonwealth Department of Human Services and Health submission indicates that people in this group have access to mainstream community care services as well as to services funded *specifically to assist people with dementia. Eighty four dementia specific projects* were funded under HACC in 1992-93 to provide services including day care, carer support, community options, home care, and information and education centres. The Department also noted that several initiatives are underway through the National Action Plan for Dementia (NAPD), some of which will benefit people using HACC services. These include the Dementia Training for Community Care Providers Project and a brochure outlining the service options available for people with dementia (DHSH: Volumes of submissions, p 280).

6.24 *Material provided by the Commonwealth Department of Human* Services and Health also gives some insight into the characteristics of people with dementia who use HACC services. Quoting data from 1990, the Department notes that 13.2% of all HACC clients had a 'behaviour' need for assistance.[3] The Department advised that information from the Community Options Projects, while likely to overstate the total proportion of consumers who have dementia, provides greater detail about the characteristics of these clients compared with others. The COPs data indicate that:

> "... *26% of COPs clients aged over 65 were diagnosed as having* dementia and they were:
>
> . slightly older than other clients;
>
> . less likely to live alone;
>
> . more likely to have a carer, especially a resident carer;
>
> . more likely to require assistance because of behaviour, continence and communication;

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3 Information on whether a client has Alzheimer's disease or other forms of dementia is not collected directly as many service providers are not professionally qualified to assess for these conditions. A 'behaviour' need for assistance includes such behaviour as wandering, disruptive behaviour and sleep disturbance. While providing some approximation for counting consumers with dementia, this category is likely to include a number of clients who do not have dementia.

- more likely to have high ADL/IADL scores;[4]
- more likely to access a higher number of hours of service; and
- much more likely to use respite services."(DHSH: Transcript of evidence, p 515)

6.25 Once again, the HACC Program is perceived as having been of great benefit to people with dementia, but scope for improvement has been identified. The Alzheimer's Association of Australia (AAA), for example, expressed support of the HACC Program in the following terms:

> "The Alzheimer's Association strongly supports the principle, goals and objectives of the HACC Program. The Association's philosophy supports the right of people with dementia to live in the community for as long as possible, as this environment provides the best opportunity for them to maintain a relatively normal and secure life. This arrangement is preferable in terms of both quality of life and cost-effectiveness."(AAA: Volumes of submissions, p 77)

6.26 Mainstream servicing appears to have had greater success with people with dementia than with other special needs groups. While there are some concerns about the appropriateness of mainstream services, these relate more to the way services are delivered and the need for flexibility than to a perception of fundamental unsuitability of mainstream services. The Alzheimer's Association of Australia confirmed that:

> "Most people with dementia who receive assistance do so through mainstream HACC services and this is appropriate. However, there is a need for dementia-specific services to assist some of those who have the most severe problems or complex needs, such as people with dementia living alone with little or no support from family members."(AAA: Volumes of submissions, pp 78-79)

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[4] ADLs (Activities of Daily Living) and IADLs (Instrumental Activities of Daily Living) are mechanisms used to measure the extent to which an individual requires assistance to carry out daily tasks in the home and the community.

6.27 The Association warned, however, that:

> "There are real needs to address the education and training issue particularly because if we do not, we get more and more calls for dementia specific services-for example, a call for segregation. We do not necessarily believe that is the best way to go. If staff are trained properly, services can look after most people with dementia. Not all people can be looked after; there will be a group who need specialist services."(AAA: Transcript of evidence, p 251)

6.28 Evidence to the Committee also stressed the need for mainstream service providers to have the knowledge and capacity to respond to the particular needs of people with dementia and to provide services in an appropriate manner. The Alzheimer's Association of Australia spoke of some difficulties encountered with mainstream HACC services:

> "A lot of services that have been going on for decades have a fairly traditional and conventional role of service provision which is to provide a service in a certain way. Given the nature of a dementing illness, it means that that is not necessarily suitable. There are a number of examples... such as the timing of a visit of someone coming into somebody's home. It might be at a time when the person is not used to having a shower, having a meal or whatever and that can be extremely disorienting and... can mean that the person either refuses the service or does not obtain the maximum benefit from the service." (AAA: Transcript of evidence, p 238)

6.29 The need for assessment mechanisms which allow identification of dementia and which meet the special needs of this group are covered in Chapter 9.

6.30 **The Committee recommends that all HACC service provider training include material relating to the special needs of people with dementia and approaches to service delivery which address those needs.**

6.31 One way which has been suggested of obtaining the needed flexibility and responsiveness for people with dementia is through the case management approach of the Community Options Projects. The major point of the submission from the Alzheimer's and Related Disorders Association (ADARDA) of NSW related to the need for case management for people with dementia and their carers:

"The case management function inherent in the model is particularly critical, as consumers can contact one person who will arrange the necessary package of assistance and respond to changes in circumstances over time - essential for a progressive disease." (ADARDA NSW: Volumes of submissions, p 2474)

6.32 The value of the COPs model for people with dementia was reinforced by the national body, the Alzheimer's Association of Australia.

6.33 **The Committee recommends that the HACC Program continue to develop the case management model, using, for example, Community Options Projects and that people with dementia be identified clearly as a special needs group for those services.**

6.34 Carers of people with dementia face special challenges, which were well illustrated by a carer who gave evidence to the Committee, saying:

"For example, when my husband could no longer work and had to retire, he had been so busy all his life that he was determined to continue to be busy. He took off at all hours of the day and I never knew where he was going. It was a case of chasing him down the street four or five times a day. They need 36-hour care... because they need constant supervision. It is like having an uncooperative teenager in an adult body. Often the carers are ageing themselves. I know people in their eighties who are struggling to care for their partner. It is almost impossible."(AAA: Transcript of evidence, p 242)

6.35 This description of the challenges for carers of people with dementia is consistent with the fact that the major need reported in terms of services for people with dementia and their carers is respite care. This is supported by the COPs data quoted above which shows that people with dementia are much more likely than other consumers of HACC to use respite. Carers of people with dementia have similar needs to those discussed for carers generally in the previous Chapter but it seems that respite, in particular, is even more critical for this group and that it must be appropriate, safe for the person with dementia and flexible.

