NSW Aboriginal Community Care Gathering Committee



# Submission to the NSW Ageing Strategy 2012

# About the Gathering

The NSW Aboriginal Community Care Gathering Committee (The Gathering Committee) comprises Aboriginal people representing Aboriginal and Torres Strait Islander communities and non-government organisations involved in support services to Aboriginal older people, people with disability and their carers and families in NSW. The Policy Positions of the Gathering Committee are designed to advance the needs, rights, interests and issues affecting community care and related services for Aboriginal and Torres Strait Islander people in NSW. The work of the Gathering involves policy development, conferences, responses to Government initiatives and regional and state networking. The Council of Social Service of NSW (NCOSS) provides the secretariat to the Gathering Committee.

The Gathering Committee meets at least four times per year and has organised five successful statewide Conferences since 2000; four of these Conferences have been specifically for Aboriginal and Torres Strait Islander workers and people concerned with community care and related services in NSW, and one Conference, *Sharing Our Way in Community Care*, was for non-Aboriginal people to promote Gathering policy positions and progress social inclusion. The most recent and very successful **Challenge Change and Choice** Conference for over 100 Aboriginal people and workers was held 8-10 March 2011 in Wollongong.

This submission has been approved by the Chair of the Gathering Committee, Nicole Winters, and the Vice-Chairs, John Gilroy and Craig Foreshew.

#### Contacting the Gathering Committee

Should you require further information or clarification on any of the comments or Policy Positions please do not hesitate to contact the Chair or Vice-Chairs of the NSW Aboriginal Community Care Gathering Committee or the NCOSS secretariat.

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#### Disclaimer

This submission represents the views of the NSW Aboriginal Community Care Gathering Committee, and does not necessarily reflect the views and opinions of NCOSS.

### Introduction

Older Aboriginal and Torres Strait Islander people experience poorer health and life expectancy than non-Aboriginal people<sup>1</sup>. Aboriginal and Torres Strait Islander people tend to develop dementia at younger ages than non-Aboriginal people<sup>2</sup>, and are more likely to need assistance with core activities than older non-Aboriginal people<sup>3</sup>. These circumstances, as well as unique roles that older Aboriginal and Torres Strait Islander people play in their communities, mean that supporting older Aboriginal and Torres Strait Islander Islander people to age well will require a range of specific strategies.

This submission is based on the policy documents of the NSW Aboriginal Community Care Gathering Committee. As well as the featured principles and recommendations, the Gathering Committee has put together a number of other principles and recommendations about service delivery, cultural competence, social inclusion, and service management, which accompany this submission (**attached**).

<sup>&</sup>lt;sup>1</sup> AIHW 2011. Older Aboriginal and Torres Strait Islander people. Cat. no. IHW 44. Canberra: AIHW. Viewed 30 January 2012, available at: <u>http://www.aihw.gov.au/publication-detail/?id=10737418972</u>

<sup>&</sup>lt;sup>2</sup> Arkles RS, Jackson Pulver LR, Robertson H, Draper B, Chalkley S & Broe GA 2010. *Ageing, cognition and dementia in Australian Aboriginal and Torres Strait Islander peoples: a life cycle approach. A review of the literature.* Sydney: Neuroscience research Australia and Muru Marri Indigenous Health Unit, University of New South Wales, available at:

http://www.healthinfonet.ecu.edu.au/uploads/resources/19517\_19517.pdf

<sup>&</sup>lt;sup>3</sup> ABS, The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples,2008, available at:

http://www.abs.gov.au/AUSSTATS/abs@.nsf/39433889d406eeb9ca2570610019e9a5/74F14511 E8C9BD6FCA2574390014AB46?opendocument

## Older People

The Gathering recognises that age does not necessarily designate a person as an *Elder*, *h*owever maybe recognised differently in each community. Different cultural protocols on the status of Elder apply to different local communities. An *Elder* is acknowledged by a community as having made a contribution to the community and as having cultural knowledge and status.

