

**ACT Government Response
Sustaining Caring Relationships
Final Report of the
Met and Unmet Needs Project in Respite Care.**

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Sustaining Caring Relationships
Final Report of the Met and Unmet Needs Project in Respite Care.
Government Response

Background

In 2002-2003 the ACT Government released a new budget initiative to address respite care needs in the ACT community. The initiative provided \$4.123 million over four years to assist carers of people with a mental illness, disability or people who are ageing.

To assist in planning for respite care services the Government commissioned a report to map current services and to provide recommendations to guide the allocation of this funding. Specifically the report was required to:

- Provide a map of existing respite services;
- Use the AIHW 1996 model of needs analysis to undertake an empirical study of the current and future respite care met and unmet needs;
- Undertake community consultations regarding access, equity and future directions for respite care delivery;
- Undertake research into local, national and international best practice models for respite service delivery; and
- Make recommendations to the ACT Government for planning service delivery over the next 5 years.

The Report addressed all forms of respite care, including services for carers of:

- Older people with disabilities, including dementia and frailty associated with age;
- Children and adults with disabilities;
- People with mental illness; and
- Kinship and family carers.

The report made 28 recommendations grouped in six themes:

- Overall issues relating to service planning, data collection, community participation, equitable access and workforce;
- System design issues;
- System efficiency;
- Access and linkages to respite care;
- Carer and consumer rights; and
- Quality of services.

While the report provides the 28 recommendations under these thematic headings, the content of many recommendations are similar. Several of the recommendations do not specifically articulate a particular direction but provide a commentary on respite care issues currently facing the ACT community.

As such some of the Government responses to the recommendations have been re-grouped to provide a more comprehensive response.

Of the 28 recommendations 25 are agreed or agreed in principle, 3 are noted and will inform future service planning. A summary of the responses is provided at [Appendix 1](#). A response to each of the recommendations is provided at [Appendix 2](#).

The consultants developed a set of principles as a guide to reform in the provision of respite care services in the ACT. The principles identified were:

1. *The system should foster and encourage independence and sustainable relationships.*
2. *Services and policies should be consumer and carer focussed.*
3. *Service delivery should be integrated and coordinated.*
4. *Services and policies should be flexible enough to meet people's real needs.*
5. *The quantity of services available must be sufficient to meet the need of carers and consumers.*

The ACT Government is supportive of the principles in guiding reform and responses to respite care needs in the community. These principles are consistent with those that have been identified in the drafting of the Caring for Carers Policy.

Empirical Analysis

In commissioning an empirical analysis the ACT Government was seeking to have a strong evidence base to guide policy and service delivery responses in respite care.

The consultancy found that there was a dearth of quantitative information on the level of service usage and unmet need in respite care services.

The Australian Institute of Health and Welfare (AIHW) 1996 model of needs analysis was not able to be replicated due to an inability to access de-identified data used by the AIHW, and also due to the small sample size in the ACT which impacts on the significance of conclusions that could be drawn from the data.

Some data from previous surveys by the Australian Bureau of Statistics and the AIHW was available which has implications for service delivery in the ACT. While the surveys are now a number of years old some main conclusions brought forward by the report highlighted that:

- Due to population ageing the number of people with profound/severe restrictions is expected to grow rapidly, particularly for age groups 55-64 years, and 75 years and older;
- Carers in the ACT are more likely to be younger, employed and more likely to have higher incomes;
- Incidences of profound/severe core activity restrictions were more predominant in groups aged 65 years and older. In the 75-84 years age group, a significant difference occurred between the national average (25.8%), and the ACT where 40.0 % of people in the age group had a profound/severe core activity restriction;
- Compared to the Australian average of 4.4%, the ACT had 7.4% of children in the 5-14 years age bracket classed with profound / severe core activity restriction; and
- 34.6% of primary carers were aged between 35-44 years, and at the time of survey 11.5% were aged between 65 and 74 years.

