

Submission to the **SENATE COMMUNITY
AFFAIRS REFERENCES COMMITTEE**

INQUIRY INTO AGED CARE



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SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE INQUIRY INTO AGED CARE

NCOSS

The Council of Social Service of NSW (NCOSS) is the peak body for the social and community services sector in New South Wales. NCOSS works with its members on behalf of disadvantaged people and communities towards achieving social justice in NSW.

NCOSS congratulates the Senate Community Affairs References Committee for undertaking this important Inquiry into Aged Care. Further NCOSS welcomes the opportunity to respond to the Terms of Reference.

NCOSS has been able to consult extensively on the Terms of Reference and appreciates the extension to the deadline provided by your officer Ingrid Zappe. Many of the documents referred to in the text can be accessed on the NCOSS website www.ncoss.org.au

NCOSS has developed this submission in conjunction with both the NSW HACC Issues Forum and the NSW State HACC Aboriginal Gathering Committee.

The NSW HACC Issues Forum is a bi-monthly meeting of non-government consumer advocacy organisations, development workers, industry peak bodies and other relevant agencies concerned with Community Care and the needs of older people, people with disability and carers. Convened by NCOSS, the NSW HACC Issues Forum discusses latest developments in community care, policy directions, government initiatives and receives regional and organisational reports at state level.

The NSW State HACC Aboriginal Gathering Committee is a group of nominated Aboriginal leaders and managers who meet to advance community care for indigenous people in NSW. The work of the Gathering involves policy development, bi-annual conferences, responses to Government initiatives and regional and state networking. Specific inclusions from the Gathering Committee are identified within the submission under Term (a) and Term (d). Consideration of the needs of Aboriginal and Torres Strait Islander people must not be limited to this advice, however. NCOSS recommends that the Senate Community Affairs References Committee undertakes specific investigation into the needs and service responses to this seriously disadvantaged group.

Thank you for receiving the NCOSS submission. For further information please contact Christine Regan at NCOSS on ph 02 9211 2599 ext 117 or chris@ncoss.org.au

(a) the adequacy of current proposals, including those in the 2004 Budget, in overcoming aged care workforce shortages and training;

Community Care Workforce

The NSW HACC Issues Forum discusses workforce issues in community care on a regular basis. Generally these issues revolve around the following points:

- The difficulty in recruiting trained staff, especially in rural and regional areas
- The lack of trained Aboriginal and Torres Strait Islander staff in community care services
- The lack of trained staff from culturally and linguistically diverse backgrounds in community care services
- The increasing casualisation of the community care workforce
- The lack of a career path for people working in community care
- Low wages in the community care sector
- Increasing expectations on staff, especially to do volunteer hours

The Volunteer Workforce in Community Care

The Community Care sector relies heavily on volunteers. NCOSS generally supports the use of volunteer workers in community care as long as they do not replace paid workers. Community Care providers which use volunteers report increasing difficulties in recruiting volunteer workers to community care services. While the incidence of volunteering is increasing, the form of volunteering is changing from traditional regular volunteering for say Meals on Wheels towards more one-off volunteering eg Clean Up Australia.

Volunteer workers in community care can be characterized into 2 main groups: management volunteers and service volunteers. Management volunteers are those who join management committees and boards. The issues facing management volunteers are numerous:

- Increasing financial and legal duties and responsibilities on the person
- Increasing financial and legal duties and responsibilities on the services
- Increasing pressures to source funding away from traditional government funding
- Increasing pressure to do more with less

There are also escalating pressures on volunteer services and the unpaid workers they engage. These pressures include:

- Increasing calls on the personal resources of the volunteers, eg in dollars & time
- Increasing obligations for training in dealing with target populations
- Increasing OH&S requirements

Aboriginal & Torres Strait Islander Workers

In its *Focus For the Future* Policy Paper, the NSW State HACC Aboriginal Gathering Committee emphasised that services to Aboriginal people should be provided by Aboriginal workers and that it is preferable assessments be undertaken by Aboriginal workers.

It should be mandatory that ACAT workers undertake cultural awareness training before assessing Aboriginal clients. Until strategies are developed and implemented to ensure that sufficient Aboriginal assessment workers can be recruited and trained, it is fundamental and culturally appropriate that Aboriginal workers accompany ACAT workers

at all times during an assessment. ACATs must ensure assessments are only carried out on Aboriginal people who are frail aged and not younger people with disabilities.

Aboriginal people must conduct any comprehensive assessments for Aboriginal clients. There must be accredited accessible and available Aboriginal specific training for Aboriginal community care workers to be able to carry out comprehensive assessments. The Australian Government must ensure that established Aboriginal community care service providers are trained in Comprehensive Assessment and be resourced to do so.