6.36 **It is recommended that the Commonwealth Department of Human Services and Health ensure that the development of innovative and flexible respite care options as recommended in Chapter 5, pay particular regard to the needs of carers of people with dementia and the development of suitable forms of respite for people with dementia.**

6.37 The Committee draws attention to the fact that the following issues were also raised and should be addressed by the Commonwealth Department of Human Services and Health and State and Territory governments in any planning proposals: the lack of appropriate support for younger people with dementia; lack of security of services; the need for services for people in the early stages of dementia; and geographic variations in the availability of services for this group.

FINANCIALLY DISADVANTAGED PEOPLE

6.38 It is estimated that some 93% of HACC consumers are in receipt of pensions. As noted by the Commonwealth Department of Human Services and Health:

> "This has significant implications when the issues of financial disadvantage and fees/donations are considered in the context of access to services."(DHSH: Volumes of submissions, p 278)

6.39 The user charging policies of individual services vary significantly and include formal income tests, donations policies, waiver of fees and policies of not charging any fees. This variation raises concerns in terms of equity and the extent to which people may be denied access, even unintentionally, on the basis of inability to pay. The Committee has heard varied points of view about the effect of user charging, with some witnesses claiming that even low fees can result in access being restricted while others state that paying at least something for a service gives a greater sense of dignity to the consumer, particularly among the elderly.

6.40 The Committee has heard evidence that many consumers have the capacity to and prefer to make some contribution to the cost of the service. One provider of home modifications services, which has a flexible fees policy under which labour costs are waived for any consumer who is unable to pay, said:

> "If the person rings me up or says to the tradesman, 'I can't pay this', we say 'Are you able to pay it off?', and if they cannot pay it off, then we waive the labour fee... We take their word for it, and I would say 90 percent of the people who use our services are receiving pensions... In the last year I have not had one person not want too pay. They are all very proud and they all want to pay." (Blue Mountains Home Modification and Maintenance Scheme: Transcript of evidence, pp 2663-2664)

6.41 Another group, representing the parents of children with disabilities and involved in the provision of respite care, pointed out to the Committee that, despite flexible fees policies and Program guidelines, some people are denied access due to inability to pay:

> "One of the parents that we have close contact with has a child with very severe disabilities. Her husband has not gone bankrupt but he is unemployed... She has only used specific home care twice this year because she cannot afford $2 an hour. It seems ridiculous, but she is too proud... In the guidelines it says that cost should not be a barrier to using the service. I have checked and it is a barrier, but in some places it is not. It is this variation."(Action Group for Disabled Children: Transcript of evidence, pp 962-963)

6.42 The Committee is also concerned that the lack of formal links between individual services make it difficult for any one service provider to take account of the fees a consumer may be paying for other HACC services. An organisation representing elderly consumers raised this issue in the following terms:

> "It is not the paying for the service that was a worry to the consumer forum. The worry was that if a person has multiple services, how much are they looking at. Suppose they have a rent component to pay and they have meals on wheels and they are paying for four or five other services" (TPU and TAS ACF: Transcript of evidence, p 1268)

6.43 The Committee considers that, in view of figures quoted in Chapter 9 regarding the usage of multiple services, the impact of separate fee charging by individual services does impact on significant numbers of HACC consumers and must be addressed by the Program. This issue was also raised by an organisation which has a formal fees policy based on disposable income, under which the majority of clients pay some fee:

> "I do not think standardisation of fees can work where there is not a key worker or care management model across all the services in Western Australia. If you are looking at saying that the client can choose a key organisation which will care manage his needs... then the fees, if there are going to be fees, should support the operational cost to care manage that."(Perth Home Care Service: Transcript of evidence, p 2311)

6.44 There is not, however, universal agreement that a more standardised approach to user charging is desirable. The Municipal Association of Victoria, while

supporting the implementation of fee charging principles, expressed opposition to standard fees:

> "It is important that there are clear principles upon which fees for HACC services are levied, however, the Association does not support the view that all HACC fees should be standardised. Local government is an equal or major funder of services and as such earns the right to set their own fees."(MAV: Volumes of submissions, p 766)

6.45 The HACC Program does not collect data on the user charging policies of HACC services. The Program has developed a set of principles for user charging but does not, at this stage, have a detailed policy on this issue. The Commonwealth Department of Human Services and Health indicated in its submission that such a policy is being developed:

> "The policy will take a big step in reducing the differences in fees practice between States/Territories and between services, and ensure financial status does not infringe upon the access of consumers to service."(DHSH: Volumes of submissions, p 278)

6.46 The Commonwealth Department of Human Services and Health has indicated that a draft fees policy was released in November 1993 for consultation and comment. Comments have subsequently been provided to the Department and have been considered by a working group of Commonwealth and State/Territory officials and a revised version is being drafted. The revised draft has not yet been released.[5]

6.47 The major challenges identified in this Inquiry for user charging are consistency and equity, multiple service users, which organisation levies the fee for multiple service users and the use to which fee income is put. The Regional Community Assessment Agency pilots recommended in Chapter 9 of this report could provide a mechanism to test a common regional approach to user charging. **The Committee recommends, therefore, that the Commonwealth Department of Human Services and Health, in conjunction with State and Territory governments, pilot a user charging system with the following features:**

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[5] Mr B Conway, Director, Community Care Strategies and Management Section, DHSH, Correspondence, 8 June 1994.

- **a simple sliding scale of fees which takes into account the generally low disposable incomes of HACC consumers with discretion to waive fees where consumers are unable to pay;**

- **the Regional Community Assessment Agency having responsibility for the assessment of the capacity of each consumer to pay for HACC services and possibly for the collection of fees (fees could be paid to the individual service provider for the convenience of the consumer and forwarded to the assessment agency);**

- **revenue generated from fees to be distributed within the region in line with regional needs based planning as recommended in Chapter 12; and**

- **an evaluation strategy for the pilot to be implemented to assess the effectiveness of the model in terms of the impact on consumers, any unintended consequences and the cost of assessment for fees and collection compared with the revenue raised.**

6.48 The implementation of this recommendation should involve full consultation with consumers and providers in the regions involved. The Committee would envisage the pilot being conducted in regions where fees are already charged.