Current issues in respite care

The consultation phase highlighted a number of deficits in the provision of respite care services in the ACT community. These fall primarily under the following areas:

- Appropriateness of models of care (ie traditional respite service versus family support models);
- Skills and training (workforce development and support);
- Fragmentation of respite services (across funding bodies, community sector and mainstream services, coordination point to facilitate access);
- Adequate data collections to demonstrate need;
- Access issues for specific client groups (carers of adults with mental illness, people from culturally and linguistically diverse backgrounds, people with behavioural problems, people with substance abuse problems, and people with undiagnosed conditions).

To ensure that the first year of funding was fully allocated from the 2002-2003 Respite Care Budget Initiative, the ACT Government responded to the early summary of the community consultations conducted by the consultants preparing the Report by funding a number of pilot and non-recurrent services to respond to a range of issues in respite care. These include:

- Flexible Family Support - A consortium of three established community providers have developed an innovative model to assist families to maintain and strengthen their capacity to support their caring relationship through the provision of flexible support arrangements;
- Home from Home Pilot – in collaboration with the Commonwealth Department of Health and Ageing, and the Department of Veteran’s Affairs, the ACT Government has contributed non-recurrent funding to a dementia respite service that will provide flexible hours of service to meet the needs of carers;
- Reduction of fragmentation of services – funding has been allocated to ACT Health and the Department of Disability, Housing and Community Services (DDHCS) to improve coordination and access to respite care services in the ACT;
- Additional family support packages – Non recurrent support packages for kinship and family carers have been supplemented at Marymead and Barnados;
- Carers of people with a mental illness – 12 month funding to enhance the community sector’s capacity to promote and support the role of carers of people with mental illness. Education and training will be provided to clinical and professional staff concerning the role of carers; and
- Respite for families where parents have a mental illness – Ongoing funded has been provided for the maintenance and provision of respite care support and services to people with mental illness and their families.

Future Directions

There continue to be a number of opportunities for improvement in the provision of respite care services for the ACT community.

The ACT Government sees the following as essential for responding to current needs for respite care:

- Evaluation of the Flexible Family Support pilots to demonstrate their effectiveness in meeting the holistic needs of families which enable them to sustain their caring relationships;
- Continuation of work through ACT Health and DDHCS to improve service coordination and access. DDHCS have engaged a project officer for 12 months to undertake a review and implementation of revised respite services in the disability sector and to establish a needs assessment and referral service. ACT Health will be calling for tenders in early 2004 to establish a centralised booking service for respite care to improve access for carers;
- Respite and support services for carers of people with challenging behaviours; and
- Supporting workforce development in the respite sector.

Future Funding of Respite Services from the 2002-2003 Budget Initiative

Allocation of the funding for the Respite Care Budget Initiative will draw on the findings of the Report and the results of the innovative pilots commissioned in 2002-2003.

In 2003-2004 a series of one off projects will be funded to improve sector development in respite care. This will include additional work around data collection to inform decision making and service funding through evidence, strengthening the respite care workforce; and innovative models of respite support that will sustain carers, families and people receiving care.

Recurrent funding will also be released through an open tender process in early 2004. The tender process will encourage applicants to undertake one or more of the following:

- An innovative approach to service delivery to meet identified demand;
- Proposals that encourage cross agency collaboration;
- Targeting specific needs groups who find it difficult to access respite services (ie people from culturally and linguistically diverse backgrounds, people with challenging behaviours).

