Submission
No 33

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

Organisation: Carers NSW
Name: Ms Elena Katrakis
Date received: 6/08/2010

NSW
Carers
AUSTRALIA

6 August 2010

The Director
Standing Committee on Social Issues
Parliament House
Macquarie St
Sydney NSW 2000

Dear Sir/Madam,

Carers NSW welcomes the opportunity to make a submission to the Inquiry into services provided or funded by Ageing, Disability and Home Care, Department of Human Services NSW.

1. Introduction

1.1 About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- be the voice for carers in NSW
- undertake research, policy development and advocacy
- provide carer services and programs
- provide education and training for carers and services providers
- build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural or linguistic background.

Carers NSW is funded by the NSW and Australian Governments, sponsorship, donations and membership fees. Membership is free for carers.

1.2 Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful. Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of aged through to the very elderly.

1.3 Key statistics about caring in NSW

According to statistics on carers from the Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers (SDAC):

- Approximately one third of all carers in Australia live in NSW
- 40 per cent of primary carers[1] cared for a partner, 29 per cent for a child, 32 per cent for other (e.g. sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income.

1.4 Format of this submission

This submission will address some of the Terms of Reference of the Inquiry with a particular focus on carers. The submission will be structured in line with the Terms of Reference. Additional matters for consideration will be addressed in the final sections of the submission.

2. Historical and current level of funding and extent of unmet need

The adequacy of funding and the extent of unmet need for services in NSW varies. Carers NSW recognises that in some cases ADHC is providing considerable amounts of funding and is successfully reducing the level of unmet need of some groups. Services for young carers are a good example of ADHC's demonstrated capacity to fund programs that meet identified needs that have long been ignored. Carers NSW believes that ADHC should be commended for their continuing commitment to young carers, and hopes to see this commitment honoured in the long term. In other areas, such as in the provision of supported accommodation options for people with a disability and respite services for carers, Carers NSW and many members of the community hold serious concerns about the adequacy of funding available, and the extent of unmet need that persists.

---

[1] A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care.

2.1 Young carers

Carers NSW has been pleased with the commitment to supporting young carers that ADHC has demonstrated in recent years. A young carer is any person aged under 26 who provides unpaid care and support to a family member who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail. Young carers have distinct needs and a different experience of the caring role to other carers. The impacts of caring at a young age can be significant, long term, and may affect all aspects of life.

ADHC has taken important steps towards meeting the significant needs of this group. Funding provided by ADHC through the *NSW Carer Program* enables Carers NSW to deliver the *Young Carer Program*. The *Young Carer Program* provides camps for young carers from across the state, a quarterly newsletter, telephone group counselling, face to face counselling, telephone support, information and referrals, the development of regional networks and community awareness and education.

Although the program has provided support to many young carers, the demand for services is greater than the capacity of the program to provide support. Applications for young carer camps greatly exceed the number of places available. For some camps such as Camp Bluegum in 2009, the number of applications was more than double the number of places, with 60 young carers attending the camp, and 79 young carers unable to attend due to limited capacity.

Carers NSW commends ADHC for their commitment to addressing the needs of young carers, and looks forward to working with them to address the significant level of unmet need which persists for many of the more than 90,000 young carers who live in NSW.[1]

2.2 Accommodation options for people with a disability

There is significant unmet need for accommodation choices for people with a disability, despite the work done by ADHC to date. As outlined in the *Stronger Together* consultation paper released this year, ADHC has increased its specialist accommodation and intensive in-home support capacity. According to this paper, the first four years of *Stronger Together* have resulted in 970 additional accommodation places being created.[2]

Carers NSW recognises the progress that has been made in improving and expanding the accommodation options that are available to people with a disability, and also recognises the challenge that rolling-out accommodation places can present, particularly in terms of the infrastructure development that is required. However, Carers NSW believes that more needs to be done and more quickly, to help those carers and families at breaking point, and to prevent other families from reaching crisis point.

The evidence suggests that the demand for supported accommodation is so significant that the number of additional places created by ADHC is out of proportion to the scale of the problem.