RURAL, REMOTE AND ISOLATED AREAS

6.49 The Committee received submissions from a number of rural areas and a small number of remote or isolated areas. Hearings were conducted in Newcastle, Launceston and the Blue Mountains to gain a greater perspective on the issues for non-metropolitan consumers and providers. A public meeting and inspection were also held at Broken Hill, along with a visit to the Nyampa Aboriginal community at Menindee, near Broken Hill. In addition, many organisations representing consumers and service providers in all areas of Australia and large service providers operating across a State or Territory gave evidence to the Committee.

Definitions

6.50 The Program has identified members of the target group living in remote and isolated areas as a special needs group for the HACC Program. It has not, however, developed a nationally consistent definition of the terms rural, remote or isolated and Program material often refers to rural, remote and isolated areas as having special needs.

6.51 The Commonwealth Department of Human Services and Health advised the Committee that each State and Territory has its own approach to definitions. These include:

- no formal definition in WA, NSW, SA, NT and the ACT (which, it is noted, has not needed to do so);

- use of ABS definitions, in some cases with variations in local practice, in Victoria and Queensland;[6] and

- a detailed classification system with seven groupings in Tasmania. (DHSH: Transcript of evidence, pp 521-523)

6.52 The Committee is concerned that the lack of consistency in definitions is likely to impede effective planning and reporting in relation to these groups. **It is, therefore, recommended that the Commonwealth Department of Human Services and Health work with States and Territories to develop and implement nationally consistent definitions of the terms rural, remote and isolated.**

Distinction Between Rural and Remote and Isolated Areas

6.53 While rural and remote or isolated areas are often linked in discussions of policy and program delivery, it is important to distinguish between them as the conditions affecting service delivery are quite different. The most significant differences relevant to the delivery of HACC services are the presence of support infrastructure, relative population density, access to services such as specialist health care and distance. While rural, remote and isolated areas are affected by these

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[6] In Victoria, the Municipal Association of Victoria has developed its own definitions.

factors, it must be acknowledged that they are greatly accentuated in remote and isolated areas.

6.54 Service delivery approaches, like case management or multi-service type outlets which are successful in reasonably well serviced and accessible rural areas may operate quite differently in truly remote and isolated locations. This is demonstrated by the comments of a service provider from the Pilbara area of Western Australia:

> "My project recently applied for increased funding to run the community options project for the whole of the Pilbara. The health department thinks that a 0.5 administrative person is enough to operate two offices and cover all of the Pilbara, considering we are running a brokerage model without any service to broker from. We effectively have to employ each individual care giver and pay them so we have a huge payroll... It is 510,335 square kilometres. Its Aboriginal population is about 10.4 per cent of its entire population."(Pilbara HACC: Transcript of evidence, p 2252)

6.55 Many of the issues raised in this section are common to rural, remote and isolated areas. It must be kept in mind, however, that many of them are more severe and more difficult to deal with in remote and isolated areas.

Service Delivery in Rural, Remote and Isolated Areas

6.56 In general, the HACC Program has brought about improvements in the provision of community services in rural and remote or isolated areas. There are, however, still significant difficulties in those areas relating to additional costs, travelling time, coverage of services, availability of the full range of community support services and the lack of infrastructure.

6.57 The Commonwealth Department of Human Services and Health said of HACC service delivery in rural, remote and isolated areas:

> "54% (1907) of service outlets (3515) are located in rural and remote areas. Approaches to provision of adequate services for people living in remote and isolated areas have included substantial cross-program links in both planning, funding and service provision. They have also focused on exploring models which are more appropriate to this

environment, like multi-purpose centres and services, which provide a range of services.

The Community Options Projects (COPs) approach has proved successful for improving access to appropriate services to isolated consumers."(DHSH: Volumes of submissions, p 280)

6.58 The multi-purpose services referred to by the Commonwealth Department of Human Services and Health are pilot services which provide a range of aged and health services in rural, remote and isolated areas. Funding provided by the Commonwealth and the States is pooled and the service is operated by a management committee selected from the local community. An evaluation of the pilot is underway. (DHSH: Transcript of evidence, p 512)

6.59 The NSW government commented on the provision of services in remote areas:

"It has never been an easy thing to handle the question of service provision in remote areas. From our experience the most useful thing to do is to treat the whole needs of the community in a very holistic way. So when you have a program that is very specific about the types of services that it is eligible to fund... it can be quite difficult to make that fit into the dynamics and operating practices of a small community... So if you lock in budgets, lock in service descriptions and lock in areas of specialisation without the flexibility to move them around a fair bit, you find that you are not doing a very efficient job..."(DOCS: Transcript of evidence, pp 33-34)

6.60 This statement was supported by the South East Regional HACC Forum which represents services across a number of rural areas in south eastern NSW. Representatives of the Forum said:

"Also when projects are funded on the ground, they are funded to provide a single type of service.

In a rural area that is not necessarily appropriate... So I guess the thrust of our recommendation is that we should be able to sit down with the government departments and say that we want a service that does all of these things."(South East Regional HACC Forum: Transcript of evidence, p 3168)

6.61 The Blue Nursing Service, a major provider of domiciliary nursing and other services in Queensland which covers all areas of the State commented on the need for adequate funding for the provision of rural services, particularly in funding of vehicles, and went on to say:

> "Access to education and support stuff is difficult in rural areas, but I actually think some of our better services are in rural areas, quite good services... I think the availability of other services is the problem-the availability of the range of services that you have got, that is the problem." (Uniting Church in Australia, Division of Aged Care and Domiciliary Services: Transcript of evidence, p 1681)

6.62 Another service provider from a rural centre in NSW raised the issue of coverage of services, particularly in terms of access for people living in outlying areas around rural town centres:

> "And another area was just lack of services to isolated areas. Often in large urban areas a whole range of HACC services are available. For people that even live in villages say 30 kilometres from a town like Bathurst, it is often very difficult for the types of services that are available in Bathurst to be provided in those areas, so we in Bathurst have quite a concern for people who do not live in urban areas and their ability to access HACC services."(Bathurst City Council: Transcript of evidence, p 2561)

6.63 In practice many rural, remote and isolated services are permitted a level of flexibility and multiple service types can be provided within a single organisation. The Committee received a number of submissions from rural service providers which provide several service types from one outlet. The HACC Unit Costs Study noted that among the services included in that study:

> "Several organisations provide services which do not fit into any single service type, while others provide services comprising several service types in... an integrated fashion..."[7]

6.64 It is apparent that the traditional HACC approach to funding services by service type requires flexibility in order to be effective in rural areas. It does not respond adequately to the needs of remote or isolated areas.