The Gathering Committee therefore recommends that:

- Specific strategies are developed by the Australian Government to attract, recruit, train and support Aboriginal people to work in community care
- National training strategies include an emphasis on Aboriginal cultural awareness.
- Training about Aboriginal cultural awareness be made continuously available to service providers.
- Co-ordinated approaches to cultural awareness training at national and state levels be developed across all departments involved with Aboriginal programs and short term advisory groups be convened to undertake this.
- Recurrent funding must be available to develop accredited training modules that address financial, management, operational and human resource issues with Aboriginal community based organisations. Traineeships should be developed for potential workers in Aboriginal Community Care services
- Specific Aboriginal training must be developed for Aboriginal Community Care service providers about aged care and HACC reforms and other initiatives, program guidelines and boundaries, eligibility and referral protocols
- Training about Aboriginal cultural awareness must be made available to service providers. If mainstream services receive Aboriginal specified funding, cultural awareness training must be compulsory for staff and management committees.

(b) the performance and effectiveness of the Aged Care Standards and Accreditation Agency in:

- (i) assessing and monitoring care, health and safety,**
- (ii) identifying best practice and providing information, education and training to aged care facilities, and**
- (iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;**

NCOSS will refer the Inquiry to the individual responses of the members of the NSW Aged Care Alliance, which is convened by NCOSS on a bi-monthly basis.

Dealing with Complaints

NCOSS is concerned however at the capacity of the Agency to work with the complaints mechanism. It seems that the residential aged care facilities complaints mechanisms are unclear, unnecessarily complex and in a few cases actively discouraged.

There is a need for clear and independent complaints mechanism which

- Provides an accessible and well known framework for complaints as opportunities for improvement in individual cases as well as to identify sector trends
- Reports publicly and uses transparent and independent processes
- Specifically responds to people from culturally and linguistically diverse backgrounds
- Specifically responds to Aboriginal & Torres Strait Islander people and communities
- Does not depend solely on written complaints
- Actively recognises and involves independent advocacy at individual and systemic levels
- Recognises and responds to concerns and complaints from relevant third parties
- Has a clear and transparent relationship with the Accreditation Agency

(c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, as dementia, mental illness or specific conditions are met under current funding arrangements;

This section of the NCOS response to the Senate Inquiry into Aged Care comprises the following sections:

1. Brief scoping of the issue of younger people in nursing homes
2. Inappropriate placement of younger people in residential aged care facilities, based on former NCOS papers and submissions
3. Transport needs of younger people in residential aged care facilities
4. NCOS proposal for the relocation of younger people
5. Issues facing people with disabilities who are ageing

1. Younger People in nursing homes

It is estimated that there are as many as 1800¹ younger people with disabilities in residential aged care facilities in NSW. NCOS and the NSW HACC Issues Forum recognise the need for a response from all levels of government and notes the Commonwealth State & Territories Disability Agreement CSTDA which identified this as a priority area.

NCOS recommends that the Australian Government negotiates with State and Territory governments to develop strategies for targetting community care services to younger people with disabilities who are relocated from residential aged care facilities to more appropriate community based supported accommodation. The active co-ordination of government programs can help to address the accommodation and support barriers that currently place younger people with disability at risk of inappropriate admission to residential aged care. The provision of such support is explicitly identified within the aims and objectives of the HACC Home & Community Care Program.

NCOS commends the attached paper: *Younger People with Disability out of Nursing Homes, 2002*. This discussion paper sets out the reasons why it is inappropriate to place younger people with disabilities in aged care facilities and seeks to promote the issues within the disability and aged care sectors and state and federal governments. The paper also provides several actual de-identified case studies to emphasise the urgency and inappropriateness of the situation.

2. Inappropriate placement of younger people in residential aged care facilities

The Following is a still-relevant amended extract from the 2001 NCOS submission to the Review of NSW Nursing Homes Act:

NCOS believes that young people with disabilities should not reside or be placed in residential aged care facilities. In developing disability services legislation at both federal and state levels, Governments have rightly declared that people with disabilities must be entitled to the same basic human rights as other members of the community and to access the same life opportunities as far as possible as people without disabilities of the same age. NCOS further contends that a person with disability should be entitled to the same rights, entitlements and protections as other people with disabilities (and, in fact, other people without disability) regardless of their place of living, especially if using government funded services.

¹ *Younger People Out of Nursing Homes, 2002*; Discussion Paper of the state-wide community working group

Public funding to disability services comes from both the Australian and State governments. While residential aged care facilities receive only Australian Government funding, they are not specifically covered under disability legislation for services to young people with disabilities. The placement of young people in nursing homes is inconsistent with the provisions of the NSW Disability Services Act (DSA). Alternatives must be found to more appropriately accommodate young people with disabilities now living in residential aged care facilities and to avoid further placement.

The NSW DSA makes provision against the future development of institutional or congregate care in that it specifies that no more than six people with disabilities should live in the same residential situation. Where only a few younger people with disabilities reside in a residential aged care facility, the intention of the DSA is contravened as this is clearly a congregate care arrangement. Where more people with disabilities reside together in a residential care facility, this represents a clear breach of the reason the Act was formed.

While young people with disabilities reside in residential aged care facilities, however, they must be accorded the same rights and protections, quality of services and considerations as other residents². Additionally, NCOSS recommends that the NSW DSA should apply to younger people with disabilities while they live in residential care facilities until more appropriate arrangements can be made.

