

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

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Inquiry into services funded and provided by Ageing, Disability and Home Care



NCOSS Submission

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About NCOSS

The Council of Social Service of New South Wales (NCOSS) provides independent and informed policy development, advice and review and plays a key coordination and leadership role for the non government social and community services sector in New South Wales.

NCOSS works with our members, the sector, the NSW Government and its departments and other relevant agencies on current and emerging (and ongoing) social, systemic and operational issues. It was established in 1935 and is part of a national network of Councils of Social Service, which operate in each State and Territory and at Commonwealth level.

NCOSS membership is composed of community organisations and interested individuals. Member organisations are diverse; including unfunded self-help groups, children's services, youth services emergency relief agencies, chronic illness organisations, local indigenous community organisations, church groups, and a range of population specific consumer advocacy agencies.

NCOSS appreciates the opportunity to submit to the Legislative Council Standing Committee on Social Issues Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care.

This submission has been written to respond as closely as possible to the Inquiry's Terms of Reference and is arranged under these as headings.

Disclosure

NCOSS has been the recipient of a grant from the Department of Human Services – Ageing, Disability and Home Care (and its predecessor agencies) for many years for the Home and Community Care (HACC) Statewide Project. NCOSS currently is also in receipt of a grant for 12 months for the Management Support Unit (MSU).

Informing NCOSS

For this submission, NCOSS has drawn on the expert advice of several of its policy forums.

NSW Aboriginal Community Care Gathering Committee

Operating since 2000, the NSW Aboriginal Community Care Gathering Committee (the Gathering) comprises Aboriginal and Torres Strait Islander workers and community members in community care and disability. They regularly meet to progress services and supports for Aboriginal¹ older people, people with disability and carers. The Gathering has convened three policy conferences (2000 in Sydney, 2003 in Coffs Harbour, 2006 in Dubbo) for Aboriginal workers in NSW and a conference for non-Aboriginal workers in Sydney in 2008. Several policy position statements have been developed during this time, the latest being *Leading Our Way in Community Care*² which sets out guiding principles and recommendations under eight priority areas. Four new policy priorities are currently under development for consultation release at its next Conference *Challenge Change and Choice* to be held in Wollongong in late 2010. NCOSS provides secretariat support to the Gathering.

¹ The term Aboriginal is deemed to include Torres Strait Islander people and communities for the rest of this submission.

² Available from NCOSS website <http://ncoss.org.au/resources/080730-leading-our-way.pdf>

NSW HACC Issues Forum

Convened by NCOSS, the NSW HACC Issues Forum meets bi-monthly and comprises representatives of relevant non-government, State-wide consumer and service provider peak organisations and networks, State-wide local government organisations and HACC Development Workers. The Forum shares regional and state information identifies and raises issues, monitors and responds to policies and initiatives relating to the HACC Program and community care sectors.

NSW Aged Care Alliance

NCOSS provides secretariat support and is a member of the NSW Aged Care Alliance, which comprises over 25 organisations concerned with the adequacy and quality of aged care and other services as well as healthy ageing for older people in New South Wales. While the Alliance mailing list covers many more associated organisations, the NSW Aged Care Alliance includes non-government consumer representatives, industry organisations, academics and others actively promoting the needs, rights and interests of older people. The NSW Aged Care Alliance meets on a bi-monthly basis at NCOSS to discuss issues and strategies to advance Alliance objectives.

Summary of Recommendations in this submission

That the report prepared for the Minister on unmet disability need and population benchmarking undertaken in 2005-06 be made public. Refer page 5.

That progress reports on Funding and Program Plans, e.g. Stronger Together and Better Together, are regularly published and that these reports align with the original Plans for easier understanding. Refer page 6.

That a set proportion of funding growth allocations in each ADHC region be earmarked for Aboriginal service provision. Refer page 9.

That ADHC consults on and implements different and innovative approaches to ensure that Aboriginal people and those from culturally and linguistically diverse backgrounds are able to access appropriate services, both specialist and mainstream. Refer page 11.

That mainstream service providers are more accountable for culturally specific funding allocations and service provision. Refer page 11.

That legislation governing Licensed Boarding Houses be amended to provide improved consumer protection, including advocate access to residents. Refer page 11.

That ADHC continues to trial person centred approaches across its client population groups and programs and that the trials have a specific and reasonable time limit so that the learnings of the trials can be evaluated and implemented more widely. Refer page 13.

That ADHC recommits to closing all disability institutions in favour of person-centred small, community based, dispersed responses to supported accommodation for people with disability. Refer page 13.

That ADHC release the Program guidelines and provide appropriate funding for Disability Advocacy and Information Services, and that such funding be properly indexed to cover the costs of providing such services. Refer page 15.