#### **Eligibility**

In acknowledging that Aboriginal people have a reduced life expectancy compared to other people in Australia, Aboriginal people must be eligible for aged care and other seniors' services from the age 45 years. Until life expectancies for all are similar, eligibility from age 45 years for Aboriginal people would ensure that they equitably receive the very necessary support services and other benefits afforded to other older people in Australia.

As the Commonwealth government takes over the operational management of all aged care programs, eligibility for Aboriginal and Torres Strait Islander people for aged care will be from age 50. The NSW government must ensure that Aboriginal and Torres Strait Islander people requiring aged care services do not experience any disruption to services, and that Aboriginal and Torres Strait Islander people in NSW remain eligible for aged care services from age 45.

#### Recommendations

- 1. All programs providing support and other services to older people must ensure that the age criteria for Aboriginal people start at 45 years. Service provision must not be disrupted in the process of aged care reform.
- 2. Aged Care Assessments must be available for Aboriginal people from age 45 years if necessary, not 50 years.
- 3. The NSW Seniors Card must be available to Aboriginal people from age 45 years.

#### Respect

Aboriginal older people must be afforded the respect of both Aboriginal and non-Aboriginal communities. The Gathering accepts the wide diversity amongst Aboriginal older people. All Aboriginal older people are not the same. This respect must enable Aboriginal older people to participate in the decisions and processes that affect their lives.

#### Recommendations

4. In order to respect Aboriginal older people, Government and non-government organisations must ensure that their interactions with Aboriginal older people are culturally responsive and appropriate in line with the cultural protocols of the local community.

- 5. Organisations must provide time to listen, engage with and dialogue with Aboriginal older people as a means of enabling them to properly participate. This means contracting, guidelines, data collection and quality assurance processes acknowledge and provide for the additional time to sit down with Aboriginal older people as a leading practice.
- 6. Organisations must allow and encourage non-invasive feedback from Aboriginal older people, with input into complaints mechanisms ensuring no retribution, especially within small communities.
- 7. Respect means ensuring that Aboriginal people are involved in the planning and implementation process of policies, programs and services. Obtaining funding to establish services specifically for Aboriginal families before relationships are forged is seen as disrespectful by Aboriginal people and Aboriginal service providers.

#### Volunteering

The Social Inclusion Committee found that Aboriginal older people do volunteer in a myriad of ways. There is often an active but invisible or unacknowledged partnership between Aboriginal older people and their communities.

#### Recommendation

- 8. Government and service organisations must ensure that assessment and supports are provided in a manner than both respects and supports encourages enables Aboriginal older people to continue to volunteer within and outside their communities. This may require flexible provision in a culturally responsive way. Guidelines, policies and procedures, operations and service delivery must sustain Aboriginal volunteering.
- 9. Volunteering does not preclude an Aboriginal older person from being eligible for community care and home support services.

#### ELDERS and Older People

Many non-Aboriginal people and service providers ask Aboriginal **Elders** to perform specific tasks e.g. openings, welcome to country, acknowledgement at events, mentoring, confidential advice etc. Often service agencies and organisations request older Aboriginal poeple and Elders to perform tasks that are the responsibility of a paid worker. This practice places a high level of unnecessary stress on our older people, resulting in stress related health complications.

The NSW Government should adopt as a general principle that Aboriginal Elders are recognised within the local communities. Methods for recognising Elders vary between localities and between Aboriginal communities.

#### Recommendations

10. Providers and people making requests of Aboriginal Elders must be required to ensure the requests are reasonable manageable and with sufficient notice. Aboriginal Elders must be provided with appropriate enablers and/or recompense as appropriate (i.e. transport or expenses). The best way to ensure this is simply to take time to ask and discuss.

- 11. Government and community providers are obligated to observe appropriate protocols when making requests for cultural acknowledgements and events. Appropriate protocols and advice can be obtained from
  - A local Aboriginal organisation
  - Local councils
  - Aboriginal Medical Services
  - The local Lands Council
  - Department of Aboriginal Affairs

Contracts and guidelines must reflect this obligation.

#### Time and Trust

Service delivery to Aboriginal older people requires time to build trust, to understand and acknowledge the lived history of the older person. Leading practice in community care to Aboriginal people ensures that visits include time to build trust, a cup of tea, a chat. Often Aboriginal older people are storytellers; the details needed for assessments etc. are often in the story.