The primary objective of the NSW Disability Services Act is to *ensure the provision of services necessary to enable people with a disability to achieve their maximum potential as members of the community*³.

Residential aged care facilities have not been developed to maximise the potential of residents but to provide adequate and proper care for very vulnerable, frail people often needing medically intensive and qualified assistance and supervision. Younger people with disabilities who live in residential aged care facilities will not benefit from their rights and entitlements to community living, a least restrictive environment and assistance to reach maximum potential while their living arrangements do not actively and specifically support these objectives. While these objectives may be in place in facilities for older people, their implementation will be very different when applied to a young person, a middle aged person, a person of retirement age, a person in older age.

The Applications of Principles in the NSW DSA describe how services provided by residential aged care facilities do not align with other accommodation services for younger people with disabilities. Several Applications of Principles demonstrate this discrepancy. In particular, the following selection of Applications of Principles⁴ typed in italics states that services and programs must be designed and administered so as to:

*a) have as their focus the achievement of positive outcomes for persons with disabilities, such as increased independence, employment opportunities and integration into the community*³,

In a nursing home, younger people with disabilities are arguably treated in the same manner as other older residents, where all necessary services are provided on-site, with limited regard to maximising increased independence or employment opportunities.

² See NCOSS Response to Review of the NSW Nursing Homes Act 1988 - Older People, September 2000.

³ Disability Services Act 1993 (NSW) section 3 (a).

⁴ Applications of Principles from the Disability Services Act 1993 (NSW) Schedule 1 clause 2.

d) meet the individual needs and goals of the persons with disabilities receiving services³,

The DSA also provides for individual service planning in order to address this principle. There are no requirements for individual service planning for future goals to be undertaken in residential care facilities aside from the medical and support requirements of that individual. Whether the younger person with disability has a medical condition or not, a regular medical and support assessment will not describe the individual goals and needs of that person.

g) promote the participation of persons with disabilities in the life of the local community through maximum physical and social integration in that community³,

If younger people with disabilities are treated in the same manner as other residents, then it is probable that any participation in the local community will be geared towards the needs of the majority, ie older people, and at the highest support level, regardless of the actual or potential ability of the younger person with disability, or their desires or preferences.

h) ensure that no single organisation providing services exercises control over all or most aspects of the life of a person with disabilities⁴,

Clearly, while residing in a residential care facility, that facility has control over most aspects of the life of that resident.

j) provide opportunities for persons with disabilities to reach goals and enjoy lifestyles which are valued by the community generally and are appropriate to their chronological age⁴,

Again, without specific action by the residential aged care facility, it is unlikely that the young person will be offered opportunities comparable or appropriate to their peers outside the facility. Where young people reside in facilities for an extended period of time, they can be exposed to decades of inappropriate old age activities without the value of participation in the activities of other life stages.

l) ensure that persons with disabilities have access to advocacy support where necessary to ensure adequate participation in decision-making about the services they receive⁴,

The use of the Commonwealth Community Visitors Scheme does not protect the interests of younger people with disabilities to the same extent as the NSW Community Visitor Scheme in funded disability supported accommodation services. The Commonwealth Community Visitor must be invited into a facility by

⁴ Applications of Principles from the Disability Services Act 1993 (NSW) Schedule 1 clause 2.

the proprietor for an identified person. The Commonwealth Community Visitor is a volunteer and cannot act as an advocate for the visited person.

The NSW Community Visitors Scheme employs part-time paid visitors who visit mainly disability accommodation services unannounced with the consent of the residents, and report on the quality of the services. These paid official visitors are qualified and skilled in understanding the needs and potentials of people with disabilities. This gives a snapshot of the service provision and an opportunity to talk to clients without the providers present. A written report is prepared for the NSW Community Services Commission, with a copy to the service provider, resulting in further action where there is any breach or unacceptable practice or quality of service. NCOSS contends that the NSW Community Visitors Scheme should be expanded to visit all government funded accommodation/residential care services where a person with disability resides.

There is concern that other disability consumer and advocacy services are not being accessed by younger people with disabilities in residential aged care facilities because younger people may be invisible within a larger population of older people. Also, as services are geared towards the needs of older people, residential aged care providers may not be even aware of any available disability advocacy support.

Many older people in nursing homes are in the final stages of declining health. This is often not the case for younger people with disabilities. Consequently, younger people with disabilities should not receive services in the same place or manner.

It must be acknowledged that older people pass away in nursing homes. It is often their last place of residence. This is a completely inappropriate environment for younger people with disabilities who may reside in a residential care facility for many years.

Any period of stay in a residential aged care facility is unlike a hospital stay where admissions are short and medical wards generally try to group similar age cohorts. Statistics demonstrate that older people in nursing homes often only reside there for between 6 months and 2 years whereas young people may have a relatively long life ahead of them.