The Australian Institute of Health and Welfare made the very conservative estimate that in 2005 the number of people with unmet demand for accommodation and/or respite services was 27,800.[3] Considering that approximately one third of people aged under 65 years with a severe or profound core activity limitation live in NSW, it is likely that a significant proportion of this demand is found in NSW. That is, there would be thousands, not hundreds of people in need of supported accommodation, yet over four years several hundred places have been created, not the thousands that are required.

Data collected for the *Young People in Residential Aged Care* (YPIRAC) *Minimum Data Set* (MDS) for 2008–09[4] gives a further indication of the level of unmet need in New South Wales for supported accommodation options for people with disabilities, and also provides some insight into the relative performance of NSW in meeting this demand.

In 2007-08 in NSW 692 people aged under 65 were admitted to residential aged care. People aged under 65 are not in the target group of aged care services, so their admittance to these facilities is in itself a case of unmet demand. In 2008-09, there were 155 users of the YPIRAC program in NSW, 129 of whom were less than 50 yrs old. For at least 58 of these people, the main reason for their entry to residential aged care was that appropriate alternative accommodation was unavailable. The YPIRAC MDS data suggests that ADHC has been less successful than other state and territory departments in providing alternative accommodation to young people in residential aged care. The proportion of service users who were offered alternative accommodation in New South Wales was 7 per cent, which was the lowest in the country, and significantly less than other states such as Tasmania (82 per cent), South Australia (43 per cent) and Western Australia (42 per cent).[5]

Although there are obvious challenges inherent in increasing supported accommodation places in NSW, Carers NSW believes that more can be done by ADHC to meet the pressing needs of these people with disabilities and their families and carers.

Carers NSW is also concerned that if the current need for supported accommodation is not met, the situation will be severely exacerbated. The high projected numbers of people with disabilities and age-related disabilities can only further increase the need for supported accommodation or other support services.

By 2016, the older population of NSW (people aged 65 years and over) is expected to outnumber the younger population (people aged 0-14 years) for the first time in the history of NSW.[6] Every Statistical Local Area (SLA) in NSW is projected to experience population growth among people aged 65 years and over.[7]

According to *Australia's Welfare 2009*[8], while there is no evidence of significant change in age-specific rates of profound or severe core activity limitation, the total number of people with this severe level of disability is rising as a result of increasing numbers of people growing older and reaching the age groups where profound or severe core activity limitation is more prevalent.[9]

It is clear that the significant unmet need for supported accommodation in NSW can only increase. ADHC must do more to address this unmet need now, and to prepare for the even more significant need that we know will exist in the future.

2.3 Respite services

Respite was one of the key issues raised by Carers NSW in our 2010-11 pre-budget submission to the NSW Government. In our consultations with carers, nearly every carer states that they want more respite. The need for more respite was also evident in the *Who Cares...?* report, and it was one of two services repeatedly mentioned during the Better Support for Carers Inquiry as both critically important and in short supply.[10]

Carers NSW acknowledges that respite services were included as a priority in the recent *Stronger Together* consultation paper released by the NSW Government. It is also true that some progress has been made in improving the capacity of respite services, in terms of reductions in the number of temporarily unavailable respite beds. However, it must be recognised that further significant increases in capacity are required. Many carers simply do not receive the respite they require, either because the respite hours allocated to them are inadequate, or the services available are inadequate or inappropriate. This unmet need is evident in the comments of carers in almost every consultation that Carers NSW conducts, and is expected to be reflected in the response of carers to the Carers NSW 2010 Carer Survey which is currently underway.