#### Recommendation

12. Service Providers must recognise that delivering supports to Aboriginal older people can take time, sometimes involving several visits for a complete assessment. Guidelines, data collections and operations must not discourage that taking of time to engage Aboriginal older people. The details can be obtained in sharing stories; the forms can be completed later.

#### Closing the Gap

The NSW Aboriginal Community Care Gathering Committee is committed to CLOSING THE GAP for Aboriginal people and communities. The Gathering contends this must involve:

- strengthening the connection between Health and community care
- increased availability of Aboriginal services
- Aboriginal older people being aware of rights under the Health Act.

#### Recommendations

- 13. Community care service provision, guidelines, contracting, and operations must be reviewed to ensure they always contribute to the *CLOSING THE GAP* strategies.
- 14. Community care sector workers must be aware of Health and other relevant services to support the needs of older Aboriginal people.
- 15. Health education models must be widely extended to Aboriginal communities.

#### **Confidentiality**

Aboriginal older people often live in small and/or well-connected communities, regardless of their geographic location in metro or rural settings. Guaranteed

Confidentiality is a trust factor that can make or break the provision of appropriate supports to Aboriginal older people.

#### Recommendations

- 16. Consent to share information must be openly negotiated upfront, and refusal respected. Workers must reassure Aboriginal older people that their information won't be used with their name for data collection and other purposes.
- 17. There must be continued training as well as enforceable consequences for workers in breach of confidentiality guidelines.

#### Back to Country or going home

Many Aboriginal older people now live away from their original lands and communities, their country. They may have been forcibly removed or moved of necessity. Sometimes, Aboriginal older people must be enabled to *go home* or *back to country*, to visit the community and return on a spiritual journey, for healing or to renew connections.

#### Recommendation

18. At times of necessity, service providers must be enabled to support/facilitate the return to country for some Aboriginal older people. A good outcome requires the provision of support at journey's destination plus any necessary support to the accompanying person, where required. The Gathering recommends the creation of a pool of resources to facilitate *back to country* or *going home* held regionally or centrally and decided on a case by case basis. This will involve return transport and support at destination, including no loss of continuity of service on their return home.

#### Elder Abuse

Elder abuse, the abuse and/or neglect of older people, can be subtle and hidden in Aboriginal communities but no less present than in mainstream communities. Aboriginal older people, remembering a history of mistreatment by officialdom, may be unwilling to act on abuse. However, abuse of elders is unacceptable in all communities and must be appropriately addressed for Aboriginal older people.

#### Recommendations

19. Strategies must be developed, consulted, implemented and promoted that address elder abuse in Aboriginal communities. These must encompass older people who reside in small well-connected communities, accounting for unintended neglect, providing viable solutions and enforceable consequences to address the situation.

#### Veterans Gold Card

Aboriginal returned soldiers and their spouses must be as entitled to the Veterans Gold Card as non-Aboriginal Diggers. When some Aboriginal people went to war, they were not yet considered citizens; thus no Veterans Gold Card recognition or entitlement. These early Aboriginal soldiers cannot access Veterans Home Care like other returned soldiers. Veterans Home Care will offer enhanced access to necessary in-home supports and assistive technologies.

#### Recommendation

20. Retrospective amendments must be made to enable eligible Aboriginal people to access Veterans Gold Card and Veterans Home Care. Then eligible Aboriginal people must be invited and encouraged to apply for their Veterans entitlements.

#### Chronic disease

Aboriginal older people experience higher incidences of chronic disease. Aboriginal older people must be assessed for ComPacks prior to discharge from hospital. ComPacks can be provided to people requiring short term home supports on leaving hospital but people must be referred before discharge. Many Aboriginal older people miss out on ComPacks because they are not referred while still in hospital.

#### Recommendation

21. Hospitals must have mandatory discharge criteria for all Aboriginal people before leaving hospital. A list of all hospitals providing ComPacks should be publicly available and on HSNet.

#### Dementia

Funded Dementia Monitoring (Early Stage) services currently begin monitoring Aboriginal people from 45 years of age. This age criteria must not be raised.