(a) the historical and current level of funding and extent of unmet need,

Short history of DADHC

Since 1995, there have been several major changes in the structure of the government agency administering support services to older people, people with disability and carers.

Up to 1994: Department of Community Services (DoCS):

Departmental focus was on children and families despite the fact that the ageing & disability funding and service provision was demonstrably larger than the remainder of the Department. Ageing & Disability seemed to be "additional" rather than integrated.

1995: Ageing & Disability Department (ADD):

Department, comprising only a Central Office, was created to provide appropriate focus on ageing and disability. ADD's role was funder and policy only. Central Office relied on the DoCS regional structure, so no separate regional structure was intended or created at that time. Government provided disability services were delivered by DoCS. The Home Care Service of NSW was a separate statutory authority; but reporting to the Director-General of DoCS.

1997-8: Ageing & Disability Department (ADD):

Regional structures, with regional staff, were created to manage operations independent from DoCS. Home Care is still separate. DoCS continued to operate the disability services program, providing group homes for people with disability.

1999-2000: Major initiative to transfer Departmental disability group homes to the non-government sector.

April 2001: Department of Ageing, Disability and Home Care (DADHC):

DADHC was created and now included both direct disability services from DoCS and the Home Care Service of NSW reported to the Director-General of DADHC.

2001-2009: While this has been a period of consolidation, several major internal reorganisations occurred up to 2009. These have included creating larger and more autonomous regional structures; bringing regional boundaries into line with Area Health Service boundaries; upgrading management staff positions etc.

2009: Department of Human Services –

Ageing, Disability and Home Care (ADHC).

This new department now includes DoCS, DADHC, Housing, Juvenile Justice and Aboriginal Affairs, with each "agency" maintaining its own operations but overseen by one Director-General. ADHC administers the Disability Services program, the HACC program and the Ageing Program, all involving a mix of direct government and non-government provided services.

April 2010: COAG decision to split HACC

COAG announced major jurisdictional changes to HACC funding and administrative arrangements, as part of the Health and Hospitals Network Reforms. Consequently, HACC as a funding program will cease by June

2012, when the Commonwealth assumes funding responsibility for support services to all eligible people aged 65 years and over and Aboriginal people aged 50 years and over, regardless of their location or current program. Accordingly, states and territories will assume funding and program responsibilities for all eligible people with disability aged less than 65 years and under 50 years for Aboriginal people. The existing HACC Triennial Plan will be the last and concludes on 30 June 2011, followed by a year of transition.

Attention diverted

During each period of change, some lasting a considerable period of time, the focus of Government veered away from the people who require and use services towards coping with the internal and structural implications for operations and management. The rationale for change was always to ensure improved services to clients and population groups but the practical focus appeared on more internal matters. This very short history demonstrates that considerable departmental time over the past 15 years has been devoted to internal administrative changes, leaving the work of progressing supports to older people, people with disability and carers significantly delayed and often behind other Australian jurisdictions.

Stronger Together

Following many years of small and irregular growth funding up until 2006, disability services were in constant crisis, managing escalating demand within fixed existing resources. NCOSS acknowledges that in the decade to 2006, funding for DADHC provided services doubled. But NCOSS has calculated this went largely to necessary upgrades and wages, because it resulted in less than 19% increase in the number of clients over that time. The ten year disability plan Stronger Together was announced in 2006, accompanied by 5 years' funding allocations, with specific funding and program targets.

Despite this very welcome Stronger Together funding 2006-2011, the increase in actual funding to services remains low as NSW was operating from a very low starting base.

A consultative process is currently underway to assess the achievements of the first phase of Stronger Together and to consider the proposed direction and funding implications for the second five year tranche of the program.

Better Together

Released in February 2007 and involving 12 government departments, Better Together is "a new direction to make NSW Government services work better for people with a disability and their families 2007-2011." Better Together identifies eight priorities containing 50 activities, many reiterating Stronger Together targets.

NCOSS knows of no public reporting against this plan.

Recommendation

That progress reports on Funding and Program Plans, e.g. Stronger Together and Better Together, are regularly published and that these reports align with the original Plans for easier understanding.

Accelerating populations

DADHC's own population projections demonstrate the increase in the number of people with disability. In its *Future Directions* Paper 2004, DADHC stated that, between 2000 and 2011, the NSW general population will grow by 8%, the number of

people with disability will grow by 18% and the number of older people will grow by 26%.

Population benchmarking

In 2005-06, the then Minister for Disability Services commissioned work on unmet disability need and population benchmarking. NCOSS understood this work, which the Minister said was completed in 2006, was designed to determine the level and nature of services and supports for populations with specific characteristics and by location. Despite assurances at the time, this work was never made public.

Recommendation

That the report on unmet disability need and population benchmarking undertaken in 2005-06 be made public.