There is evidence to suggest that demand for respite is increasing. For example, a 2009 progress report for the *Commonwealth State/Territory Disability Agreement* (CSTDA) on specialist disability services found that funded respite services registered the highest growth in service users relative to target population. In 2007-08, 31,500 people used CSTDA-funded respite services compared with 20,500 in 2003-04, corresponding to an increase from 96 respite users per 1,000 target population in 2003-04 to 137 per 1,000 in 2007-08. Over the same period, government expenditure per respite service user fell by 16 per cent in real terms. Data on hours of respite received show a downward trend from an average of 12.1 per respite user per week in 2003-04 to 10.5 hours per week in 2007-08.[11]

The *Home and Community Care Program 2007-08 Annual Report* indicated that the highest average hours of service to clients by assistance type was for centre-based day care (130 hours) followed by respite care (86 hours). It is important to note, as stated in the report, that these averages are a rough measure of service provision and do not reflect the experiences of individuals. For example, some clients receive services throughout the entire year and others for only short periods.[12]

The evidence suggests that the amount of government funding in real terms for respite per service user has decreased. Meanwhile carers have identified increased respite availability as a high need for their caring role. Carers NSW believes that respite is an essential service for carers and that currently funding for respite is inadequate.

3. Flexibility in client funding arrangements and client focused service delivery

The feedback Carers NSW receives from carers indicates that more flexibility is needed in service delivery and funding arrangements. Although key policies such as *Stronger Together* promise a 'person-centred approach' and '...systems which are capable of meeting people's choices and needs', this is not yet the reality experienced by carers using ADHC services. Carers complain that it is they who must meet the requirements of the service and not the other way around. Carers who can not fit around rigid program guidelines do not receive the services they need.

3.1 Respite services

Of particular concern to carers is the lack of flexibility in the delivery of respite services, as indicated above. Among the concerns that carers have communicated to Carers NSW regarding the flexibility of respite services are:

- lack of appropriate respite places for the person they care for, especially for those with high support needs, for whom the only available option is often a residential care facility
- being offered services they don't need but denied the services they do, for example, being repeatedly and exclusively offered over-night respite despite stated need of after-school respite
- imposition of a 'minimum' length of respite, meaning the carer must use more of their allocated respite hours than is necessary
- lack of transport options between home and respite, and between school or day programs and respite
- lack of culturally appropriate respite services for Aboriginal people and for people from culturally and linguistically diverse backgrounds.

It is vital that changes are made to the delivery of ADHC funded respite services so that services are more closely aligned with the needs and choices of the carer and the person with a disability, including Aboriginal people and people from culturally and linguistically diverse backgrounds. Respite needs to be more flexible, and driven less by fixed program structures and more by the needs of the people who use it. It is the services who must meet the needs of the people, instead of the current situation where it is the carers and people with a disability who must meet the needs of the service or go without. Carers NSW recognises the challenges involved in providing responsive, flexible services, but believes more can and must be done to ensure that people receive they support they need, when they need it.

4. Internal and external program evaluation including program auditing

Carers NSW, as a provider of ADHC funded services for carers, has had mixed experiences of ADHC's program evaluation processes. Program evaluation is a crucial step in the development and delivery of effective programs. For effective program evaluation to occur, adequate funding must be allocated to evaluation, which must be carefully planned and executed in a timely fashion. It is our experience that at times ADHC's program evaluations are conducted in an ad hoc fashion and are limited by the failure to set funding aside for the purpose.

For example, Carers NSW is one of the providers of the *Support Coordination Program for Older Parent Carers*. After the initial funding period for this program ended, ADHC made the decision to undertake an evaluation of the program. This evaluation occurred close to the end of the funding period. The delay incurred created much uncertainty for all the providers, for Carers NSW as an organisation, for the staff employed to deliver the program, and most importantly, for the people receiving much needed support through the program.

Ultimately the outcome of this evaluation process was satisfactory. However, the manner in which it was conducted, especially the lack of timeliness of the evaluation, was concerning to Carers NSW and risked damaging the capacity of the organisation to continue to provide the program.

5. Any other matters

5.1 Consultations with carers

Carers NSW has been pleased with the efforts of ADHC to consult with relevant stakeholders, including Carers NSW. Carers NSW appreciates the consultative approach that ADHC has been taking, and the capacity they have demonstrated to respond to feedback from relevant stakeholders. However, Carers NSW believes that the strength of ADHC's consultative processes could still be improved, and that consideration must be given to the inclusion of key non-government stakeholders such as Carers NSW in interagency committees chaired by ADHC, especially the Young Carer Interagency Committee. The exclusion of key stakeholders on the basis of their status as non-government organisations is detrimental to the knowledge and effectiveness of this and other committees.