#### Recommendation

22. Under the proposed changes to aged care, the age criteria for Aboriginal people for assessments will increase to 50 years. The entry criteria for eligible Aboriginal people must remain at 45 years.

# Aboriginal Carers

Carers are usually family members who provide support to children or adults who have a disability, mental health problem, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, friends or children of any age. Carers may care for a few hours a week or all day every day. Some carers are eligible for government benefits, while others are employed or have a private income<sup>1</sup>. People employed to provide support services are staff, not carers.<sup>4</sup>

# Grandparents raising grandchildren and as carers of people with disability

Aboriginal grandparents raising grandchildren and/or as carers of people with disability must have their own needs addressed as older people, in the context of the family situation, whether short-term, occasional or continuing. This situation often remains unrecognised or unacknowledged in the community and in Community Care. Many Aboriginal households are multi-generational. Integrated service provision and flexibility to encompass changing needs will avoid unnecessary family breakdown, illness or exploitation.

Grandparents raising grandchildren are often receive only the age pension and may be unable to pay fees/co-payments or cover costs of their own care and supports needs.

#### Guiding Principles:

- (a) The roles, rights and responsibilities of Aboriginal carers must be recognised and acknowledged.
- (b) The needs of Aboriginal carers and those they support are not identical, and therefore carers' needs will require specific attention.
- (c) Aboriginal carers must be able to access a range of supports and services that are appropriate and flexible to their needs throughout their lives and have a choice about relinquishing care. Support services can include respite, emotional support, practical support and financial assistance.
- (d) Supports and services to address carers' needs are to be equitable across regions, and regional networks.
- (e) Aboriginal carers must be included in services as partners in care especially during assessment, service delivery and reassessment.
- (f) Aboriginal carers should be able to access education and training courses, for example, first aid and other practical supports. Aboriginal carers must also have the opportunity to access training about the social, emotional and physical impact of

<sup>&</sup>lt;sup>4</sup> Updated from Carers NSW website July 2008

caring. This training could be formally recognised as prior learning to assist Aboriginal carers with entry into tertiary courses and/or the workplace.

- (g) Culturally appropriate information is to be available at all times when needed and in a timely manner and in language that is culturally appropriate and in a variety of formats and mediums.
- (h) Advocacy assistance must be available to family carers when they are dealing with services. There are presently only limited avenues for assistance for carers or the person they support, especially during assessment, service delivery or reassessment.

#### Recommendations:

- 23. A new whole of government Carers Policy for NSW must be developed as the *Carers Action Plan 2007-2012* expires, and must specifically recognise Aboriginal carers. This must be appropriately resourced and implemented.
- 24. Positions must be identified at a regional and local level for working with Aboriginal carers. The regional development positions should involve developing and coordinating different services with the disability, aged care and other sectors. The local positions should be carer-support specific.
- 25. All services working with Aboriginal carers must ensure that appropriate referrals are made and must ensure that services work together. Aboriginal carers should be supported through a seamless system of Aboriginal carer support wherever they live in NSW.
- 26. Assessment of the needs of the carer must be separate from that of the care recipient. This is a vital first step in providing protection and support to enable family carers to sustain their caring roles. Like the client's assessment, these assessments should be as holistic as possible.
- 27. Culturally appropriate information is to be available at all times when needed and provided in a timely manner, in language that is culturally appropriate and in a variety of formats and mediums.
- 28. Aboriginal carers must be able to access education and training courses, eg. first aid and other practical supports. Aboriginal carers must also have the opportunity to access training about the social emotional and physical impact of caring. This training should be formally recognised as prior learning to assist Aboriginal carers with entry to tertiary courses and/or employment.
- 29. Culturally appropriate information for Aboriginal carers is to be available at all times when needed.
- 30. Service Providers must ensure that they are aware of the family circumstances of Aboriginal grandparents raising grandchildren. Assessors and providers must ensure they understand the context of the family situation and household of the Aboriginal older person to minimise the inequities due to less information leading to less access to support.