Continuing unmet need

NCOSS acknowledges that DADHC has met or exceeded its Stronger Together targets so far. However, there is clear evidence that unmet need is accelerating beyond annual allocations.

Stronger Together focussed on specific targets within three areas: children, young people and families; adults with disability; and system improvements. Stronger Together has delivered at least the following:

- a new certainty in supports to school-leavers with disability and their families,
- greatly improved therapy within schools
- intensive family supports for families in or near crisis with children with disability
- expansion of attendant care for adults with physical disability to determine the services that best support them and
- increased respite

Despite these improvements, NCOSS still receives desperate inquiries from families of younger people with disability in or referred to nursing homes, from people or families requiring equipment, needing appropriate nearby respite, people calling for supported accommodation for adults with disability. Similarly, NCOSS hears from people coming to or entering a complex disability system seeking help to discuss their immediate and future needs and wanting referrals to necessary supports.

In 2003, the ABS conducted a survey looking at the extent to which need was met among older people needing assistance with at least one everyday activity. The Productivity Commission³ details that in NSW, 37.3% people aged 70+ years living in households had self-reported total or partial unmet need, the highest in Australia.

System still in crisis

While Stronger Together has improved the adequacy of the disability support system since 2006, NCOSS contends that it has been a good first step only. Without deliberate and continued investment in disability supports, the system for many people with disability and their loved ones will remain in crisis. People and families soon learn that to enter the disability support system under many programs, they must be in clear or imminent crisis. ADHC supports to people with disability must deal with crisis, but they must also provide necessary supports at the time of request. The current process results in managing emotional turmoil by providing temporary band-aid stop-gaps which often become permanent as competing crisis needs arise.

³ Productivity Commission Report on Government Services 2010, Chapter 13 Aged Care

Undermet need

The Productivity Commission is increasingly describing "undermet need". It is important to recognise that disability can affect all aspects of a person's life and that of their family. Many people with disability require few or no supports while some people with disability require one or more supports provided in an integrated manner towards whole-of-life outcomes. For example, often the disability support service requires appropriate transport, for to do one without the other can result in either diminished effectiveness or unreasonable hardship. The support service might require specific equipment or home or other modifications before the service can be delivered.

For people and families, the provision of necessary support often requires other accompanying services/supports at the same time. Similarly, a family might accept the offer of respite for their loved one with very high support needs as a temporary measure, when they actually desperately require appropriate supported living / accommodation. In each of the above cases without the accompanying enabling service, ADHC can correctly indicate that services were provided to meet the specified need but those very people and families would indicate **undermet need** rather than needs met. NCOSS contends that sometimes the provision of the specified support without the accompanying enabling service can be self-defeating.

NCOSS sets out priorities for unmet need

Both the 2010-11 NCOSS pre-budget submission *A Community Services Stimulus Package* and the 2011 NCOSS election platform *Vote 1 Fairness in NSW* set out broad priorities⁴ for essential improvements to disadvantaged people and communities and within the human services sector. The identified priorities for supports to older people, people with disability and carers, however, are not limited only to ADHC. NCOSS has developed costed recommendations in the following:

- Increased funding and other improvements in Home & Community Care
- Access to Seniors Card benefits for Aboriginal people
- Acceleration of accommodation options for people with disability
- Self-directed support funding for people with disability
- Parity for post-school programs
- *Towards 2030* priorities for older people.

NCOSS further notes that the provision of transport as an enabling service to all other support services can be critical to the effectiveness and responsiveness of supports to the individual.

Other unmet needs

Due to the short timeframe of this Inquiry, it has not been possible to cover all aspects of unmet need. Accordingly, NCOSS cannot provide comment on:

- the needs of people with disability who are ageing. NCOSS is a member of the Futures Alliance and endorses the Blueprint⁵ for action on this issue.
- the needs of people with disability with mental health issues. NCOSS supports and endorses the work on the NSW Council for Intellectual Disability on this issue.
- the needs of people with mild disability who often have low support needs (translating into very low support priorities) but may experience disproportionately high social disadvantage.

⁴ Available from NCOSS website: www.ncoss.org.au

⁵ Available from Jo-Anne Hewitt Director of UnitingCare Disability

- (b) variations in service delivery, waiting lists and program quality between:
- (i) services provided, or funded, by ADHC,
 - (ii) ADHC Regional Areas,

Home Care Service NSW

The Home Care Service of NSW maintains no waiting lists, despite the recommendation of the 2005-6 NSW Public Accounts Committee Inquiry into Home and Community Care Program and Services. While talking to the regions, NCOSS hears constant frustrations from people and providers who try to access support services from Home Care Service. If capacity is full on the day, the caller is asked to call another time and/or given other phone numbers. Ordinary people may interpret this as being rejected by the entire HACC system and may not call again. There has been some improvement in recent times but regional variations still occur, despite the centralised system.