Professor Tony Broe⁵ increasingly refers to residential aged care facilities as acute care hospitals in the level and type of care now provided. There is no doubt about the inappropriateness of people with disabilities or anyone else residing in hospitals. When coupled with the fact that, in the absence of more appropriate alternatives, younger people with disabilities may reside in residential care facilities for many years, this represents a serious breach of the rights and entitlements of those individuals. It could be argued that this is an unintentional and subtle return to the now-discredited placement of people with disabilities in institutions.

Nursing homes and hostels have, in some cases, provided full-time residential care for people with disabilities in the absence of more appropriate supported accommodation. Adequate and responsive supported accommodation services to people with disabilities must be provided to avoid inappropriate institutionalised care for younger people.

⁵ Professor Tony Broe at the Australian Association of Gerontologists Symposium in July 2000

The Aged Care Assessment Teams (ACATs) are the usual gateway into the residential aged care system. As multi-disciplinary teams which focus on assessment for service provision to older people, it is inappropriate for ACATs to assess and place younger people with disabilities. The separate developmental and “opportunity” philosophy necessary in service provision to younger people may not be a feature of regular work practices of ACATs. While some members of ACATs may have disability experience, qualifications in geriatrics do not equip ACAT members to work with people with disabilities. Therefore, ACATs’ role, when approached with a younger person with disabilities, must be to refer to a more appropriate assessment system which focusses on people with disability.

Many issues remain unresolved in the placement of younger people with disabilities in residential care facilities. These include the emergence of the need for appropriate supported accommodation for people with disabilities growing older and becoming aged; an appropriate model of service provision for younger people with disabilities needing medium to long term intensive nursing care.

NCOSS recommends that both levels of government develop a policy framework for addressing these and the following issues towards the best possible outcomes for younger people with disabilities:

- The re-location of younger people with disabilities currently in aged care facilities to more appropriate community-based supported accommodation with necessary support services.
- The development of a No Admissions policy to aged care facilities for younger people with disabilities. This should also apply to younger people with disabilities with increasing nursing care needs living in group homes at risk of inappropriately transferring to aged care facilities
- Support for people with disabilities in later life and/or entering retirement.
- Extension of the “ageing in place” philosophy for people with disabilities
- Appropriate service supports for people with disabilities with increasing nursing care needs including the capacity for younger people with disabilities with high level nursing care needs to maintain service provision with a developmental focus
- Capacity for younger people with disabilities with high level nursing care needs to have opportunities to participate in the community and to interact with peers.
- Immediate responses to the desperate need for appropriate supported accommodation for people with a physical disability, a brain injury and an alcohol or substance abuse related brain injury.

3. Transport needs of younger people in residential aged care facilities

As previously stated, NCOSS believes that younger people with disability should only reside in community settings regardless of their support needs. Younger people with disability should not be admitted to or reside in residential aged care facilities. NCOSS is

part of an active campaign to obtain alternative accommodation and supports for younger people with very high support needs.

NCOSS⁶ has found that this principle is supported by the residential aged care facilities, who are eager to ensure that younger people with disability are more appropriately supported in the community. Several of the returned consumer surveys and consumer interviews involved younger people with disability. Younger people in residential aged care facilities are likely to have some differing transport needs compared to older residents, they may want after hours transport to social activities and regular access to community facilities.

One younger man with disability who lives in a nursing home wanted to attend the local TAFE for a computer course. After much deliberation, he was unable to go just because of the lack of appropriate transport.

Story from a survey interview.

Until younger people with disability can be more appropriately supported in community accommodation, their transport needs are critical to their socialisation, avoiding personal isolation, the maintenance of connections with the community and opportunities for individual growth and development. As for older residents, transport can be the linchpin towards active integration with other people and into the community. As for older people, the transport needs of younger people with disability must be individually assessed and addressed, and planned and arranged as for other people with disability living in the community.

NCOSS recommends that, until younger people with disability now living in residential aged care can be more appropriately re-located, the transport needs of younger people with disability must be individually assessed and addressed, and planned, resourced and arranged as for other people with disability living in the community.

4. NCROSS proposal for relocation of younger people

NCOSS acknowledges that the NSW Department of Ageing Disability and Home Care will be undertaking a review of younger people in nursing homes to report in 2006. Given that those younger people who now live in nursing homes have each been assessed as to their support needs and levels of care before entry into residential aged care facilities, NCROSS believes that there is a much more effective method to progress this issue to the benefit of the younger people and state and federal governments.

Given that the Australian Government already accepts financial support responsibility for the 400 or so Commonwealth-assessed younger people with disabilities now living in nursing homes in NSW, NCROSS contends that their support could more effectively, accurately and responsively be provided using the existing Commonwealth funding with appropriate top-ups in a home-style situation. This change would align service provision to these younger people with disabilities towards the current Commonwealth and state legislation which prefers people with disability to be offered the same life chances, eg accommodation, opportunities etc, as people without disability of the same age.