- 31. Grandparents are informed of the rights and responsibilities in raising grandchildren and caring for people with disability, and are assisted to exercise their rights, including access to advocates, legal support and other services.
- 32. Community care workers also require this information to support Aboriginal older people, as well as managers in order to support policies and procedures in cases of exploitation of the Aboriginal older person.

# Service Development, Co-ordination and Effective Management

#### **Guiding Principles**

- (a) Funding bodies must be responsible to ensure that all government funding to community care (including all services to older people, people with disabilities and their carers) for Aboriginal communities is operating effectively and receives adequate resources.
- (b) To ensure appropriate access, community care services must be transparent and accountable to Aboriginal people so that service provision is inclusive of the local Aboriginal community. Service Providers will ensure that nepotism must not override community business and service delivery.
- (c) Aboriginal people will operate their organisations:
  - i. in a culturally appropriate manner to each local community
  - ii. along effective and efficient management and financial accountability principles.
- (d) To ensure resources are efficiently managed, accountability and reporting procedures should be consistent across all government funding bodies.
- (e) Within mainstream services, Aboriginal identified positions (including indigenous positions), Aboriginal identified funding and resources must be transparent and retained only for Aboriginal people. Mainstream services should be clear in reporting results or service outputs; i.e. reporting on how many Aboriginal people use and access services.
- (f) Multi-purpose service outlets are highly recommended but may not be suitable for all local Aboriginal communities due to cultural and geographical factors.
- (g) Aboriginal HACC Development Officers, as full time workers, are required in all regions in order to link services, provide training and support, facilitate local cultural awareness training for workers and communities and to assist local communities to respond to the needs of Aboriginal people.
- (h) Departmental requirements including Minimum Data Set (MDS), Annual Returns and reports, validation, and quality reviews must take into account specific service provision to Aboriginal people. HACC and other community care standards, quality assurance and contracting should be applied in an Aboriginal culturally appropriate manner to the local area.
- (i) To achieve appropriate and quality work practices within service provision, Aboriginal networking must be recognised and adequately resourced at all levels.
- (j) Partnerships between Aboriginal and non-Aboriginal services and workers are critical to the adequate provision of support to Aboriginal older people.

- (k) All Aboriginal staff in NSW Health, including Aboriginal Patient Liaison Officers and Aboriginal Health Education Officers and other hospital staff (eg discharge, ComPacks, social workers, transport etc) should know, understand and refer to community care systems and services.
- Effective, accessible and culturally appropriate complaints procedures must be recognised as an important consumer rights principle, and must be inclusive of Aboriginal consumers and service providers.

#### **Recommendations**

- 33. Existing effective Aboriginal service models are to be identified and examined for suitability for other Aboriginal communities within NSW taking into account regional environmental cultural factors. A number of innovative Aboriginal projects should be established and evaluated. Additionally, resource materials should be developed to assist Aboriginal services in creating and establishing new services to address gaps.
- 34. Strategies to improve both government interdepartmental co-ordination (Health, ADHC, Commonwealth etc.) and service provider co-ordination (Health, HACC, CACPs other Commonwealth programs etc.) must specifically respond to Aboriginal needs.
- 35. To achieve improved appropriate and effective work practices, networking between Aboriginal providers and with non-Aboriginal providers must be recognised and adequately resourced at all levels.
- 36. All Aboriginal and non-Aboriginal service providers and funding bodies must have culturally appropriate complaints procedures meeting the needs of Aboriginal and Torres Strait Islander people.
- 37. Government agencies which provide funding must come together in a partnership agreement to develop a standard consistent approach to accounting and reporting procedures to avoid multiple and duplicate reporting systems.
- 38. Aboriginal HACC Development Officers, as full time workers, must be funded and adequately resourced in all regions in order to link services, provide training and support, facilitate local cultural awareness training for workers and communities and to assist local communities to respond to the needs of Aboriginal people.
- 39. Mainstream managers and workers have the responsibility to encourage and support partnerships between Aboriginal and non-Aboriginal services and workers.
- 40. Indigenous Co-ordination Centres and the NSW Aboriginal Community Care Gathering Committee must create effective ongoing links to ensure that local projects and planning include a consideration of community care at every stage.