The future of the Home Care Service of NSW, one of the largest HACC providers, is uncertain after the COAG decision on the HACC split.

Aboriginal and Torres Strait Islander people and communities

NCOSS acknowledges the success of the Aboriginal ADHC employment strategy which has resulted in welcome increases to the number of Aboriginal staff within the agency. This has not however translated into similar increases in non-government organisations.

The NSW Aboriginal Community Care Gathering Committee reports vast unmet need for support services for Aboriginal older people, people with disability, carers and families and within their communities.

The Australian Institute of Health and Welfare⁶ says

“In general terms, the severe disability rates for Aboriginal and Torres Strait Islander people are more than double those of other Australians (2.1 to 2.4 times).”

In 2008, the Australian Human Rights Commission reported that:

“In the 2006 Census of Population and Housing, a total of 19,600 Indigenous peoples (approximately 4% of the total Indigenous population) were recorded as requiring assistance with core function activities (self-care, mobility and/ or communication) on a consistent basis. The level of assistance required by the Indigenous population was twice as high as that required by the overall Australian population.

According to the NATSISS 2002, due to differences in the way disability data were collected in remote and non-remote areas, comparisons with the non-Indigenous population are limited to those Indigenous respondents living in non-remote areas. When the effects of age differences were removed, the disability rate among Indigenous respondents was 1.4 times higher than among the non-Indigenous population⁷.”

Aboriginal older people

The Gathering advises that most older Aboriginal people do not enter residential aged care preferring care and support at home in their communities. This is exemplified in the comparatively high take-up rates of packaged aged care (services

⁶ Australian Institute of Health and Welfare, *Introduction to disability and disability services* on website: <http://www.aihw.gov.au/disability/natpic/index.cfm#population>

⁷ Australian Institute of Health and Welfare and Australian Bureau of Statistics, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2008*, ABS cat no 4704.0 (2008) p 55.

equivalent to residential aged care but provided at home) and usage of HACC and other community care programs by Aboriginal people.

More Aboriginal people seek at home supports than their non-indigenous counterparts, compared to residential care. For 2008-09, NSW reported a high proportion of Aboriginal HACC clients (compared to non-Indigenous) aged 50-70 years at 8%, the national average at 5.5%; and Aboriginal clients aged 70+ years at 1.4%, national average 1.1%. However the degree of unmet or undermet need remains high in NSW compared to Victoria and Australia as a whole. The Productivity Commission⁸ indicates that in 2009 NSW reported the lowest number of Aboriginal aged care (ie. residential and packaged care) recipients per 1000 Aboriginal people aged 50+ years at 29.6; the Australian average was 47.2 and Victoria reported 69.1.

NCOSS is advised that the ADHC New England region has a long-standing convention of allocating a standard proportion of every HACC growth allocation to Aboriginal service provision, before other priorities are distributed. This is not practice for all other regions.

Recommendation

That a set proportion of funding growth allocation in each ADHC region be earmarked for Aboriginal service provision.

Aboriginal people with disability – Comparative Disability Data

The Productivity Commission advised that:

NSW has experienced low and varied data response rates. This led to underreporting of service user numbers for all years and affected the comparability of the data across the years and with other jurisdictions.

However, given that this has been the situation for a number of years and there is scant other public data to examine, NCOSS is using the data as an indicator only rather than actual results. NCOSS further expects that the impact of Stronger Together expenditure should be accelerating improvement in some areas of data reporting and NSW comparisons.

For 2008-09, NSW reported⁹ the highest proportion, after the Northern Territory, of Aboriginal HACC clients aged under 50 years (compared to non-Indigenous) at 12.9%, the national average was 7.8%.

In 2007-08 NSW reported¹⁰ the lowest number, equalling Tasmania, of Aboriginal people using disability accommodation support services per 1000 Aboriginal people aged less than 65 years: NSW 1.4, Victoria 9.4, Australia was 2.8. Comparing usage of accommodation support services per 1000 Aboriginal people in the potential population: NSW scored 15.9, Victoria was 104.6, and Australia was 39.9. Even allowing for data under-reporting, the unmet need in NSW is obvious and concerning.

In the same year, NSW reported¹¹ the lowest number, after Tasmania, of Aboriginal people using community support services per 1000 people in the potential Aboriginal population. These services include therapy support, counselling and early childhood intervention.

⁸ Productivity Commission Report on Government Services 2010, Chapter 13 Aged Care

⁹ ibid

¹⁰ Productivity Commission Report on Government Services 2010, Chapter 14 Disability Services

¹¹ Productivity Commission Report on Government Services 2010, Chapter 14 Disability Services

For 2007-08, NSW reported¹² the lowest number of Aboriginal people using community access services per 1000 people in the potential Aboriginal population: NSW 28.3, Vic 126.0, Australia 44.9. Community access services provide opportunities for people with disability to gain and use their abilities to enjoy their full potential for social independence, including learning and life skills development and recreation/holiday programs.