Summary of Recommendations

Recommendation		Government Response
1	There should be an integrated flexible ACT-wide approach to planning for and meeting the care and support needs of families and all people with disabilities or illness, whatever their age, who require assistance including respite care.	Agreed
2	A strategy for collecting future data on met, unmet and partially met need should be developed.	Agreed in principle
3	There needs to be a targeted focus on improving access to mainstream services and programs for people with disabilities or affected by illness (whatever their age), both by addressing barriers to full participation and also by providing services which facilitate more independent living and work towards full community participation.	Agreed
4	Further work is needed to explore cultural attitudes and other factors which affect access to appropriate respite care and other support services by people from culturally and linguistically diverse backgrounds.	Agreed
5	Research is needed to identify whether there are workforce shortages in relation to support and respite service workers, and whether this is affecting the availability of such services for those who need them.	Agreed
6	Any needs assessment required to access services, including respite, should look at the needs of ALL the participants in the caring relationship – both the carer(s) and the person being cared for, and any other people involved in the caring situation eg family members, friends, helpers.	Agreed
7	Services and government programs need to be self-reflective and change so that they better meet the needs of carers, the family unit and the people being cared for.	Agreed
8	Services need to be providing better quality respite arrangements, which provide positive opportunities for the person being cared for.	Agreed
9	There is a need for more innovative flexible models that support families and other caring groups in the manner which suits them best, and is most appropriate for the person being cared for.	Agreed
10	There is a need for rapid entry/easy exit emergency respite arrangements for both residential and home-based respite.	Agreed
11	Greater innovation in residential respite is also needed – options such as holiday breaks, improved activities and better ways to monitor the quality and responsiveness of such care are some examples where service development is required.	Agreed
12	Service funding contracts should be used to influence providers to provide high quality services which better meet the needs of carers and people being cared for.	Agreed

13	The ACT Government should examine the possibility of working with Home and Community Care (HACC) and Commonwealth State Territory Disability Agreement (CSTDA) service providers to improve the quality of data collected under each minimum data set (MDS); and develop the capacity to link data relating to individual clients and families.	Noted
14	Development of a comprehensive screening and assessment tool to be used by providers of a wide range of community and health services is needed.	Noted
15	The establishment of a central register of vacancies in residential and non-residential respite care and related programs could reduce the significant time and resources that services seem to spend in locating spaces for people in need.	Agreed
16	Until the broader system planning proposed in recommendation 1 above is implemented, there is a need to pay particular attention to transition points where consumers and carers are falling through gaps.	Agreed
17	Many carers are unaware of the availability of respite care services, and how to access them. There needs to be a strategy for increasing the awareness of carers and consumers about where to go for assistance.	Agreed
18	There remain considerable problems of access to respite for carers of any people with challenging behaviours, whether the behaviour is related to mental illness, intellectual disability, age-related dementia or trauma.	Agreed
19	Carers of people with psychiatric disabilities often have a need for assistance when someone is becoming acutely ill. Pilots should be developed to explore better ways of providing support to families in these situations.	Agreed
20	When a person with a disability is admitted to a hospital, discharge planning arrangements need to focus on better ensuring that people and their carers are properly connected into the community services they need to optimise their recovery, their health and well-being, rather than focussing on the desire for early discharge.	Agreed
21	Services should have sufficient flexibility to focus on the assessed needs of the caring unit rather than be required to have a prerequisite diagnosis.	Agreed in principle
22	Where a person with a disability or an illness requires a higher level of care temporarily eg due to illness, the greater availability of “step-down” facilities may also be able to provide some “step-up” assistance, where the needs of a person being cared for temporarily increase beyond the capacity of the carer or family unit.	Agreed
23	Adequate ways of receiving and monitoring feedback need to be put in place and systemic accountability to deal with feedback must be developed and implemented.	Agreed
24	There is a need to develop mechanisms to ensure that carers who will be responsible for looking after someone post-discharge are actively involved in their care planning.	Agreed
25	There is a recognition in some areas, such as family and kinship carers that a quality respite arrangement is based upon the establishment of relationships for the person who is being cared for. Innovative models which seek to achieve this should be piloted and evaluated.	Agreed

26	Improved training and skills development of respite care staff will be required to provide better quality and more appropriate respite arrangements. This could also form part of any new services pilots.	Agreed
27	Training and tools looking at and addressing the specific needs of individual services users are also required for taxi drivers, public transport operations, police and other mainstream agencies which interact with people with disability or illness or which provide the capacity for people to use other services.	Agreed
28	The implementation of formal outcome standards system for respite care should be considered as a way of improving both the quality and responsiveness of care. Such as system may well draw attention to what is expected and address some of the current quality issues.	Noted

Government Response to the Recommendations

The Recommendations were presented in six themes, the Government response addresses these themes.