5.1.1 Consultations with carers

Carers NSW recognises that ADHC has demonstrated a commitment to consulting with carers. For example, in recent months carers have been included in consultations held for the *Review of the National Disability Service Standards* and the second phase of *Stronger Together*, the NSW Government's plan for people with a disability.

Carers NSW commends ADHC for involving carers in these consultations, but has concerns about the way in which some of these consultations were managed. Carers NSW received phone calls from carers following both consultation processes expressing discontent with some elements of the consultation. Carers NSW would like to highlight two key issues.

5.1.2 Costs of participation borne by carers

Carers NSW believes that carers must be reimbursed for their expenses and remunerated for their time, particularly when they are expressly invited to participate in a consultation. For example, a carer from regional NSW received a personal invitation from ADHC to attend a *Stronger Together* consultation with the Minister for Disability Services. The carer had to make a 200 kilometre round trip to attend the consultation, incurring financial costs and sacrificing half a day of her already limited time. However, no reimbursement or remuneration was provided, nor was any support or assistance arranged in terms of transport, respite or child care. If the contribution of carers is valued, and consultation processes are to be accessible, provisions must be made to ensure that carers are able to attend and that they are not disadvantaged through their participation.

5.1.3 Quality of consultation processes

ADHC must also give due consideration to the way in which consultation processes are managed. Following consultations held for the *Review of the National Disability Service Standards* in June 2010, Carers NSW received a complaint from a carer regarding a consultation held by a service provider of ADHC funded services, on behalf of ADHC. The carer complained that finding out information about the consultation session was difficult, an incorrect address was given, the venue was not accessible to people with a disability (who were told that they must wait until they got home to go to the toilet), carers were excluded from the process being told that the consultation was not for them, and most concerning of all, the consultation was held on the premises of a local service provider, inhibiting participants from expressing their views and experiences of the Disability Service Standards for fear of compromising the services and treatment they receive from the organisation running the consultation.

Carers NSW does not believe that the quality of this consultation session would have been indicative of the general standard of this consultation process. However, it illustrates the seriousness with which ADHC must treat consultative processes in order to ensure that;

- information about the process is available to relevant stakeholders
- consultations are accessible to people with a disability and their carers
- consultations are delivered in such a way that participants can confidently and freely express their views
- consultations are not overly proscriptive and do not restrict the participants from having their say.

Carers NSW supports the efforts of ADHC to involve relevant stakeholders in their consultative processes, but believes that ADHC must be accountable for the way in which these consultations are run, and for the provision of funding for these consultations. Transferring responsibility for running consultations to service providers and other organisations is not only risky in terms of the quality and appropriateness of the consultations that will result, it is also unfair on the organisations involved who although supportive of such processes, should not be left to bear the costs involved.

5.2 Information provision

Carers NSW believes that the provision of information about services provided or funded by ADHC could be much improved. It is our experience that the difficulties that many carers experience accessing information compromises their ability to access services.

It is well established that carers have diverse and significant information needs. The *Who Cares...? Report on the inquiry into better support for carers* released in April 2009 identifies access to information about supports, services and assistance as one of the six main challenges faced by carers.[13] The *Who Cares...?* report identified that carers need increased access to information, education, training, family and carer advocacy, case management and care coordination services. Barriers to accessing information for carers included an overly complex and fragmented service system, limited time of carers, language and unawareness of rights to services and the lack of availability of information in specific service settings.[14]

The provision of information by ADHC must be simplified and improved so that carers know what services exist and how to access them, without having to spend time, energy and resources they do not have to find out what they need, or 'stumbling' upon services and supports long after they are first required. Clear and comprehensive information should be pro-actively provided to carers and other service users by ADHC and by providers of ADHC funded services. ADHC must be accountable for ensuring that information about their services is received by those who need it, in a format that they can understand.