NSW reported low proportions of Aboriginal people using respite services per 1000 Aboriginal people aged under 65 years: NSW reported 2.6, Victoria was 15.9 and the national average was 3.3.

Only NSW Aboriginal usage of Commonwealth funded disability employment services approached national averages. However, the 2010 Social Inclusion Report¹³ stated:

"In 2006-07, 61% of people using disability employment services found employment, but people with a physical or psychiatric disability as well as Aboriginal and Torres Strait Islander Australians and those born in non-English speaking countries have poorer outcomes."

People from culturally and linguistically diverse communities

NSW reports¹⁴ the following differences between target population proportions and special needs recipient proportions in June 2009:

- Aged care residents from a non-English speaking country = -23.1%
- CACP recipients from a non-English speaking country = +5.7%
- HACC recipients from a non-English speaking country = -9.4%

For disability services in 2007-08, NSW¹⁵ reported 5.6 people born in a non-English speaking country using accommodation support services per 1000 potential population aged less than 65 years who were born in a non-English speaking country. This compares to 35.5 people born in an English speaking country using accommodation support services per 1000 potential population aged under 65 years who were born in an English speaking country.

Similarly, for disability community support services comparative figures under the above criteria for non-English users is 18.8 compared to 102.9 for English-speaking users. In disability community access services, NSW reported 15.2 non-English users compared to 51.9 English speaking users.

NSW disability respite services reported 0.2 people born in a non-English speaking country using respite services per 1000 people aged under 65 years who were born in a non-English speaking country. This compares to 1.2 people born in an English speaking country using respite services per 1000 people aged under 65 years who were born in an English speaking country.

The story was similar for disability employment services. There are 129.6 people born in a non-English speaking country using employment services per 1000 potential population compared to 233.3 people born in an English speaking country using employment services per 1000 potential population.

¹² *ibid*

¹³ How Australia is Faring, Report of the Australian Social Inclusion Board 2010

¹⁴ Productivity Commission Report on Government Services 2010, Chapter 13 Aged Care

¹⁵ Productivity Commission Report on Government Services 2010, Chapter 14 Disability Services

Clearly there is significant inequity in support services to people with disability from culturally and linguistically diverse backgrounds. The provision of supports in a culturally appropriate and responsive manner is a constant challenge but one that is worth the investment of time and resources. This also involves enabling services such as the supply of interpreters, critical to reducing barriers to access.

Balance of mainstream and culturally specific services

Both the Aboriginal Gathering Committee and the NSW Ethnic Communities Council advise NCOSS that aged and disability supports must be provided in a culturally appropriate manner. The challenge is to find the suitable balance between the provision of culturally responsive mainstream (general) services and specific services specialising only in an identified group such as Aboriginal people or Chinese clients, in order to address inequities for these groups.

Mainstream providers tend to channel Aboriginal people or non-English people directly into specialising services without first asking the person's service preference. This can place unreasonable demand on the few specialising services while reducing the obligation of the many mainstream providers to respond to the entire community. Specialist services are often designed to complement mainstream services, not simply to replace them.

Recommendation

That ADHC consults on and implements different and innovative approaches to ensure that Aboriginal people and those from culturally and linguistically diverse backgrounds are able to access appropriate services, both specialist and mainstream.

Recommendation

That mainstream service providers are more accountable for culturally specific funding allocations and service provision.

People with disability in Boarding Houses

There is a relatively small group of especially vulnerable people with disability living in licensed Boarding Houses or licensed residential centres (LRCs). NCOSS is a member of CASA and supports its advocacy for more appropriate accommodation support to this population and better consumer protection. The Disability Services Act and disability standards do not apply to licensed boarding houses because they are not funded by government. The Active Linking Initiative is a program of low per capita supports to enable people in LRCs to access and participate in the local community. The provision of individual advocacy is critical to the health and wellbeing of this particularly at risk group of people with disability. Individual advocacy must be deliberately funded by ADHC and LRC operators must be compelled to allow advocates access to residents. ADHC has been unreasonably slow to create the necessary improvements to the governing legislation. CASA has participated in several consultations to this end with disappointingly little results.

Recommendation

That legislation governing Licensed Boarding Houses be amended to provide improved consumer protection, including advocate access to residents.

(c) flexibility in client funding arrangements and client focused service delivery

Disparate programs

ADHC provides support services to older people, people with disability and carers under a range of separate programs. These are largely provided in silos, with separate (and sometime conflicting) program guidelines, differing eligibility criteria, varying service mechanisms and differing uncoordinated fee structures.