EACH or Extended Aged Care at Home provides nursing home level care to an older person in their own home rather than at an aged care facility. Similarly CACP or Community Aged Care Packages provide hostel level care to a person at home. The

⁶ *On the Road Again* The Transport Needs of People in Residential Aged Care; NCROSS 2003

funding amounts to packages match the funding to a bed in an aged care facility for the assessed level of care. These aged care packages are proving increasingly popular with both consumers and government funding bodies, particularly among Aboriginal and Torres Strait Islander and Culturally & Linguistically diverse communities.

The younger people with disabilities now living in nursing homes could be transferred to an EACH or CACP package, whereby the funding is used to support the person either at home or in a small group situation. This would meet their needs much more directly, provide desirably more individualised service which responds to the needs of a younger person and would be situated within local communities. These younger people might require some top-up funding to establish an appropriate accommodation venue and a period of time to become accustomed to the transition back into the community.

Apart from the obvious benefits to the younger person, this would free up precious facilities for future places available more appropriately to frail older people.

NCOSS proposes that this transfer of younger people onto packages occurs at each release of new aged care packages rather than with existing funding. This means that, when the Commonwealth announces a release of new aged care places (ie beds and packages), a certain number of the packages are quarantined for younger people with disabilities who now reside in nursing homes and hostels.

5. People with disability who are ageing

NCOSS recommends that the Australian Government identifies the needs of people with disability who are ageing; explores innovative models for service delivery; and provides appropriate services for people with disability who are ageing.

At present 11% (30,200) of those aged 45-64 and 4% (13,000) of those aged 65 or over with severe or profound core activity restrictions report an early onset disability (i.e. acquired before age 18). It is anticipated that there will be an increasing number of people with an early onset or longstanding disability who are ageing. Between 2000 and 2006, the total number of people with a severe or profound core activity restriction is expected to increase by 11.6% (137,600 people).

The provision of support to people with disability who are ageing requires specific and considered responses from both Australian and State Governments. NCROSS, in association with an industry group comprising Aged and Community Services Association of NSW & ACT and ACROD (the peak association representing non-government disability service providers), held a range of consultations with both industry and consumer groups to develop a recommendation/position paper *Finding Solutions* to be shortly released. The paper supports the sentiments of many in the disability sector that there is a need for better responses into the needs of people with disability who are ageing. The industry group further identified in its consultation a need for increased information available to providers on examples of good practice and collaboration between service providers, and the need for non-vocational retirement options for people with disability who are ageing. Partnerships between different service providers can be enhanced through a government commitment to regional support and development resources to facilitate collaboration.

NCROSS recommends that the Australian and NSW Governments implement a strategy to meet the needs of people with disability who are ageing by pursuing the recommendations from the *Finding Solutions* Report covering the following areas:

- continuing to research the needs of people with disability who are ageing in 2004-05;
- engendering improved information, communication and collaboration between Government and non-Government providers of disability services, community care and residential aged care.
- establishing trial pilot projects to develop non-vocational retirement options for people with disability who are ageing, with guaranteed funding for successful projects;
- creating clear pathways between government support programs for people with disability in transition as they grow older.

(d) the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly; and

This section of the NCOSS response to the Senate Inquiry into Aged Care comprises the following sections:

1. Adequacy of HACC in NSW
2. Priorities for HACC in NSW
3. Extract from a NSW Regional HACC Network
4. The Home Care Service of NSW
5. Community Care for Aboriginal & Torres Strait Islander People
6. Unmet needs of Older Aboriginal and Torres Strait Islander People
7. Transport needs of people in residential aged care.

1. Adequacy of HACC in NSW

NCOSS, through its involvement in the NSW HACC Issues Forum, has considered the adequacy of the HACC program at many of its meetings since its inception in 1987. Many members of the HACC Issues Forum are involved in the annual forward HACC planning processes at local, regional and state levels.

It is generally agreed that all areas of HACC, both metropolitan and rural, as well as services to people with disabilities and special needs groups are significantly under-resourced. The plethora of HACC and HACC-like programs to support older people can be confusing for consumers, their carers and providers alike. The NSW HACC Issues Forum, however, welcomes any investment of funds to address the sometimes overwhelming unmet need.

The HACC Issues Forum has been calling for several years for a 20% increase in annual funding to the HACC program. This increase should be sustained for some years to address the backlog of demand in community care.

As the population ages and needs increase, demand for community care services is escalating beyond supply. It is generally accepted that HACC presently addresses only 50% of identified need for home-style support services. The Productivity Commission on Government Services 2003 again reported NSW as the lowest per capita HACC spending state in Australia.

In many cases, HACC is considered to be a prevention style service but as the older population increases and as people live to an older age, the demand for more intensive supports is increasing. There is a sound argument for low level supports at an early stage to avoid any unnecessary escalation to crisis, often resulting in the provision of preventable, expensive and sometimes inappropriate supports to older people and their carers.

The Australian Government has recognised the invaluable support of carers to older people. However, as demand for community care services increases without commensurate supply, carers themselves are correctly and increasingly turning to community care programs for support.