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7 Department of Health, Housing and Community Services, "Aged and Community Care Service Development and Evaluation Report No. 7: Home and Community Care Program Unit Costs Study, AGPS, Canberra, 1993, p 1.

6.65 **The Committee recommends, therefore, that the Commonwealth Department of Human Services and Health, in conjunction with the States and Territories, investigate the effectiveness of various approaches to service delivery in rural areas and, particularly, in remote and isolated areas and develop a rural and remote areas policy which encourages the funding of flexible approaches to service delivery including multiple service outlets with flexibility in the allocation of funds between service types. The policy must address the particular needs of remote and isolated areas.**

Case Management and Brokerage

6.66 The case management and brokerage model of the COPs and Linkages projects has been identified as being particularly effective in rural, remote and isolated areas. This success has been largely due to the capacity of the model to be flexible and innovative. As noted earlier, however, in remote areas where the infrastructure of HACC services and other health and community services is limited, the model is more difficult to manage and modifications to the standard funding formulae may be necessary in remote and isolated areas.

6.67 The national evaluation of the COPs model found that the flexibility of the projects was among their most important features. The evaluation stated:

> "The projects' flexibility meant they could respond according to the local service context. For example, where HACC services were not available in South Australian rural areas, the projects used neighbours and local people as contractors and organised volunteer networks to support clients. This meant the projects had a positive impact on strengthening local support networks. In New South Wales remote areas, it was clearly cheaper to employ a local person than to rely on the Home Care Service sending someone long distances from a major centre."[8]

6.68 The evaluation report went on to note that among the people considered to benefit most from the additional services which can be purchased by the projects are:

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[8] Department of Health, Housing and Community Services, "Service Development and Evaluation Report No. 2, It's Your Choice, National Evaluation of Community Options Projects", AGPS, Canberra, 1992, p 70.

"... clients who live in areas where existing services are very limited, In these circumstances the ability to purchase services increases the range and appropriateness of assistance that can be provided."[9]

6.69 The views expressed in the evaluation report are largely supported in the evidence to this Inquiry.

6.70 **The Committee recommends that, consistent with recommendations in Chapter 10, case management projects be established in rural, remote and isolated areas to ensure full geographic coverage of these areas. It is further recommended that case management projects funded in remote and isolated areas receive funding which recognises the particular difficulties inherent in providing services in sparsely populated remote and isolated areas.**

6.71 While Chapter 10 recommends case management only for high need clients, the nature of remote and isolated areas, and to a lesser extent rural areas, means that case management and brokerage may be appropriate for low and high need consumers in those areas and could provide the only mechanism to achieve access to needed services. **The Committee recommends, therefore, that guidelines for these projects in rural, remote and isolated areas take account of the particular needs of these areas and allow greater flexibility in terms of target groups and that staffing levels for the projects recognise the greater demands involved in remote and isolated areas where there are few established services.**

Costs of Service Delivery in Rural and Remote and Isolated Areas

6.72 It is commonly stated that there are greater costs involved in providing services in rural areas and particularly high costs involved in remote and isolated areas. There is, however, limited analysis of these costs. The Unit Costs Study commissioned by the Commonwealth included a number of rural and remote services. The study noted an absence of any clear trend in the cost of these services. It did find, however, that the services did not appear to incur a greater proportion of costs on travel than was the case for urban services. It was suggested that this may result from factors like small catchment areas for the rural and remote services. The report of the study suggested that:

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[9] ibid, p 72.

"The absence of any clear trend in the cost of rural services may reflect:

- workers in metropolitan areas receiving higher wages which counter the effect of cost disadvantages in the remote areas

- relative service costs mirror Program resource allocations and organisational history rather than cost comparisons between similar services in different locations

- service providers seek to minimise the cost of isolated consumers by recruiting workers nearby or by not providing service."[10]

6.73 It must be recognised, however, that this study was not intended as a statistically valid sample of HACC services and its results can not be extrapolated to all remote or rural services. **The Committee recommends that the Commonwealth Department of Human Services and Health in consultation with the States and Territories investigate the additional costs of providing community care services in rural, remote and isolated areas in order to develop funding models for these areas which recognise any additional costs identified.**

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10 Department of Health, Housing and Community Services, "Aged and Community Care Service Development and Evaluation Report No. 7: Home and Community Care Program Unit Costs Study, AGPS, Canberra, 1993, pp 101-102.

CHAPTER 7

IMPROVING CONTINUITY BETWEEN HEALTH AND COMMUNITY CARE

7.1 Evidence of a lack of continuity between the health system and community care has been a major feature of this Inquiry. Issues relate primarily to the impact of health sector policy on consumers who require post acute care or palliative care or rehabilitation services, which are designated as 'no growth' areas under the HACC Program.

7.2 Concerns raised during the Inquiry include increasing demand for post acute and palliative care, lack of discharge planning, definitional problems and the possible implications of casemix funding of hospitals on the HACC Program.

HISTORY AND RATIONALE OF THE NO GROWTH RESTRICTIONS

7.3 At the inception of the HACC Program, the Commonwealth and the States and Territories agreed that, in order to achieve the intended focus of the Program on basic maintenance and support services for the frail elderly and younger people with disabilities, it would be necessary to restrict some other areas which had been funded under the subsumed legislation. As a result, some service types were deemed to be out of scope in the Program and others were included, but subject to restrictions on growth.

7.4 The Home and Community Care Act 1985 specifies that services providing accommodation or a related support service and the provision of aids and appliances are out of scope in the HACC Program. The Act also states that the following services will be eligible for funding, while no alternative funding arrangements have been made, to the extent required to maintain them at the level at which they operated prior to the introduction of the HACC Agreements:

- rehabilitative services directed primarily towards increasing level of functioning;
- services providing direct treatment for acute illness, including convalescent or post acute care services;
- services specifically for people with the same disability, other than those with dementia;
- services primarily for families in crisis; and
- palliative care services.[1]

7.5 The legislation also provides that projects falling within the no growth restrictions are to be reviewed by the Commonwealth and the State and for alternative funding arrangements to be made if Ministers see fit. In the event that no alternative funding arrangements are made the services were to continue to be eligible for funding subject to the no growth restrictions.