5.2.1 Education needs of carers

The *Who Cares...?* report also identified that carers have significant education needs. Carers are increasingly required to manage complex health and care needs of people with serious medical conditions, disability, mental illness and terminal illness, and need information and education to be able to do so.[15]

Carers also need education and support to be able to access and better use services. In our 2010-11 pre-budget submission to the NSW Government, Carers NSW recommended that education courses be funded for carers about the use and benefits of respite in order to increase the utilisation of respite services by carers. This recommendation is based on a report by Alzheimer's Australia which demonstrates that respite may be better utilised by carers if they have received education about it. Alzheimer's Australia found that when carers attended an education course that included information about using respite 95 per cent of them felt that they would be comfortable using respite compared to 43 per cent prior to the course. This report indicates that as well as needing education about how to use respite and its benefits, sometimes carers also 'need permission' to use respite services.[16]

5.2.2 Consistency of information provided by ADHC

Carers NSW is concerned by the inconsistency of the information provided to carers by ADHC. Carers in different regions are often given different information, and have different understandings of the services available. The regional variations between information supplied by ADHC suggests that either there is poor communication in some or all regions, that misinformation is provided, or that ADHC policies and programs are being interpreted differently by different area offices.

5.2.3 Impacts of inadequate information provision

Carers NSW is at times concerned by the number of carers with unrealistic expectations of ADHC services, particularly regarding the availability of and application processes for supported accommodation for people with a disability. Unrealistic expectations, and as a consequence unrealistic plans for the future can be caused by the provision of incorrect or unclear information.

Carers NSW has had contact with carers who believe themselves to be on a waiting list for supported accommodation for their adult child with a disability. Many of these carers are themselves ageing, and their plans for the future depend upon their child being accepted into supported accommodation. In some cases it has eventuated that the waiting list the carer is on does not in fact exist. In other cases the waiting list does exist, but the carer is not on it as they were unaware that they had to re-apply every twelve months. In other cases the carer has not been informed that the waiting list they believe themselves to be on has long since been disbanded, or the service that it was for has been closed.

As has been stated above, Carers NSW believes that more supported accommodation places need to be rolled out, and more quickly. Carers NSW also believes that carers need clear and current information about what services are available, about the eligibility criteria and allocation processes for these services, and also a clear and forthright indication of the likelihood that they will receive these services, and when. Carers have a right to know what support they are likely to receive so that they can plan for the future accordingly.

5.3 Telecare initiatives

Carers NSW believes that ADHC and other human services departments in Australia are failing to implement innovative services proving to be very effective in other comparable nations. An important example is the Telecare initiatives being implemented around the world, which have the potential to play a vital role in the future provision of care by ADHC. Telecare has been defined by the Scottish Government as:

> "the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology to trigger human responses, or shut down equipment to prevent hazards."[17]

Evidence from the Scottish experience of implementing Telecare initiatives indicates that Telecare can have significant benefits for older people, people with disabilities, their carers and the disability and community care systems. For carers the benefits identified include:

- feeling more relaxed and less stressed
- feeling more confident about the safety and wellbeing of the person they cared for
- having more opportunity to get away from their caring situation and take a break
- feeling better supported in their caring role
- improvements in their relationship with the care recipient
- the ability to remain in paid employment (for some carers).[18]

A growing body of international evidence suggests that Telecare can also have considerable benefits for the sustainability of the disability and community care systems.[19] Telecare has been found to:

- enable people to stay in their homes for longer
- reduce the need for acute home care
- delay admissions to residential care
- reduce the number of unplanned hospital admissions
- reduce the number of delayed discharges from hospital.[20]

Telecare can result in significant savings, and may assist ADHC to meet the significant future demands for services alluded to earlier. According to the evaluation of the Scottish Government's *National Telecare Development Programme*, in 2007-08 (the first main year of operation) savings totalling £11.15m were identified. In 2007-2010 the likely savings were valued at around £43 million, an anticipated benefit to programme funding cost ratio of 5:1.[21]

It is clear that Telecare, while not a panacea for all of the challenges facing ADHC, does have the potential to transform our capacity to meet the significant and growing need for services and support, and to make caring more sustainable.