Service users requiring more than one type of support must demonstrate eligibility for each separate program, and then learn the requirements, obligations and expectations of each provider before receiving services and providing consents along the way.

The increasing rigidity of various service systems has resulted in a plethora of other programs, each attempting to fill gaps let by existing programs. Consequently the service system is complex and resistant to change.

This indicates that potential service users must fit into the system, rather than the system meeting the needs of the service user.

Person-centred approaches

NCOSS warmly welcomes the new focus on person-centred client focussed supports, with the emphasis moving away from the provider system (but still maintaining a strong and active interest) towards the person with disability. The success and expansion of and escalating demand for the Attendant Care scheme attests to the importance of this new approach.

ADHC has four disability related person-centred trials underway, each testing a more flexible approach to particular client groups or service programs. While this is a welcome improvement, the trials have no guarantee of continuing if successful. In vigorously supporting these trials NCOSS is concerned that existing operational requirements such as accountability, contracting, monitoring, quality and data collection may be inhibiting a proper understanding of the outcomes of the trials. ADHC must be certain to modify these operational requirements in order to enable the new approaches to be as successful as possible.

Service providers want flexibility

NCOSS also notes that, in previous years during the NCOSS regional visits to regional and country centres, disability providers consistently complain of the lack of flexibility in guidelines and contracts to meet the needs of their service users with disability. This complaint is second only to inadequate resources.

Self-directed support funding

The ultimate objective will be self-directed support funding, where the person with disability has a personal budget thereby becoming the purchaser of the supports they require, in the manner and at the time they require them. NCOSS has prepared a short description of how self-directed support funding could work, see appendix 1.

IMPACT & Better Service Delivery Project in HACC

After the invitation only National HACC Forum in 2008, NCOSS joined with ACS and other non-government organisations in NSW to actively develop and promote a more goal-oriented person centred approach to HACC service delivery. In 2009, this

approach became the IMPACT¹⁶ approach. Members of the working group have been presenting on IMPACT since that time. ADHC commenced the Better Service Delivery Project in late 2009 to trial and promote more flexible services to older people. This project is specifically examining short term flexible approaches in four trial sites, as well as general awareness-raising for HACC providers. NCOSS supports this initiative as an important step along the way to universal long term individualised and self-directed funding mechanisms direct to older people and people with disability, supported by a vibrant community care and disability industry.

Recommendation

That ADHC continues to trial person centred approaches across its client population groups and programs and that the trials have a specific and reasonable time limit so that the learnings of the trials can be evaluated and implemented more widely.

(d) compliance with Disability Service Standards,

Institutions and congregate care

NCOSS calls on the NSW Government to uphold its earlier commitment to close all disability institutions. This commitment was delivered in October 1998, by the then Minister Faye Lo Po, with an announced deadline of 2010. The Community Services Commission at the time estimated that this could be achieved in seven not twelve years.

NCOSS shares the view of many people with disability and their families as well as Disability advocacy organisations and others in the disability sector, that large groups of people with disability living on one site with shared supports does not comply with either the spirit or the letter of the NSW Disability Services Act.

NCOSS believes that desperate families will simply request any stop-gap support to create some form of certainty in their lives and the future of the person with disability. Having been beaten down by an unresponsive system, often for many years, many desperate families dare not propose and cannot conceive of a better way.

Significant and long term evidence¹⁷ shows that over time, people with disability become vulnerable to rigid systems that dilute individual responses in favour of the large group. Disability institutions, regardless of renovations or improvements, cannot provide the best outcomes for people with disability.

Recommendation

That ADHC re-commits to closing all disability institutions in favour of person-centred small, community based, dispersed responses to supported accommodation for people with disability.

¹⁶ IMPACT approach: more information www.impactnsw.com

¹⁷ Some relevant evidence and resources:

- Refer the works of Eric Emerson Lancaster University UK; Christine Bigby Latrobe University Victoria,
- Victorian Government Dept Human Services Making Life Good in the Community http://www.dhs.vic.gov.au/disability/improving_supports/kew_redevelopment/evaluation_of_community_living,
- Disability Enterprises *A Place to Call Home* DVD
- www.supportedliving.com.au

A good life

People with disability must not be expected to live in situations that would be unacceptable for other members of the community. If the object of the disability support system is for people with disability to have a good life, then congregate living must not be a long-term option. NCOSS is concerned that the present funding investment in large congregate care, or redevelopments or villages or intentional communities, will dictate the future for others not choosing (often actively rejecting) this outdated form of supported accommodation.

National Disability Quality Standards

The present implementation of the Disability Service Standards will allow congregate providers to comply with ADHC contracts. The review of National Disability Quality Standards has a much greater focus on the individual and their needs and outcomes. NCOSS contends that the anticipated release of the revised National Standards will compel ADHC to review its attention to and investment in congregate care, in favour of community living in small configurations, dispersed housing, responsive to individual needs, before crisis occurs and as part of life course planning.