OVERALL ISSUES

- 1. There should be an integrated flexible ACT-wide approach to planning for and meeting the care and support needs of families and all people with disabilities or illness, whatever their age, who require assistance including respite care.*

Agreed

The ACT Government supports the development of an integrated and flexible system response that meets the needs of those people who require respite care. The outcome of this study has led to a greater cross sector and cross portfolio understanding of respite within the ACT. Cross agency collaboration has been undertaken in responding to the needs identified in the Respite report and determining future resource allocations in the community sector.

Flexible Family Support pilots have been commissioned to provide a broad focus across varying areas of respite care need. The pilots will run for 3 years and are targeting families with young children with disabilities (age 0-7), families with teenagers or young adults (aged 16-23 years) with disabilities; frail carers who require additional support to continue their caring role; ageing parents who require increasing support from their children, and families experiencing an unexpected event such as an acquired disability; death of carer or major illness leading to incapacity to care; or family breakdown.

Recurrent funding for additional respite care services will be allocated through a tender process early in 2004 and an emphasis will be placed on cross agency collaboration. Applicants will be assessed by a working group from ACT Health, the Department of Disability, Housing and Community Services (DDHCS) and the Department of Education, Youth and Family Services (DEYFS).

- 2. A strategy for collecting future data on met, unmet and partially met need should be developed.*

Agreed in principle

Appropriate data collection is essential for guiding policy and service delivery responses. A number of data collection activities occur through service purchasing activities and data collections such as the Home and Community Care Minimum Data Set. Improvements to data collections will continue to be encouraged.

The lack of data in the community sector is recognised nationally and has resulted in the development of national minimum data set collections in the areas of community mental health, disability services and the Home and Community Care (HACC) program. These databases have been developed jointly by the Commonwealth and States/Territories and are in various stages of implementation. There is a commitment through the Commonwealth State

Territory Disability Agreement (CSTDA) and the HACC agreement to improve the data collections for community services using the agreed national minimum data sets.

Mental Health ACT is considering the development of Minimum Data Set (MDS) of non government organisations in the mental health sector. It is anticipated that the mental health MDS will take another 3-5 years to come on line.

In recognition of the gaps in these data collections, the Government will allocate additional one off funding in 2003-2004 to develop more comprehensive data regarding general levels of need, unmet, met and partially met need. Establishing sound empirical evidence on the level of demand for respite services will be essential in responding appropriately to the needs of families and carers in the community.

- 3. There needs to be a targeted focus on improving access to mainstream services and programs for people with disabilities or affected by illness (whatever their age), both by addressing barriers to full participation and also by providing services which facilitate more independent living and work towards full community participation.*

Agreed

The ACT Government supports increased community participation and access to services for people with disabilities or illness and their carers. Through the ACT Health Action Plan the Government has committed to improve access of disadvantaged people and people with disabilities to services. The 2002-2003 Respite Budget Initiative allocated funding to carers of people and children of parents with a mental illness, and for pilot projects concerning dementia and flexible forms of respite.

- 4. Further work is needed to explore cultural attitudes and other factors which affect access to appropriate respite care and other support services by people from culturally and linguistically diverse backgrounds.*

Agreed

The Government recognises that people from culturally and linguistically diverse backgrounds view and use services differently. Through the HACC Program Carers ACT are funded to provide support for carers from culturally and linguistically diverse (CALD) backgrounds and also to Aboriginal and Torres Strait Islander carers. Also under the HACC Program funding is provided for a multicultural liaison officer to assist clients from CALD backgrounds to access services within the HACC sector. The Commonwealth funds a similar initiative to assist people from CALD backgrounds to access residential care services through the Partners in Culturally Appropriate Care program.

The Home from Home respite pilot, funded by the Commonwealth, Department of Veteran's Affairs and the ACT Government will be targeting flexible day respite services to specific CALD groups in the community.

Through the allocation of recurrent funding in 2003-2004 the Government tender will consider proposals to provide innovative services to special needs groups in the community, including people from CALD backgrounds.