5.4 Needs of Aboriginal people

The experiences, needs and concerns of older Aboriginal people, Aboriginal people with disabilities and their carers are distinct in many ways from other Australians. This is a result of a number of complex factors, including cultural values and beliefs, the disadvantage experienced by Aboriginal people and their history of loss and dispossession. Services for Aboriginal people and their carers must be culturally appropriate, accessible and responsive to the needs of these individuals.

Aboriginal people are more than twice as likely as the general population to need help with core daily activities because of disability.[22] They have lower life expectancy and suffer an overall burden of disease that is 2.5 times that of the general population.[23]

The prevalence of disability and disease in the Aboriginal population has implications for the needs of carers. According to the 2006 census, Aboriginal carers were up to three times as likely as other carers to need assistance with core activities themselves. In total, at least 2,100 Indigenous carers needed help with core activities.[24] This has obvious implications for the impacts of care provision on their health and wellbeing, their capacity to care, and their own level of need for services and support, both as carers and in their own right as individuals.

ADHC needs to provide more responsive and flexible services to Aboriginal people and their carers, and needs to address its capacity to deliver culturally appropriate services. The failure to provide adequate, appropriate services leads to people with disabilities and their carers going without much needed support.

Carers NSW experience of delivering Koori Carer Yarning Camps for mental health carers has demonstrated the cultural diversity of Aboriginal people, and has led us to develop the *Koori Carer Yarning Resource Manual.*

As explored in the manual, Aboriginal people may have different cultural understandings which impact on the accessibility and appropriateness of services. Examples of different cultural understandings may include concepts of kinship and family relationships, community and the individual, disability, place, healing, communication styles, gender relations and protocols. Another significant factor may be widespread mistrust of government or social services within Aboriginal communities, which has been formed by their communities' experience of these organisations. [25]

It must be recognised that mainstream disability and carer services are not culturally neutral, but are founded on cultural tenets of the dominant Australian culture, evident, for example, in the individualistic approach of services and medical understandings of disability. Flexible and culturally appropriate services must be available in all geographic areas, including rural and remote areas to ensure that services provided by ADHC are accessible to Aboriginal people and their carers.

5.5 Needs of people from culturally and linguistically diverse backgrounds

Carers, older people and people with disabilities from culturally and linguistically diverse backgrounds have distinct needs. While many issues are common for carers regardless of their cultural background or ethnicity, research undertaken by Carers NSW and Down Syndrome NSW in 2007 identified that carers from culturally and linguistically diverse backgrounds experience additional issues and have distinct support needs. These include:

- isolation of carers even though they belong to a tight knit community. There is often an assumption that people of specific cultural backgrounds rely on strong family ties. However, migration often means leaving behind the family members and friends who would otherwise have provided support.

- stigmatisation of people with disability or illness is common. This may inhibit carers from self identifying as carers or recognise the need to access services and support.
- language and communication barriers between carers from culturally and linguistically diverse backgrounds and service providers are a common issue. Often carers cannot access appropriate translated information to assist them in their caring role. Carers need to be able to access bilingual staff as well translated material to assist them to access and use services appropriately.
- cultural concepts of disability, illness, ageing or caring are often different from mainstream Australian perceptions. Flexibility in service delivery is needed to ensure service delivery appropriately addresses the cultural needs of carers.

It is vital that the cultural and linguistic diversity of older people, people with disabilities and their carers is supported by ADHC. Carers NSW is pleased with the commitment ADHC has shown to people from culturally and linguistically diverse communities, through, for instance, the establishment of the ADHC Cultural Diversity team. However, feedback from carers, service providers and members of the *Strategic Carers Action Network CALD Advisory Group* (chaired by Carers NSW), indicate that there is still unmet need for culturally appropriate and accessible services for culturally and linguistically diverse communities across NSW.

5.6 Needs of gay, lesbian, bisexual, transgender and intersex people

Carers NSW believes that ADHC is not effectively meeting the needs of Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) people and carers. ADHC needs to provide culturally appropriate services and supports, which respect and respond to the needs and choices of this group.