7.6 The rationale for the no growth restrictions is encapsulated in the words of Senator the Hon Don Grimes, the Commonwealth Minister responsible for HACC at the inception of the Program:

> "In developing and strengthening the range of services, the priority under the HACC Program will be to provide access to ongoing care to that large number of frail aged and younger disabled people who need help but who have had little or no support in the past in receiving the services they, and their carers, require to stay at home."[2]

7.7 The Minister spoke further of the rationale for the no growth category, saying:

> "The services so designated as compared with those for the prime HACC target group tend to meet short term and often intensive needs. Moreover, they tend to reflect a rather limited view of using support services as a means of assisting the hospital system to reduce average length of stay."[3]

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1 *Home and Community Care Act, 1985*

2 Australia, Senate 1985, *Debates*, vol. S 111, p 2125.

3 Australia, Senate 1985, *Debates*, vol. S 111, pp 2125-2126.

7.8 The First Triennial Review of the HACC Program examined the situation of the no growth services in 1989 and supported the continuation of the limits on growth. The Review also addressed the need to define the no growth areas more clearly and proposed revised definitions based on purpose of intervention. The Review stated, however, that the definitions would have no place in individual client assessment and should not be utilised to qualify or disqualify individual clients. The intention was that they would help to identify classes of clients eligible for HACC funding and to categorise at a global level the types of services provided and to measure provision.[4] The definitions are now reflected in the HACC National Guidelines. The definitions of post acute care and palliative care are as follows:

> ". **direct treatment of acute illness and post acute care services** involve the provision of after care in the form of continuing management or treatment of the effects of an acute illness or injury for which hospital (including day surgery) admission or medical attention was required. They also include post partum care... Such care is aimed at curative ends rather than maintaining the person's present state of functioning or health. The care provided is such that if it were not provided, hospital or convalescent care would be required.
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> . **palliative care services** involve the provision of care to a person with a terminal illness (i.e. death anticipated within three to six months). This type of care involves the relief of pain, provision of comfort, maintenance of mobility, specific treatment for the terminal condition with the provision of personal care... The care provided is such that if it were not provided, hospital or hospice care would be required."[5]

7.9 The Triennial Review working group views on the no growth issues were summarised as follows:

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4 Home and Community Care Review Working Group, "First Triennial Review of the Home and Community Care Program - Final Report of the HACC Review Working Group to Commonwealth, State and Territory Ministers", AGPS, 1988, pp 11-15.

5 "Home and Community Care Program - National Guidelines", AGPS, 1989, pp 32-33.

". the no growth restrictions should be retained;

. levels of provision of no growth services should be measured...;

. at the global level these measurements would be used by service providers at an appropriate aggregate level to ensure that the balance between 'no growth' and 'in-scope' services corresponds to different funding sources available; and

. where no growth services are expanding alternative funding sources should be identified and negotiations undertaken to match the additional demand with additional funds."[6]

IMPACT OF THE NO GROWTH RESTRICTIONS

7.10 Evidence to this Inquiry indicates that the no growth restrictions on post acute and palliative care have continued to work against continuity between acute health care and community care. The Commonwealth Department of Human Services and Health acknowledged the difficulties posed by the no growth restrictions:

> "The capacity of HACC funded organisations to respond to the needs of post acute and palliative care consumers... is limited. The most immediate consequence of this is the difficulty of ensuring a smooth transition for such people from hospital to the community."(DHSH: Volumes of submissions, p 283)

7.11 Most of the post acute and palliative care in the HACC Program is provided through generic service providers, particularly home help and nursing services, which also provide 'in-scope' basic maintenance and support services. These service providers may also receive funding from other sources such as State health departments, the Medicare Incentives Program or disability services programs.

7.12 It is apparent to the Committee that the onus for maintaining the no growth restrictions has fallen mainly to service providers, who struggle to keep an appropriate balance between in-scope and no growth services in the face of

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6 Home and Community Care Review Working Group, op cit, p 17.

increasing demand for both categories of service. Efforts to pursue alternative funding arrangements for growth in these areas have largely occurred at the level of individual service providers seeking funding under other programs rather than any formal action by the governments responsible for HACC. Service providers continue to find the definitions of post acute and palliative care inadequate and there is considerable confusion about the categories of services subject to the no growth restrictions and the variability of enforcement of the no growth restrictions.

7.13 The ACCNS, for example, raised the concerns of community nursing agencies, advising the Committee that prior to the introduction of the HACC Program, nursing services were funded with a broad brief to provide community nursing services to both the current HACC target group and to people requiring post acute and palliative care and to the chronically ill. ACCNS went on to say that:

> "With the introduction of the HACC Program and the delineation of target and non target groups service providers were required to redefine their patient populations. They were also asked to make inappropriate choices as to the level of service provision they would provide to the non HACC target areas such as post acute and palliative care."(ACCNS: Volumes of submissions, p 23)

7.14 There is little evidence of formal attempts by either the Commonwealth or the States/Territories to develop links between the sectors or to clarify the boundaries and responsibilities of the programs involved. Attempts to address the need for alternative funding sources for the no growth services and for greater continuity have been piecemeal. The Medicare Incentives Program, for example, funded a number of projects to provide post acute, post partum, palliative care and rehabilitation to patients discharged from hospitals. The Commonwealth has also funded recently, pilot transition care packages under which ACATs perform a budget holder function to ensure the provision of services for elderly patients discharged from hospitals. Some State health departments have instigated projects to provide hospital care at home or to provide post acute care. None of these approaches, however, form a consistent or equitable approach to the issue and pressure on the HACC Program continues. ACCNS offered the following comments on the funding situation:

> "Funding difficulties... have arisen because there was a belief that these services would be funded through other Commonwealth and State Programs. The only Commonwealth funding made available for the Non HACC Target Group was the $25M Medicare Incentive Funding.