Implications of the COAG decision to split HACC

The COAG communiqué states there will be no major changes to the provision of HACC services before June 2015. This decision means that all existing HACC services that support people with disability under 65 years will, in essence, become disability services, thereby subject to Disability Service Standards.

NCOSS is uncertain how ADHC plans to safeguard the provision of HACC-style in-home supports for people with disability who now use HACC services and for those requiring this support into the future. NSW appears to report¹⁸ the lowest proportion of HACC clients aged less than 50 years in Australia, at 9.5% or 22,144 people with disability now using HACC in NSW; with Victoria reporting 12.9% and Australia at 11%.

Despite the comparatively small proportion, there is a large number of people with disability looking to ADHC to continue essential in-home style support services beyond the COAG changes. These services include Transport, Case management, Home maintenance & modifications, Meals and food services, Domestic assistance, Personal care, Respite, Social support, and Community nursing. ADHC must seek to preserve the unique strengths, systemic regional and state development and grassroots coordination provided by non-government HACC Development Officers and policy positions, Multicultural Access Program workers, Ageing & Disability workers in local government councils.

¹⁸ Productivity Commission Report on Government Services 2010 Chapter 13 Aged Care

(e) adequacy of complaint handling, grievance mechanisms
and ADHC funded advocacy services,

Disability Advocacy and Information Services

The provision of ADHC funded disability advocacy and information services has been marred by a decade of threatened cuts and program reforms which are only now beginning to settle. As a result organisations have faced sometimes crippling uncertainty, loss of expertise, inability to plan and operational problems. After several intensive rounds of consultation and negotiation, each derailed by either internal departmental changes or 5 yearly Commonwealth reviews, ADHC will soon release separate revised program guidelines for NSW Disability Advocacy and Information services.

The importance of independent information and advocacy for people with disability and their families cannot be overstated. The specialist disability services system can be prohibitively complex. Issues arise in all aspects of the life of a person with disability (as for others without disability), both inside and outside the specialist disability system, but requiring expert advice and knowledge to negotiate and resolve. People with disability can require particular assistance to exercise their rights, entitlements and responsibilities to minimise the negative impact of disability.

It is in ADHC's interests to ensure adequate independent advocacy support to raise and handle issues in the most open and transparent manner for ADHC direct and funded services. This can provide a good mechanism for service and systems improvement; it can capture and handle minor issues before escalation and can serve to resolve issues at the earliest possible time.

Some people with disability require advocacy support to access ADHC or service provider complaints mechanisms or even the NSW Ombudsman when an issue arises. Advocates can work on an individual or systemic basis, across government agencies, private and public corporations and locations.

ADHC's own Intake and Referral Process refers ineligible callers to the very few non-government information providers, and several other systems also rely on them such as Commonwealth Carelink and even the Home Care Service NSW.

Promised funding increases to disability advocacy and information services have not been realised. Consequently, funding has not kept pace with population growth and accelerating demand.

Recommendation

That ADHC release the Program guidelines and provide appropriate funding for Disability Advocacy and Information Services, and that such funding be properly indexed to cover the costs of providing such services.

(f) internal and external program evaluation including program auditing
and achievement of program performance indicators review

Integrated Monitoring Framework

Around 2005, the Integrated Monitoring Framework (IMF) was developed and implemented. Designed to be applied to all ADHC funded organisations on a three year cycle, the IMF comprised a self-assessment prior to a site visit by departmental officers. This would result in an action plan for redress or improvement that was agreed between both parties. Despite the additional workload, funded organisations welcomed departmental involvement, many advising that it was the first time ADHC obtained a good understanding of their operations, challenges and achievements. NCOSS supported the implementation of the IMF, recognising it as a contract, operational and management compliance monitoring tool only. The IMF did not measure or identify the quality of service provision to clients. It is important to recognise that mere activity does not equate with quality in service provision or progress for the person with disability or older person.

HACC services were previously accustomed to regular monitoring against the HACC standards but the IMF was relatively new for many disability providers. For a significant period preceding the IMF, disability services had been monitored by the department on a crisis basis only.

Quality Monitoring Framework

In 2008-09, NCOSS participated in the initial development of a Quality Monitoring Framework (QMF), which aimed to integrate the IMF but include quality measures. NCOSS had some concerns that early versions of the QMF measured only the quality of the organisation rather than the quality of service to clients.

Regular monitoring suspended

The IMF was suspended from July 2009, initially to trial the QMF, but then all state work was postponed while the national disability standards review and consultation commenced. The Commonwealth's development of common aged care standards was already well underway and ADHC was anticipating an earlier COAG announcement on the future of HACC.