- 5. Research is needed to identify whether there are workforce shortages in relation to support and respite service workers, and whether this is affecting the availability of such services for those who need them.***

Agreed

Workforce issues have been identified in both Government and non-government services, and across varying health sectors at a local and national level. While there are established professional workforce profiles, the provision of community based services has not been profiled locally in the ACT nor on a consistent basis nationally.

A workforce survey, plus follow up education, training and development work, will be funded out of the 2003-2004 Budget Initiative funding to address this issue.

The Health Action Plan has identified the need to build sustainable workforces across the acute and community sector. Within the disability sector as outlined in the Government's action plan, *Steps to Reform*, a Disability Reform Workforce Working Group has been established to consider a number of workforce issues, both within Disability ACT and the disability sector in general.

The Department of Disability, Housing and Community Services is undertaking a workforce audit of the disability sector in order to appropriately plan for workforce needs. ACT Health is currently negotiating to extend this to include respite care workers in the community.

SYSTEM DESIGN ISSUES

- 6. Any needs assessment required to access services, including respite, should look at the needs of ALL the participants in the caring relationship – both the carer(s) and the person being cared for, and any other people involved in the caring situation eg family members, friends, helpers.***

Agreed

The Government supports the notion that families should be appropriately supported in their caring role. The trial of the Flexible Family Support pilots will allow families the opportunity to identify what kinds of supports and services they need in order to sustain and manage the family unit.

A number of initiatives are currently underway in Mental Health ACT to address this issue. A carers project funded from the 2002 – 2003 respite initiative with additional funding through the 2003 - 2004 budget will educate clinical staff about the role and needs of carers. Other examples include the work with the Community and Health Services Complaints Commissioner in relation to privacy legislation. Moves have been made to include service providers and carers in the definition of the “treatment team” so they can be fully involved in planning care for the individual.

The Caring for Carers Policy developed by DDHCS has recognised the need for carers, and people receiving care to be treated as a partnership to ensure that both individuals are clearly recognised and supported outside the caring relationship.

7. *Services and government programs need to be self-reflective and change so that they better meet the needs of carers, the family unit and the people being cared for.*
8. *Services need to be providing better quality respite arrangements, which provide positive opportunities for the person being cared for.*
9. *There is a need for more innovative flexible models that support families and other caring groups in the manner which suits them best, and is most appropriate for the person being cared for.*

Government Response - Recommendations 7 – 9

Agreed

The Flexible Family Support Project will take a holistic focus on the needs of the family as well as the person being cared for. Participating families will be supported to maintain and strengthen their natural capacity to meet the needs of family members, and enable them to stay together and be welcomed, contributing members of their communities.

Participating families will have greater capacity to strategically target the expenditure of respite funds on goods and services that will provide the form of carer relief that will best meet their individual circumstances.

The family support model will also enhance the capacity of communities to value and support frail older people, people with dementia, people with challenging behaviour, people with mental health illness, people with disabilities, children with ongoing medical conditions or disability, and their families.

The Home from Home Pilot which has been primarily funded by the Commonwealth Department of Health and Ageing, and the Department of Veteran's Affairs, with a funding contribution of \$20,000 by the ACT Government. This pilot will provide flexible respite support for carers of people with dementia. The service will operate from 8am to 8pm Thursday to Sunday providing carers with more appropriate access times during work hours and over the weekend. Transport services will be provided to increase accessibility for those carers who do not have access to transport.

The effectiveness of these pilots will be evaluated.

The Community Health Day Care Program has extended its hours of operation at Tuggeranong and Belconnen Health Centres with a specific focus on respite for carers, and dementia assessment and appropriate support and treatment programs. The program provides clients with access to aged care and therapeutic rehabilitation. Relocation of the day services to the larger health centres means that clients have improved access to allied health services such as physiotherapy, nutrition, occupational therapy, nursing services and podiatry services.

10. There is a need for rapid entry/easy exit emergency respite arrangements for both residential and home-based respite.