Only negligible amounts of this funding were made available to home nursing services... Member agencies request, that as a matter of urgency, negotiations between the Commonwealth and States occur to bring to an end this funding debacle which has now been in existence for almost a decade."(ACCNS: Volumes of submissions, p 23)

7.15 Stage 1 of the Mid-Term Review of Aged Care examined the links between acute and long term care for the aged and found that:

"Notwithstanding the clarification provided in the Triennial Review, the specification of the "no growth" post acute care area has become increasingly problematic in recent years for a number of reasons. Alternative sources of funding have not been forthcoming and

providers felt that competition between groups forced them to juggle resources and clients."[7]

7.16 The definitional problems which continue to prevent accurate measurement of the no growth areas and to trouble service providers attempting to operate within Program guidelines are typified in the comments of the Royal District Nursing Service (RDNS):

"... we have always had these definitional problems with HACC. It has been one of the problems that has made it difficult for it to be the success that it should have been.

When does a frail aged person who is 80 years old and has come out of hospital with a broken hip come back into frail aged and when are they still post acute? What about a person who is frail aged and being cared for as a specific HACC patient who is then diagnosed as being terminally ill? When does that person become a palliative care person and become part of a no-growth area?"(RDNS: Transcript of evidence, p 887)

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7 Department of Health, Housing and Community Services, "Aged Care Reform Strategy Mid-Term Review 1990-91: Report", AGPS, 1991, p 168.

IMPACT OF ACUTE HEALTH CARE POLICY AND PRACTICE

7.17 There is a high level of concern among HACC providers, consumers and governments about the impact of acute health policy on HACC services and on demand for post acute and palliative care. These concerns revolve around a fear that trends toward early discharge, reduced lengths of stay and day surgery have led to increased pressure on the community care system to provide support without corresponding increases in community care funding.

7.18 The anecdotal evidence of increasing demand for post acute and palliative care in the community and of increased usage, despite the no growth restrictions is strong. There is, however, limited empirical evidence of any increase in demand. Nor is there an established baseline to demonstrate which of these services were provided at the inception of the Program. While many service providers have given some details of the level of post acute and palliative care occurring in their particular service, many have been unable to, and the information which is available does not allow the Committee to draw broad conclusions about growth in this area.

7.19 In 1988, when concerns about demand pressures on the no growth areas were already being expressed, the Triennial Review of HACC undertook some investigations of the level of no growth services under HACC. These indicated that between 20 and 30 per cent of occasions of service by nursing agencies fell within the no growth areas and about 12 of home help services (this figure was based only on figures from NSW).[8] The Mid-Term Review of Aged Care, on the other hand, quoted ACCNS figures for 1991 which indicated that post acute care accounted for 16% of all community nursing clients.[9] In the absence of detailed analysis of no growth provision data it is not possible to draw any useful conclusions.

7.20 While much of the concern about pressures on the no growth areas of HACC is attributed to the advent of casemix, it must be acknowledged that casemix has not yet been widely implemented in Australia, and it is unlikely that HACC services are feeling any widespread effects of the casemix approach at this stage.

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8 Home and Community Care Review Working Group, op cit, p 16.

9 Glidden, T and Finch, C, "Patient Dependency and Resource Allocation in Domiciliary Nursing", Australian Council of Community Nursing Services, Sydney 1991, quoted in Department of Health, Housing and Community Services, "Aged Care Reform Strategy Mid-Term Review 1990-91: Report", AGPS, 1991, p 168.

Concerns about early discharge, day surgery and reduced lengths of stay predated moves toward casemix. As noted above, the First Triennial Review of HACC referred to pressure arising from these factors as early as 1988. It can not be denied, of course, that casemix funding provides incentives for increased patient turnover and therefore early discharge. However, the Committee recognises that casemix will simply continue and possible intensify trends which have been apparent for some time.

7.21 Despite the lack of empirical evidence there is a general acceptance that there is pressure on post acute and palliative care provision under HACC and that this pressure emanates from hospital policies. The Commonwealth Department of Human Services and Health, for example, stated:

> "The Commonwealth... has actively encouraged States and Territories to improve the efficiencies of their hospital systems. States/Territories and hospitals, coerced by budget constraints, also apply pressure for early discharge to achieve efficiencies. These activities significantly increased demand for community based services. However, changes in hospital/medical practice have not always been matched by improvements in discharge planning, with the appropriate infrastructure to support these patients in the community."(DHSH: Volumes of submissions, p 283)

7.22 These views are echoed by some State and Territory governments. The NSW government said in relation to the impact of casemix funding on community care:

> "The trends towards casemix models of hospital funding and the further development of day only surgical procedures may also prompt greater demand for some of these services.
>
> With casemix... greater incentives are created for early discharge of patients. Studies from the United States... have shown that there has been a decline in the health of patients upon discharge and an increase of demand for outpatient and other community based services."(DOCS NSW: Volumes of submissions, p 1701)

7.23 These views are supported by consumer and service provider organisations. The APSF, for instance, said of the conflict between long term care and post acute care needs:

"One of the things that is putting pressure on the program at the moment is people who are coming out of hospital and needing services. More and more we are seeing people being told that they can no longer get services because these people have a greater need. Yes, they do have a need, but whether or not it should be at the expense of people who are living in the community, and trying very desperately in some cases to live in the community, is a case in point."(APSF: Transcript of evidence, p 84)

7.24 The service provider view of increasing demands is well represented in the comments of the Victorian Branch of the Australian Nursing Federation:

"From what we hear, there is an increase. I would also make the point though, that the public health system in Victoria over the last five years has taken very significant funding cuts. So we have seen a gradual decrease in the funding and therefore a gradual build up of early discharge. But the introduction of casemix and casemix funding in Victoria is primarily aimed at making budget cuts... as we are seeing people being pushed out... far earlier than they should be. Certainly the Royal District Nursing Service and the local district nursing services... are finding great difficulty in dealing with the increase."(ANF: Transcript of evidence, p 695)

7.25 Although widespread, the perception of increasing demand is not unanimous. The Victorian Department of Health and Community Services said:

"As yet we do not have any firm statistical evidence that a shift is going on. That being said, some of the more dramatic changes in hospital funding in Victoria have occurred... since the beginning of July this year, and we do not have any firm statistical data that would confirm costshifting from one sector to another."(DHCS VIC: Transcript of evidence, p 653)

7.26 The Mid-Term Review of Aged Care summed up the current position in regard to demand for and supply of post acute care services in the following terms:

"The information currently available on the use of post acute community care is piecemeal. While a picture is emerging of the significance of this group of clients to service providers, it is not yet possible to estimate the proportion of all older people discharged from acute care who currently use community services. Nor is it possible to estimate the further need for these services and the extent to which

discharge is delayed for want of community services. This is an important area for further research."[10]

IMPROVING CONTINUITY

7.27 The Committee is convinced that concerns about the impact of lack of continuity between acute health care and community care are soundly based and that options to improve the position must be pursued. In the HACC Options/Discussion Paper produced as part of this Inquiry, the Committee proposed three options to deal with the difficulties inherent in the provision of post acute and palliative care under the HACC Program and the consequent lack of continuity between acute health and community care.