2. Priorities for HACC in NSW

Home and Community Care (HACC) is a joint Commonwealth-State funded program that delivers a range of support services to older people, younger people with disabilities and carers to assist them live independently in the community and prevent the inappropriate admission to residential aged care. The services provided through this program include home nursing, personal care, home help, transport, respite care, some health services, food services and home modification and maintenance.

The Australian Government also provides community care through other programs including Community Aged Care Packages and Veterans Home Care. These services are an important avenue of support for the approximately one in five people in NSW with disability, or the half of older people aged 65 and over who have a disability. The services are also particularly important where people with disability or older people do not have access to the informal care and support provided by family and friends. It is estimated for example that the percentage of older persons 65 and over who lived alone in 2002 was 29.9%. Per capita Commonwealth and State expenditure on HACC services in NSW has traditionally lagged behind that of other states. The 2003 Productivity Commission Report on Government Services indicates that in 2001-02 NSW had the lowest per capita expenditure on HACC services for persons aged 70 years and over including Indigenous people aged between 50 and 69. In NSW an average of \$504 was expended for this group of people, a low figure in comparison to the \$756 expended in ACT. An ageing population will further place strain on existing services, with a projected increase of 26% by 2011. Growth to the HACC program has been compromised by inadequate indexation.

Growth funds for increased costs to the HACC program are measured utilising the Commonwealth Own Purpose Outlays (COPO) indexation method. According to Aged and Community Services Association NSW & ACT this indexation method does not reflect the true costs associated with running services, estimating that, between 1999-2000 and 2001-02, the HACC Program in NSW has been underfunded by between \$17.6m and \$28.5m. Indexation for the same period to HACC services in NSW was estimated at 6.36% according to the COPO method; other indices suggest a figure closer to 14% for increased in costs for this period. In 2004-05 there has been very welcome growth allocation in NSW to the HACC program of approximately 8.6%.

Despite this healthy allocation to the program, growth has been compromised in NSW by the State Government's contribution to funding the SACS Award and some of the pressures which been placed upon HACC services. In 2003-04 around \$4m or 21% of this growth figure represents the NSW Government commitment to meeting last year's SACS Award increases. HACC services in NSW continue to experience financial pressure relating to the increasing costs maintaining existing levels of service, and meeting the costs of volunteers, fuel and vehicle costs, increased OHS responsibilities, training obligations and management and administrative costs. For example, some services have had to meet costs for increased public liability insurance, which in some instances have doubled in the past year.

HACC services have also been placed under unnecessary strain waiting for the Australian Government and the NSW Government to sign off funds in the 2002-03 HACC State Plan. The Plan was finally signed off in late August 2003, but this has resulted in further delays from the Department of Ageing, Disability and Home Care in rolling out service agreements to organisations. This has made it extremely difficult for services to plan ahead for the coming year and placed other services awaiting growth funding under financial pressure.

The Home Care Service of NSW is the largest provider of community care services in NSW, and receives a large percentage of its funding from the HACC program. The High Needs Pool (formerly the Virtual Pool) provided by the Home Care Service NSW is for Home Care recipients who require 60 hours or more service support per month. There are presently 300 people on the waiting list for the High Needs pool, and it is not clear that this situation will be remedied quickly. Despite an anticipated increase in funding for the Home Care Service in the 2004-05, State Budget papers anticipate that there will be a reduction in the average number of hours of service provided to Home Care customers in the coming year.

NCOSS, through its consultations, continues to identify unmet demand for regular services from the Home Care Service of NSW at the local level around the State. The accessibility of HACC services to people from culturally and linguistically diverse communities must also improve. Whilst people born in a non-English speaking country represent 20.7% of people over 70 years of age, according to 2001-02 HACC Minimum Data Set information only 13% of HACC recipients are born in a non-English speaking country. In 2003 the NSW Government made a commitment to develop an action plan to improve services for people with disability and older people from culturally and linguistically diverse backgrounds. This would be an important opportunity to address some of the barriers that prevent people from culturally and linguistically diverse communities accessing HACC services through funding for cultural competency training, bi-lingual workers and improving access to translators.

Another area that could benefit from better prioritisation of resources is the provision of community care support to people with mental illness. HACC services are well placed to provide outreach programs to assist people with mental illness to be involved within their communities and to prevent deterioration as a result of their illness. NCOSS consultations in NSW have indicated that there are around 1,000 people with moderate mental health support needs who could benefit from this program across NSW.

The NSW HACC Issues Forum has identified training and development as a high priority within community care in NSW. Presently there is a lack of consistency in funding for training of staff, volunteers and boards involved in HACC services, with a lack of coordination in order to ensure the adequacy of funds for training across the different regions of NSW. The NSW HACC Issues Forum has indicated that there is a need for more standardised community care training, particularly basic orientation training for new HACC workers and dementia training and awareness, to be delivered equitably across NSW.