Agreed

ACT Health supports crisis respite for frail older people through the Burrangiri Crisis Respite Centre. An Aged Care Assessment is not required to enter the service, and referrals can either be received formally or informally from the carer themselves. This increases the capacity of the service to provide emergency respite care.

ACT Health will release a tender in early 2004 to establish a centralised booking system for respite services in order to increase access for carers, and this booking service should assist access to crisis respite services.

11. Greater innovation in residential respite is also needed – options such as holiday breaks, improved activities and better ways to monitor the quality and responsiveness of such care are some examples where service development is required.

Agreed

It is acknowledged that there is great difficulty in accessing residential respite care in the ACT and the majority of care provided occurs in a residential aged care facility. The ACT Government is working with the Commonwealth Government to develop more innovative ways in which residential respite care can be provided.

With regards to residential respite services funded by the ACT Government, the performance of services in responding to demand, and the delivery of quality care will continue to be monitored through purchasing arrangements.

One off funding of \$50,000 will be allocated in 2003-2004 to further research into best practice models in respite care. In addition, a recurrent allocation of \$400,000 per annum will be made available to the sector through competitive tender, calling for new, innovative models of respite care. Joint proposals between various service providers will be encouraged.

12. Service funding contracts should be used to influence providers to provide high quality services which better meet the needs of carers and people being cared for.

Agreed

Current service funding agreements support the provision of flexible client focussed high quality services. Through contract negotiations the Government will work with providers to deliver services that are provided in a responsive manner, and meet the care needs of both the family/carer, and the person being cared for.

SYSTEM EFFICIENCY ISSUES

- 13. *The ACT Government should examine the possibility of working with Home and Community Care (HACC) and Commonwealth State Territory Disability Agreement (CSTDA) service providers to improve the quality of data collected under each minimum data set (MDS); and develop the capacity to link data relating to individual clients and families.***

Noted

Minimum data set collections are under a continuous improvement cycle and are monitored at both the ACT and Commonwealth level. The data collected under the HACC and CSTDA Minimum Data Sets is transmitted on a quarterly basis. There are continuing improvements to the data collections.

The possibility of linking data sets is currently being explored with the Commonwealth but there is a range of privacy issues to be considered before data linkage can occur.

- 14. *Development of a comprehensive screening and assessment tool to be used by providers of a wide range of community and health services is needed.***

Noted

The implementation of a standard screening and assessment tool will be part of the centralised booking and referral service to be tendered in early 2004. Information sharing protocols and privacy issues will need to be considered carefully as part of this service.

- 15. *The establishment of a central register of vacancies in residential and non-residential respite care and related programs could reduce the significant time and resources that services seem to spend in locating spaces for people in need.***

Agreed

The ACT Government supports the notion of a central access point for respite care services, as this would increase accessibility to services for people and their carers. A sub-group of the ACT Respite Care Working Group is exploring the possibility of establishing a central register to advise of vacancies in residential respite.

In 2002-2003 \$150,000 of one off funding was allocated across ACT Health and the Department of Disability, Housing and Community Services (DDHCS) to address the fragmentation of respite services. DDHCS is looking at undertaking a review and implementation of revised respite care services, and to establish a centralised needs assessment and referral service.

ACT Health has allocated their portion of the one-off funding (\$75,000) for a centralised respite assessment and booking service, to be piloted within the Home and Community Care sector. If the pilot is successful, it is planned that it would be extended across all respite care and community support services.

Further one-off funding of \$40,000 will be directed towards research and improvements in information technology, for the centralised respite booking system.

\$400,000 per annum has also been earmarked for new, innovative models of respite care. The tenders calling for this service will encourage joint applications from service providers to achieve greater service integration.

The ACT Aged Care Advisory Council have also identified the fragmentation of services as one of the key priority areas in their work plan.

The ACT Government will also work with the Commonwealth to establish a central register for residential respite care vacancies. The Commonwealth has recently commissioned Carers ACT to establish a centralised booking service for residential respite care.