Reports from the NSW Anti-Discrimination Board[26], the Australian Human Rights Commission[27] and Alzheimer's Australia[28] detail the discrimination often experienced by GLBTI people in aged care and community care services, and the desperation with which older GLBTI people in particular will avoid using services for fear of discrimination and being "forced back into the closet". These reports also identify the absence of the needs of GLBTI older people in policy, training, research and program guidelines.

The needs of GLBTI carers are also significant, and often overlooked. GLBTI carers are some of the most hidden carers in the community and they require support and services which foster their full inclusion. Often GLBTI carers face challenges because of:

- discrimination and marginalisation
- equity of access to all services
- recognition of their caring relationships, for example, informal friendship networks
- absence of family support
- higher incidences of drug use and depression
- social isolation
- unawareness that mainstream services may be able to offer them support
- non-inclusive language and imagery used to describe services and supports.

Carers NSW is aware that often a GLBTI carer will not feel comfortable accessing mainstream services such as support groups for carers because they may face discrimination as a result of their same-sex relationship with the care recipient.

Carers NSW has heard from carers who are often the only person in a support group with a same sex partner and do not feel able or comfortable to share their story with the group. This suggests that some services for carers such as support groups would benefit from being specific to the GLBTI community, and also that there is a need for greater awareness from service providers of, and training in, sensitive and appropriate service provision to GLBTI communities.

Recently the Australian Government Department of Health and Ageing (DoHA) has provided funding to ACON and the Aged and Community Services Association NSW & ACT to provide targeted training to residential aged care services to improve their understanding of the needs of older GLBTI people. Carers NSW has also received a small amount of funding from FaCHSIA to address the needs of this group.

Carers NSW is disappointed that ADHC is yet to follow the lead of its Commonwealth counterparts, and has not made any significant efforts to address the identified need of GLBTI people and carers. Despite the evidence of unmet need available, increasing awareness in the community of these needs and recognition from Commonwealth government departments, the requests of organisations such as Carers NSW to ADHC for support for this group have been unsuccessful.

5.7 Person-centred services

Australia is following a trend towards 'individualised funding', similar to consumer-directed care in the United Kingdom and some other OECD (Organisation for Economic Co-operation and Development) countries.[29] Although AIHW acknowledges that the potential for individualised funding and other individual support arrangements to achieve person-centred service is not without concerns.

AIHW indicated that factors that contribute to success include funding levels in relation to need, community attitudes, and the ability of people with disability to access infrastructure and mainstream services such as housing and transport. Viewed from this perspective, individualised funding addresses the 'choice' criterion of person-centred service; five other criteria for person-centeredness relate to information, representation and participation, access, accountability and redress.

ADHC is trialling some individualised or person-centred models, and Carers NSW supports the NSW Government's acknowledgement that "...there needs to be greater priority given to making the specialist disability system person-centred..."[30] Carers NSW believes that giving carers more control over the services they use is important for increasing their choices and quality of life. It is essential, however, that any shift towards a person-centred approach, where the carer is at the core of decision-making about their lives, avoids creating more work for the carer and does not leave them to navigate the complex service system on their own. Models such as that being trialled in the *my plan, my choice*: Individualised (Packaged) Support Participatory Action Research Strategy (currently being undertaken by ADHC) are important as they provide support for the carer to be able to make and exercise an informed decision. In the *my plan, my choice* pilot being conducted by Carers NSW the carer receives assistance from a support planner and a support intermediary. For many carers, similar or other assistance to plan and arrange support will be needed in a person-centred approach, and as such must be available for all carers if and when they require it.

5.8 Future changes to funding structure

ADHC is currently the lead administrator of the HACC Program, in partnership with the NSW Department of Health and the NSW Department of Transport. The HACC Program provides key general aged and community care services in NSW. From July 2012, the Commonwealth will take over responsibility for HACC aged care services for people 65 years and over, and Aboriginal and Torres Strait Islander people aged 50 years and over.