7.28 The first of the three options - to retain the no growth restrictions and monitor levels of provision of these services - gained limited support. It is seen as a continuation of the present unsatisfactory situation. Attempts to categorise and monitor provision of services in the no growth areas have had limited success to date, largely as a result of the definitional problems discussed earlier.

7.29 Views on the remaining options - a transfer of resources from the health budget to the HACC budget to enable HACC to meet demand or transferring responsibility for these services to hospitals - were mixed, although there was general support for the principle that the health sector should be responsible for the costs associated with its policies and practices. There are mixed views as to how this could be achieved in a way which ensures that services are available and that continuity is assured for consumers, particularly the elderly and people with degenerative conditions who may experience a number of acute episodes while having ongoing long term care needs.

7.30 The resolution of the discontinuity between acute and long term community care has a number of components which must be examined to enable a sensible solution to be proposed. These components, which can not be considered in isolation, are:

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[10] Department of Health, Housing and Community Services, "Aged Care Reform Strategy Mid-Term Review 1990-91: Report", AGPS, 1991, p 169.

. responsibility and funding mechanisms;

. service delivery approach; and

. the point of interface between acute care and community care.

Responsibility and Funding Mechanisms

7.31 Evidence in support of the principle of hospitals taking responsibility for post acute care included the statement by the Australian Council of Social Service that:

> "If you say that you need to address the no-growth areas in terms of funding, it is possible to say that part of the funding that is going into the health care system needs to recognise that people's care does not finish at the hospital door. If people are being discharged earlier from hospital and they require nursing care from the time of immediate discharge, it is possible to conceive that some resources can be channelled through the health system... recognising the primary need there is a health need not an ongoing community need."(ACOSS: Transcript of evidence, p 48)

7.32 Some governments also supported the principle that community care services for post acute and palliative care needs should be funded by hospitals. Officials from the Tasmanian government for example, stated:

> "We have had some discussions... about the notion that the acute care system should be a budget holder for no growth or post acute
>
> community nursing. Therefore, the hospitals should pay for any additional demand."(DCHS TAS: Transcript of evidence, p 1158)

7.33 There is a general perception that increased patient turnover has led to realisable savings in hospital budgets. The Committee accepts, however, that such savings may not be as great as is assumed in some quarters and may simply result in the vacated bed being filled more quickly. A representative of the Hunter Area Health Service, for example, said:

> "... the presumption is when there is an early discharge that nobody is going back in behind that person in the hospital bed... people are going

straight back into the bed so there is really no savings on the acute hospital system. You are arguing that therefore the funding should follow them into the community to provide the home support. My argument is that there are no savings on the acute care system because of the throughput."(Hunter Area Health Service: Transcript of evidence, p 1408)

7.34 The Commonwealth Department of Human Services and Health also stated that increased patient turnover does not necessarily lead to savings in hospital budgets:

"I think in the acute care area... it is a more efficient use of an increasingly expensive resource. I think the myth that sometimes operates in this area is that there are large savings in hospitals as if there was some reduced cost overall. We are talking about better health outcomes and faster discharges through more expensive and more effective procedures. I do not think that necessarily translates into there being a bucket of money that somebody is nicking off with instead of putting it out into the community."(DHSH: Transcript of evidence, pp 634-635)

7.35 The Committee accepts that increased patient turnover does not necessarily translate into large savings from the hospital budget, although it is clear that the implementation of casemix in Victoria is being used to contribute to significant realisable savings in the health budget. In any case, it enables the hospital sector to increase the number of patients it treats and to reduce waiting lists. It is also clear that these changes are being achieved with the assistance of community care services which are nominally provided to give long term support to a specific target group requiring this support to live in the community. For these reasons, the Committee is convinced that the health budget should take responsibility for the cost of the community based services which enable this to be achieved.

7.36 The Committee has pursued with a number of witnesses, ways in which hospital funding could recognise the costs of community care related to an acute episode or a terminal illness. Casemix funding, while still in its early stages, clearly is the future direction of health funding and it is in this context that funding mechanisms must be pursued. The casemix approach was described to the Committee in the following terms:

"The basic idea underlying casemix is to utilise information relating to mix of cases in hospitals and to then make decisions about managing patients rather than a measure such as bed days or a measure such as what the hospital received in the last year. It is moving the hospital system towards payment on the basis of outputs rather than inputs.(DHSH: Transcript of evidence, p 616)

7.37 The basis for these payments under the casemix approach as it is being implemented in Australia is the Diagnostic Related Group (DRG). To date the development of DRGs has focused on acute episodes and the costs associated with them. The Commonwealth Department of Human Services and Health said:

"Certainly, DRGs have been developed for the acute in-patient episode. That is very specifically the reason for them. To the extent that they will be used in the hospital system, they will be confined to things in or around that episode."(DHSH: Transcript of evidence, p 3197)

7.38 However, it has been acknowledged that while DRGs are a mechanism for costing and funding acute care episodes, it may well be possible to develop more sophisticated measures which can account for all aspects of an acute episode or a more chronic condition such as terminal illnesses. The Commonwealth Department of Human Services and Health advised the Committee that:

"In terms of the development of payment systems, we certainly believe that looking at creative ways of bundling a DRG payment for either pre-admission tests or some post-admission types of community based care and follow-up would be very appropriate. But, as I say, it is at a relatively early stage."(DHSH: Transcript of evidence, p 3197)

7.39 It is clear then that, while the current DRGs do not do so, it is technically possible for casemix funding to take account of the post acute community care costs associated with an acute episode by including an additional component for post acute care in a bundled DRG category.