3. Extract from a NSW Regional HACC Network

The following is an extract from a NSW regional HACC network in response to the Terms of Reference of this Inquiry:

A Home Maintenance & Modification provider emailed the following info:

“Services are being placed under pressure eg. requests for Home Modifications to be done or else the Home Care/ CACP provider will withdraw services to the client due to OH&S issues. Without additional funding I CANNOT meet the growing demand for urgent work. OH&S is a rapidly growing concern for ALL service providers. This raises both moral and practical problems with

relation to meeting the guidelines as set out for every service assisting clients.”

This provider also said she used to receive two urgent cases per month now its six urgent cases per week. There is a complete lack of resources and staffing in the sector.

There is a high turnover of staff - this service has its fourth coordinator in as many years.

There is a six month wait for bathroom modifications.

There is a two month wait to see an Occupational Therapist (OT) - Home Modification services can't do any thing without the OT.

PADP [Program of Aids to Disabled People, a NSW Government program] has a waiting list, they lend their equipment for eight weeks, after this people are referred to HACC services.

There is an assumption by government that there will be family support, but this is not always available.

There are very few advocacy services around.

Agencies are not advised about exit policies, people do not want to go into nursing homes, a Community Options provider stated that we are becoming post acute care facilities. There are no convalescent facilities any more.”

4. The NSW Home Care Service of NSW

The NSW HACC Issues Forum is concerned at the increasing difficulty in accessing the NSW Home Care Service (HCS). The HCS is the largest community care provider in NSW, providing mainly domestic assistance and personal care services. In some rural and regional areas, it is the main government instrumentality and the sole provider of community care services to older people. In recent years, HCS has also assumed the role of auspice of new and/or expanded services eg Community Options, Aboriginal services, community transport and others. The NSW Audit Office has been reviewing the HCS and is due to report shortly.

At present, the HCS retains no waiting lists. Members of the NSW HACC Issues Forum report extreme difficulty in accessing HCS, due to both escalating demand and the cumbersome use of the call centre to process consumer approaches. There is concern that the HCS use of statewide targets of service provision does not reflect demand in local areas. The service is not flexible enough to consumers. The Forum reports inadequate service provision in NSW in domestic assistance and personal care services and the need for more referral points into the system. N calls for improved transparency of referral services in the HCS call centre and there should be an appeals process for people unable to get services. Further, the HCS does not operate in isolation and consequently must create improved relationships with other community care providers and programs.

5. Community Care for Aboriginal People

There is an urgent need to improve the accessibility and appropriateness of community care services for Aboriginal people in NSW.

Community Care⁷ plays an important role supporting older persons and people with disability from an Aboriginal and Torres Strait Islander background. The low utilisation of

⁷ *Fairer Taxes & Better Services*; 2004/05 State Budget, NCOSS

residential aged care by Aboriginal people places an increased emphasis on community-based supports. Further, the fact that only 2.8% of the Aboriginal and Torres Strait Islander population are aged 65 years and over, compared to 13% for the non-Indigenous population, emphasises the importance of providing appropriate care to Aboriginal people as they age.

It is important to note that many Aboriginal people with disability do not currently utilise most disability services. NCOSS notes the employment of culturally appropriate staff and volunteers can ensure that services are appropriate and are utilised by Aboriginal people. But emphasis must also be placed on improving the responsiveness of generalist services to Aboriginal communities.

In July 2002 the State Gathering Committee released a report entitled *Focus for the Future*. The document provided a range of recommendations and guiding principles derived from the 2000 State Gathering conference, necessary to enhance autonomy and self determination, Aboriginal representation within the system, needs and assessment, service development, coordination and training.

Delegates at the 2003 DADHC sponsored *Focus for the Future: Moving Forward* State Gathering in Coffs Harbour identified a very strong need for improved resources and coordination for community transport services for Aboriginal people. These services must to be delivered in a flexible manner that is appropriate for Aboriginal communities. Improved management of community resources within and between localities could improve the delivery of transport services for Aboriginal people, particularly in rural and regional areas where large areas can be covered more effectively through coordination between different service providers. DADHC has provided support for a transport pilot project in the Western region, which has usefully improved the sharing of community resources to deliver culturally appropriate services to Aboriginal communities.

NCOSS consultations in Walgett in 2003 suggest that coordination projects (such as mobility management offices) could help to utilise existing resources better and improve the availability of flexible transport options for Aboriginal people.

NCOSS encourages Australian Government to provide recurrent funding for innovative projects that demonstrate an ability to effectively improve outcomes for Aboriginal people. The 2003 Focus for the Future conference highlighted the need for Aboriginal workers and Aboriginal services to work more closely together in order to share resources and build networks. There are a number of inequities in the employment of Aboriginal HACC development workers in NSW. These are vital for linking services and service systems, providing training and support and for assisting local communities. Focus for the Future conference delegates in 2003 voted that HACC Gatherings for Aboriginal and Torres Strait Islander workers in community care should be held at least once every two years in order to maintain networks of support, coordination and development, to share innovative practice and to improve the responsiveness of services.