To date, ADHC has communicated some information about the changes to the sector, through briefings held with HACC service providers and peak organisations representing people who receive HACC services. While Carers NSW appreciates the information provided to date, it is essential that a much greater effort is made in the lead up to July 2012. ADHC needs to implement a comprehensive communication and awareness strategy to inform service users about these changes and to minimise concern and uncertainty about future service provision, particularly in vulnerable population groups that depend upon these services.

Conclusion

Carers NSW appreciates the opportunity to make this submission to the Inquiry into services provided or funded by Ageing, Disability and Home Care, NSW Department of Human Services. If you require any further information about Carers NSW' submission to this inquiry please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely,

Elena Katrakis
CEO
Carers NSW

Endnotes

---

[1] Australian Bureau of Statistics (2004) Summary of Findings: 2003 Survey of Disability, Ageing and Carers, Canberra

[2] NSW Government (2010) Stronger Together: the next five years – a consultation paper, Sydney.

[3] Australian Institute of Health and Welfare (2007) Current and future demand for specialist disability services, Canberra.

[4] Australian Institute for Health and Welfare (2010) Younger People with Disability in Residential Aged Care Program: Report on 2008-2009 Minimum Data Set, Canberra.

[5] Ibid

[6] Australian Bureau of Statistics (2004) Older People New South Wales, Commonwealth of Australia, Canberra.

[7] NSW Department of Planning (2010) Population NSW Bulletin 2010, NSW Department of Planning, Sydney.

[8] Australian Institute of Health and Welfare (2009) Australia's Welfare 2009, AIHW cat.No. AUS 117, Canberra.

[9] Ibid

[10] House of Representatives Standing Committee on Family, Community, Housing and Youth (2009) Who Cares...? Report on the inquiry into better support for carers, Canberra.

[11] Australian Institute of Health and Welfare (2009) Disability support services 2007-08: national data on services provided under the Commonwealth State/Territory Disability Agreement, Canberra.

[12] Australian Department of Health and Ageing (2009) Home and Community Care Program – 2007-08 Annual Report, Canberra.

[13] House of Representatives Standing Committee on Family, Community, Housing and Youth (2009) Who Cares...? Report on the inquiry into better support for carers, Canberra.

[14] Ibid

[15] Ibid

[16] Alzheimer's Australia (2009) Respite Care for People Living with Dementia "It's more than just a short break" Discussion Paper 17, Canberra.

[17] Joint Improvement Team (2008) National Telecare Development Programme in Scotland Glossary of Terms and Definitions, Scottish Government, Edinburgh.

[18] Carers Scotland (2009) 'A weight off my mind' Exploring the impact and potential benefits of Telecare for unpaid carers in Scotland, Edinburgh.

[19] Ibid

[20] Ibid

[21] Beale S, Sanderson D and Kruger J (2009) Evaluation of the Telecare Development Programme, Final Report, York Health Economics Consortium, York.

[22] Australian Bureau of Statistics (2008) Summary of findings: 2006 ABS Census of Population and Housing, the Health and Welfare of Australia's Aboriginal and Torres Strait Islander People, Canberra.

[23] Vos T, Barker B, Stanley L, Lopez AD (2007) The burden of disease and injury in Aboriginal and Torres Strait Islander peoples 2003, Brisbane.

[24] Australian Bureau of Statistics (2008) Summary of findings: 2006 ABS Census of Population and Housing, the Health and Welfare of Australia's Aboriginal and Torres Strait Islander People, Canberra.

[25] Carers NSW (2010) Koori Carer Yarning Resource Manual, Sydney.

[26] NSW Anti-Discrimination Board (2005) Forum on ageing and discrimination in the gay, lesbian, bisexual, transgender and intersex communities - working paper, Sydney.

[27] Australian Human Rights Commission (2007) Stories of discrimination experienced by the gay, lesbian, bisexual, transgender and intersex community, Sydney.

[28] Alzheimer's Australia (2009) Dementia: Lesbians and Gay Men, Canberra.

[29] Australian Institute of Health and Welfare (2009) Australia's Welfare 2009, AIHW cat.No. AUS 117, Canberra.

[30] NSW Government (2010) Stronger Together: the next five years – a consultation paper, Sydney.