#### **Guiding Principles:**

- (a) Self-determination in the provision of community transport is essential to appropriate services to Aboriginal people. Such self-determination must cover service delivery, development, monitoring and evaluation, planning and implementation.
- (b) Transport issues should be regularly discussed at all Aboriginal state and regional representative forums.
- (c) Aboriginal community care clients and carers must be eligible for transport services wherever they are in the state.
- (d) Transport funding that comes into a region must appropriately respond to the entire target population i.e. proportion towards Aboriginal people.
- (e) Transport should be enabling and flexible so as to respond to Aboriginal cultural needs.
- (f) Culturally appropriate drivers will provide culturally responsive transport to Aboriginal people.

To achieve this, the following is required:

- locally appropriate cultural awareness training for all transport drivers
- flexible and responsive transport services to better support Aboriginal older people, people with disabilities and carers.
- (g) Aboriginal transport must not rely on Aboriginal volunteers. Aboriginal transport should be resourced appropriately to provide paid Aboriginal drivers. Volunteers should provide complementary services not essential transport services.
- (h) The participation of Aboriginal people in the transport workforce must be increased, including the employment of mechanics, maintenance people, service administration etc.
- (i) Aboriginal people are part of the community. Mainstream transport has been funded to provide a service to the entire community. Mainstream transport should be transparent on how many Aboriginal people use funded transport services.
- (j) Aboriginal people should be free to use an Aboriginal specific transport service or a mainstream service depending on their preference and needs.
- (k) Aboriginal people are identified as a special needs group under community care programs. As such, mainstream community transport providers should ensure they are providing culturally appropriate service to Aboriginal older people, people with disabilities and carers. Aboriginal specific transport services should have local Aboriginal management and will ensure that drivers and volunteers are culturally appropriate to the community they serve.

- (I) Aboriginal transport has historically been poorly resourced and services providing transport to Aboriginal people have lacked recognition. These services must be adequately funded to provide culturally appropriate services.
- (m) ADHC and Transport for NSW should champion the need for culturally responsive transport to support community care consumers in the areas of health, education and training, employment and so on. For example, this will include services to transport grandparents, generations living together due to economic inequities and other common living situations that could involve older people.
- (n) Fees for service must not be forced upon Aboriginal families. Financial disadvantage is a common access barrier for Aboriginal people in accessing transport.
- (o) The definition of "disability" is a significant barrier to services for Aboriginal people. Transport is a critical enabling service for the support of Aboriginal older people and people with disability and families.
- (p) Some Aboriginal service providers provide transport for people with a disability to address financial disadvantage experienced by families.

#### Recommendations

- 41. DADHC must co-ordinate with the Ministry of Transport on the provision of community care to improve transport for older people, people with disabilities and their carers.
- 42. Government Departments ensure that Aboriginal transport issues are included on the agendas of state and regional forums and other representative structures.
- 43. Strategies must be developed and implemented to ensure that community care clients can access services if they move location or while in transit.
- 44. Local Community Care Forums should always discuss transport issues. Local transport working groups could be established and could comprise Aboriginal people who join together to discuss transport issues and work towards local solutions. The establishment of similar groups is required at the Regional, State and National levels.
- 45. Appropriate funding as determined through consultation processes is allocated to develop and maintain these local, regional, state and national community care transport groups.
- 46. An Aboriginal specific needs analysis should be conducted to ensure that transport is provided in a culturally appropriate manner that allows for flexible service delivery.
- 47. The Ministry of Transport Aboriginal State Co-ordinator will co-ordinate and resource Aboriginal community care transport working groups and identify and ensure adequate resources.
- 48. Adequate transport resources are provided to Aboriginal carers to ensure their needs are addressed.

- 49. The application of fees must not limit access to necessary transport services for Aboriginal people, especially in rural and remote areas.
- 50. Establishing a shared understanding of 'disability' with Aboriginal communities will overcome confusion and misunderstanding between disability and community care services and Aboriginal people.
- 51. Transport providers could work with Aboriginal community managed organisations and Government to coordinate necessary responses, amend prohibitive guidelines and to relieve the resource burden placed on staff.