ACCESS AND LINKAGES TO RESPITE CARE

- 16. Until the broader system planning proposed in recommendation 1 above is implemented, there is a need to pay particular attention to transition points where consumers and carers are falling through gaps.*
- 17. Many carers are unaware of the availability of respite care services, and how to access them. There needs to be a strategy for increasing the awareness of carers and consumers about where to go for assistance.*

Government response to recommendations 16 and 17

Agreed

The ACT Government projects looking at the reduction of fragmentation in respite care services, the Caring for Carer's Policy and the ACT Children's Plan will assist in identifying areas where consumers and carers are missing out on services. The implementation of a centralised booking system will further improve access to services.

Ensuring that information about supports and services is available to carers when they first begin their caring role is important. This aspect is being considered in the development of the Caring for Carers' Policy.

The Care Options booklet produced as part of the Home and Community Care Program, and the respite care booklet produced by the Commonwealth also provide information to carers and consumers regarding services available in the ACT and region.

- 18. There remain considerable problems of access to respite for carers of any people with challenging behaviours, whether the behaviour is related to mental illness, intellectual disability, age-related dementia or trauma.*

Agreed

The Flexible Family Support model of care may provide an appropriate service response to those carers who have difficulty in accessing respite and other support services in their caring role. Additionally the Home from Home pilot will provide flexible day respite for people with challenging behaviour. In addition the Commonwealth Government has allocated funding to a new dementia project which will provide three Canberra aged care homes with clinical support and training to help them manage residents with challenging behaviours more effectively.

In allocating recurrent funding, services and programs which can demonstrate addressing the needs of specific target groups such as those people with challenging behaviours, will be encouraged.

- 19. *Carers of people with psychiatric disabilities often have a need for assistance when someone is becoming acutely ill. Pilots should be developed to explore better ways of providing support to families in these situations.***

Agreed

A carer's project funded in 2002-2003 will assist in raising awareness amongst clinicians of the need to consult with families and carers.

The 2003-04 Budget provided for \$240,000 for supported accommodation with both the "step up" and "step down" approach, which will help families to some extent. An extra \$800,000 was also allocated to increase the Belconnen Community Mental Health Teams and to provide extended hours of cover for Woden and Tuggeranong Teams. This will provide extra clinical support for consumers, which should in turn, assist carers.

- 20. *When a person with a disability is admitted to a hospital, discharge planning arrangements need to focus on better ensuring that people and their carers are properly connected into the community services they need to optimise their recovery, their health and well-being, rather than focussing on the desire for early discharge.***

Agreed

ACT Health has undertaken a review of discharge planning services in the ACT, and supports the development of comprehensive discharge plans which link patients with appropriate services in the community relative to their care needs, and involves their carers/families in discharge planning.

- 21. *Services should have sufficient flexibility to focus on the assessed needs of the caring unit rather than be required to have a prerequisite diagnosis.***

Agreed in principle

It is acknowledged that due to funding requirements and legislative frameworks around some services, a formal assessment and diagnosis of a condition is required in order to be eligible for access. The funding of the Flexible Family Support Pilots addresses the requirement for increased flexibility with respite services. These Pilots provide for a high degree of flexibility in meeting the needs of families and those cared for

- 22. *Where a person with a disability or an illness requires a higher level of care temporarily eg due to illness, the greater availability of "step-down" facilities may also be able to provide some "step-up" assistance, where the needs of a person being cared for temporarily increase beyond the capacity of the carer or family unit.***

Agreed

The ACT Government will commence construction in 2004 on a sub-acute facility to provide rehabilitation, transitional and psycho geriatric care. Once completed this service will fulfil an important need in the community through the provision of appropriate step-down care.

Within Mental Health ACT the 2003-04 Budget provided for \$240,000 for supported accommodation with both the “step up” and “step down” approach, which will help families to some extent.

CARER AND CONSUMER RIGHTS ISSUES

- 23. *Adequate ways of receiving and monitoring feedback need to be put in place and systemic accountability to deal with feedback must be developed and implemented.***

Agreed

The ACT Government supports the development of appropriate feedback systems that allow carers and care recipients to have input in the way in which services are provided. The terms of reference for the Caring for Carers Policy currently being developed, has identified feedback and complaints as being one of the barriers carers face in seeking support.