6. Unmet needs of Older Aboriginal and Torres Strait Islander People

Aboriginal and Torres Strait Islander people⁸ have been disadvantaged for many years without access to many of the opportunities other Australians take for granted. The issues

⁸ NSW Aged Care Alliance Federal Election Issues Kit 2004; NCOSS.

for older people from Aboriginal & Torres Strait Islander communities are complex and require deliberate attention.

Because Aboriginal people have lower life expectancy than other people in the population, their timely access to aged care services can be delayed and the appropriateness of those services can be diminished without attention to individual needs and cultural responsiveness. Additionally, the number of older people in Aboriginal and Torres Strait Islander communities is increasing. Consequently, the usage rate of many community support services by Aboriginal people is unacceptably and disproportionately low.

In 2003 in New South Wales, a statewide Gathering of Aboriginal and Torres Strait Islander workers in community care and disability services determined that the most important ways to provide equitable access to appropriate services were to progress the autonomy of services to be delivered to Aboriginal people by Aboriginal people with quality training, proper representation within decision-making systems as well as a deliberate investment in Aboriginal and Torres Strait Islander service provision.

Specific issues raised by the Gathering Committee identified the following needs were of a critical nature to older people and their family carers from Aboriginal communities:

1. Due to the lower life expectancy, it is crucial to lower the access ages for aged care and community care support services to 45 years in line with the HACC program.
2. Improved access to health care for older people and their family carers. Health care must be culturally responsive and involve an Aboriginal worker in direct service provision. This especially but not exclusively includes increased access to dialysis treatment, dental care and oral health and other health services.
3. Specific access to community care services which are provided by Aboriginal people in culturally respectful ways. At present, such access is inadequate and ad hoc, and includes access to mainstream services by Aboriginal people and the provision of Aboriginal and Torres Strait Islander specific services.
4. Family carer needs are paramount to equitable access to support services. Deliberate attention is required to assess and address the specific needs of family carers of Aboriginal older people.
5. The provision of and access to appropriate, local and affordable housing to Aboriginal and Torres Strait Islander people and communities is critical to the wellbeing of Aboriginal older people and their family carers. Housing has been included as part of the National Aboriginal Health Strategy. More resources are needed for the Commonwealth State Housing Agreement to support Aboriginal People.
6. Transport is a long-neglected issue but an enabling service to other critical support services for Aboriginal and Torres Strait Islander people. Affordable, accessible and responsive transport for health, cultural, personal business and social reasons is woefully inadequate within Aboriginal and Torres Strait Islander communities. This could be included as part of the National Aboriginal Health Strategy.

7. Transport Needs of People in residential aged care

NCOSS recommends the Report completed in December 2003 *On the Road Again*⁹. This recent Report highlights the inadequacy of funding to provide essential health, personal business and social transport services to older people in residential aged care facilities.

The Report covered the provisions of residential aged care and community care programs, guidelines, health-related transport, planning requirements, the needs of carers, the use of scooters and delivered services into facilities.

The Report found that

- approximately one third of people in residential aged care facilities were without significant access to family and friends, that
- many residents would prefer to use transport services more often to travel to appointments and outings, that
- a major barrier to travel for many older residents was the lack of an accompanying escort
- people from culturally and linguistically diverse backgrounds were unlikely to use any transport services except family
- there were vast inequities in access and eligibility to subsidised taxi transport
- residents were only able to pay \$10 per week or less on transport
- many residential aged care facilities were desperate for available, affordable and accompanied transport services for their residents

Major recommendations in the report centred on the provision by the Australian Government of a Residential Aged Care Transport Supplement and the establishment of regional mobility management systems to best utilise existing resources.

⁹ *On the Road Again* 2004 NCOSS available on the NCOSS website www.ncoss.org.au

e) the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

In the NCOSS Report *Earlier Discharge – Monitoring the Outcomes of Hospital Discharge* (December 2002), the impact and monitoring of early discharge from hospitals on patients, families and communities was clearly described. In summary, the report showed that the responsibility for post acute convalescence has been transferred onto patients and families and into the community without a commensurate increase in community care (particularly HACC) services to address this need. It seemed to be assumed by hospitals that because community care services existed, there would be adequate supports for people returning home, despite the fact that community care was never intended to respond to the general population with sub-acute needs, never designed as a quick response solution to early discharge and that community care guidelines and funding contracts prevented this service provision. Further “A key concern for NCOSS has been the lack of effective monitoring of the outcomes of hospital discharge.”

There have consequently been several innovative trial responses to address the need for community care services after discharge.

The NSW government through NSW Health has been trialling, in conjunction with Community Options Projects NSW, a new system entitled ComPacks, which is specifically funded to respond to the needs of people who are being discharged from hospital. The Evaluation Report is about to be released but the success of the trial is outstanding. ComPacks involves short-term case management and brokered non-health community care services to the person upon discharge. The Project has involved hospitals and Community Options providers in 11 areas. Demand to join the Project from other areas has put extreme pressure on NSW Health to continue and extend the funding.

Other innovative projects have been implemented in Macarthur and New England regions. Entitled Temporary Assistance Programs, these have been localised partnerships with NSW Health to provide short-term community care support to people as they leave hospital.

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