7.40 **The Committee recommends, therefore, that:**

- **post acute, palliative care and rehabilitation in the community be funded from the health budget;**

- **the Commonwealth Department of Human Services and Health develop mechanisms to cost and fund the post hospital component of treatment for acute episodes and terminal conditions and funding for this component should be included in future Medicare Agreements; and**

- **the implementation of these arrangements give due regard to the practical aspects of service delivery and the recommendations on this matter made below.**

7.41 While funding mechanisms and government guidelines can achieve a level of responsibility for post acute care on the part of public hospitals, they do not achieve the philosophical change and degree of commitment which is necessary if all parts of the acute health sector are to accept responsibility for the full acute episode. Day surgery facilities and private hospitals also need to consider their responsibilities to patients who are discharged while still requiring assistance. The Committee is of the view that all acute health care facilities must accept that responsibility for a patient does not end at the hospital door. Rather, these facilities must accept an ethical responsibility for their patients either until health is restored or until responsibility has been transferred in a coordinated way to another organisation. These facilities may, of course, purchase services from HACC providers and may wish to do so via the Regional Community Assessment Agency.

7.42 **The Committee recommends that the Commonwealth Department of Human Services and Health encourage the private hospital and health insurance sectors through their relevant peak organisations to adopt standards in relation to early discharge, day surgery and post acute care and to work closely with the proposed Regional Community Assessment Agencies in developing those standards.**

Continuity and Service Provision

7.43 While funding responsibilities are important to governments and, to a lesser extent, service providers, continuity and ease of access to community support is the prime consideration for consumers.

7.44 While generally there is a need for continuity, this is particularly important for the elderly and for people who had been receiving community care services prior to admission to hospital. The Australian Pensioners' and Superannuants' Federation said of the distinctions between in-scope and no growth services:

> "From an older person's point of view, these distinctions, in a sense, do not matter."(APSF: Transcript of evidence, p 88)

7.45 Governments involved in HACC have shown some acceptance of a model involving health budget funded services being provided, on a purchase of service basis, by existing community care providers:

> "The department's position on that issue, and also the position of HACC officials when they discussed the issue, felt that probably the most effective way of dealing with it, is that the acute sector agencies should pay for the community care... it would be in their interests, even if they were not so inclined - I think they probably would be - to purchase services that people leaving hospitals early require. We do not yet have a technology to enforce that happening but I think that is one of the avenues."(DHCS VIC: Transcript of evidence, p 653)

> "For instance, if we want to fund community care in a HACC-Type model for people who were not in the frail aged or the continuing younger disabled category but were still needing some community care following post-discharge, et cetera, it would make sense to integrate that with a HACC program as long it was funded separately rather than cost-shifted to the program."(HDWA: Transcript of evidence, pp 2100-2101)

7.46 The fate of post acute and palliative care was discussed at the Forums conducted during the Inquiry. While there was support for hospitals taking responsibility for the cost of these services, there were serious reservations about expecting hospitals to fulfil these responsibilities, including:

- a lack of confidence that hospitals, unless compelled, would actually provide the services required;

- for many elderly consumers, who were receiving HACC services prior to the acute episode, discontinuity would result if hospitals were free to purchase services from any provider they choose;

- lack of expertise among hospitals in providing community services;

- frail aged people and people with degenerative disabilities may move in and out of acute and post acute episodes regularly making it almost impossible to identify which clients fall into which category at any point;

- definitional problems, eg. much of what is called post acute care is not - it is post-discharge long-term care; and

- creates more boundaries, and potential gaps, for consumers - the aim should be for seamless service provision from consumer perspective regardless of funding sources.

7.47 The Australian Council of Community Nursing Services expressed further concerns about the effect of allowing hospitals to provide post acute and palliative care through whatever mechanism the hospital may choose:

> "It is ACCNS' experience that the hospitals will not seek service provision from HACC funded home nursing services but establish their own outreach services. These types of services are proliferating across Australia as a result of Medicare incentive funding. ACCNS is concerned that hospitals have no experience in the provision of home nursing. They are selective about whom they will treat and generally provide service within a limited catchment area. This is leading to increasing fragmentation of home nursing services with duplication of service in some areas."[11]

7.48 Reservations were also expressed about the impact on elderly consumers of separating post acute and palliative care from HACC. The aged move

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[11] Ms R McKenzie AM, President, Australian Council of Community Nursing Services, Correspondence in response to HACC Options/Discussion Paper, 3 May 1994.

between acute care, rehabilitation and convalescent care, post acute community care and long term maintenance and support and:

> "A definition based on arbitrary time limits has low validity. Consider: person who at discharge requires a continuation of "HACC type" services received prior to hospitalisation, supplemented by additional services required for a variable period... Is a dual funding system envisaged in which services are provided through HACC at the prehospitalisation maintenance level and additional supports funded by a post-acute scheme through the Health System, to be transferred to HACC at an arbitrary period after discharge."[12]

7.49 The Committee accepts these concerns and considers that any system of delivering post acute services must provide for adequate discharge planning and continuity of care and should encourage use of existing expertise and community resources.

7.50 **The Committee recommends that post acute and palliative care and rehabilitation services currently falling within the no growth areas of HACC be provided in the following way using the Regional Community Assessment Agency as the point of interface between acute care and post acute care and, subsequently, HACC long term support where required:**

- **all public hospitals liaise with the Regional Community Assessment Agencies through discharge planners or community liaison staff;**

- **the Regional Community Assessment Agency to have the authority to determine in conjunction with discharge planners the type and level of services to be provided and advise the range of providers from which the hospital may purchase those services;**

- **in the case of consumers who have been receiving HACC services prior to admission to hospital, the Regional Community Assessment Agency is to have the authority to direct the hospital to purchase services where appropriate from the provider which had previously provided those services; and**

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12 Cullen, J and Creasey, H, Senior Specialists, Geriatric Medicine, Concord Hospital, Correspondence in response to HACC Options/Discussion Paper, 12 April 1994.

the Regional Community Assessment Agency be responsible for ensuring a smooth transition for the consumer from post acute support to long term support where this is required in line with the role recommended for these agencies in Chapter 9 of this report.