ACT Health has recently undertaken to sign a Memorandum of Understanding with the Health and Community Care Complaints Commissioner. The MOU provides for clear lines of communication and responsiveness in the event in which a complaint is made against services funded by ACT Health. A new computer based consumer complaints system is also proposed which will enable consumers to provide feedback. The system will be located with the Health and Community Services Complaints Commissioner.

- 24. *There is a need to develop mechanisms to ensure that carers who will be responsible for looking after someone post-discharge are actively involved in their care planning.***

Agreed

This recommendation was made in relation to carers in the mental health area. Mental Health ACT has taken seriously the complaints of carers that they have been excluded from planning the care of those they care for on the basis of " client confidentiality." This was also raised by the Community and Health Services Complaints Commissioner, in his report on services for consumers at risk of harm.

Mental Health ACT is now working with the Community and Health Services Complaints Commissioner to address the issue in a number of ways, including using a broad definition of the “treatment team” within which confidential information can be shared, so that carers can be included in the team where appropriate. Clinical staff are also actively seeking the agreement of clients to include carers in decision making by emphasizing the positive benefits of their involvement.

QUALITY OF SERVICES ISSUES

- 25. *There is a recognition in some areas, such as family and kinship carers that a quality respite arrangement is based upon the establishment of relationships for the person who is being cared for. Innovative models which seek to achieve this should be piloted and evaluated.***

Agreed

The Flexible Family Support models will be evaluated to examine their ability to build supportive relationships within families and the community. The Government will continue to explore innovative models for respite and support to enhance caring relationships.

- 26. Improved training and skills development of respite care staff will be required to provide better quality and more appropriate respite arrangements. This could also form part of any new services pilots.*

Agreed

The Government agrees that it is essential for staff to be adequately trained and resourced in order to provide quality and timely services. In 2003-2004 the Government will be allocating one off funding for workforce development in the area of respite care.

- 27. Training and tools looking at and addressing the specific needs of individual services users are also required for taxi drivers, public transport operations, police and other mainstream agencies which interact with people with disability or illness or which provide the capacity for people to use other services.*

Agreed in principle

Within the community all people with disabilities or illness, and their families' carers should be treated with respect to their specific needs. All services and organisations are encouraged to adopt this as part of their standard operating principles. Through existing standards in the community and funding for workforce development the Government will aim to ensure that that staff and agencies in the respite care sector are able to respond appropriately to individual service users.

- 28. The implementation of formal outcome standards system for respite care should be considered as a way of improving both the quality and responsiveness of care. Such as system may well draw attention to what is expected and address some of the current quality issues.*

Noted

Agencies funded under the Home and Community Care and disability programs are compliant with national HACC and Disability Service Standards. Commonwealth funded aged care facilities need to comply with Aged Care Standards monitored by the Aged Care Standards and Accreditation Agency.

The Government acknowledges that the National Disability Service Standards are hard to interpret and difficult to measure.

The Government has commenced work on establishing a project to develop ACT Disability Standards, which will incorporate and expand on the National Standards. The project will aim, through stakeholder consultation and expert advice, to develop ACT specific standards with measurable indicators. The Government and the Disability Reform Group are in agreement that the standards and indicators will become an integral component of Disability ACT's quality monitoring and management framework.

The Government will establish a comprehensive quality framework for the provision of disability services in the ACT. The quality framework will include the following key elements:

- a set of performance standards and quality indicators that support monitoring and evaluation of service performance, and encourage continuous quality improvement;
- strategies of self assessment, external assessment and auditing to monitor
- results, evaluate outcomes and provide data for an ongoing cycle of quality planning;
- incident reporting systems that support safe practice and continuous improvement;
- strong and responsive internal complaint and client feedback processes;
- an independent complaints resolution processes, accessible and timely;
- independent assessment of service performance including auditing of performance and compliance with standards and legislation, with a particular focus on health and safety; and
- effective use of facts, data and knowledge to support the way strategies and plans are developed and how they are deployed.