Data collection and performance reporting

NSW has reported the lowest return rate of HACC data in Australia for several years. This has greatly improved in recent years following ADHC's HACC data remediation and training project and the creation of the Minimum Data Set (MDS) helpdesk. However, the NSW return rate remains very low in both HACC and disability services, resulting in evaluation problems with activity comparisons, performance assessments, client numbers and value for money.

Public reporting against programs

The ten year disability plan *Stronger Together* 2006-2016 is in its final year of the first 5 year funding allocation. *Stronger Together* when it was released contained a table at the back which shows for each year, what the increase in funding is, the purpose/program for spending e.g. therapy service for children with disability, how many people/clients will benefit. NCOSS congratulated then Minister Della Bosca and ADHC on the clear targets and plans as explained in the initial document. Progress reports were published in January 2007, January 2008, June 2008, June 2009, and June 2010. While NCOSS believes that ADHC has met or exceeded its promised targets, this has been quite difficult to analyse given that the progress

reports rely on narrative descriptions rather than also reporting against the targets and tables contained in the original document.

In April 2008, Premier lemma launched *Towards 2030: Planning for our changing population*, "the first NSW whole-of-government strategy to actively plan for demographic change". Towards 2030 described five strategic outcomes, containing 13 priorities with 119 identified activities across the range of government agencies. The activities of each of the 13 priorities were grouped into

- What will continue to be done (55 activities)
- What will be done in the next 12 months(35 activities)
- What will be done in the next 5 years (29 activities)

NCOSS knows of one progress report released in June 2009 that again largely used narrative to report against each broad priority and that reported on activities from the first year, again making the results very difficult to analyse. Of the 70 activities reported, the results were categorised "*completed*" (2 activities), "*on track*" (63 activities) and "*to be completed by April 2010*" (5 activities) but these did not align with the narrative.

While this effectively thwarts a critique of the Plan's results, it also serves to obscure any real achievement in the *Towards 2030* Plan. The ADHC Office for Ageing has promised that reporting will be much easier to follow and analyse in the next progress report.

(g) any other matters.

Coordination amongst government agencies

ADHC puts a premium on good coordination between non-government providers of support services to older people, people with disability and their carers. While Better Together has been designed to facilitate good coordination between government agencies, systemic difficulties are still occurring which result in additional hardship for clients. Some examples include:

- Planning approvals for retirement villages without due regard to the additional resources required to support a dramatic rise in the number of older people in that locality.
- Coordinating Commonwealth programs with state programs where guidelines seem to clash e.g. fees arrangements for CACP clients needing supplementary HACC services. Guidelines are clear but their implementation varies.
- Essential disability equipment that cannot be installed without home modifications but the often extended waiting times for each stage (the renovation queue and the equipment queue) must be simultaneous rather than consecutive. Sometimes the perverse situation arises where the modification cannot be carried out until the equipment is supplied, but the equipment cannot be supplied until the modification is complete.
- Some disability programs (eg. post-school programs) indicate the use of community transport services where community transport guidelines specifically prohibit such services except with spare capacity and at often unaffordable full cost recovery to consumers.

These are only a few of the examples regularly discussed with NCOSS. There must be a better way.

Recruitment and employment

There will always be competition between government and non-government providers with stark wage inequities between workers in the same jobs but working in government or non-government organisations. Until there is wage parity and an equalising of conditions, non-government providers will continue to train workers to enter the government sector. Further, the constant turnover of ADHC staff and internal shifting of roles can make dealing with ADHC more difficult than necessary for clients and their carers.

ADHC in a leadership role

NCOSS has long argued that ADHC should be the leader in issues for older people and people with disability within government. ADHC should act as a centre of expert advice to other government agencies and should play an accountability role in their responses to older people and people with disability.

Easier access to support services

NCOSS is seriously concerned at the oft unchallenged assumption that easier access to complex service systems can be provided by a one-stop shop or single entry point. While this can be part of the solution, it is not a panacea. One-stop shops rely on a well-known and promoted shopfront / entry point, expert coordination and adequate intake resources. Single entry can create bottlenecks resulting in "queues before the queues" and presumes access to a cohesive seamless no-silo service system. NCOSS supports the concept of simplified access instead of single access, where there is no wrong door, where a person can get access to the entire

system wherever or whenever they first encounter it and where systemic knowledge is a shared responsibility amongst assessors and providers.

NSW Aboriginal Community Care Gathering Committee

- Additional feedback

At its July meeting, the NSW Aboriginal Community Care Gathering Committee developed additional feedback to the Inquiry:

- ADHC demonstrates consistently poor consultation and communication with Aboriginal services and communities
- ADHC does not respect the autonomy of non-government services, including Aboriginal specific services
- ADHC is not holding mainstream services accountable for Aboriginal service provision. Where an organisation has won funding on a premise of Aboriginal service provision, that organisation must openly account for the Aboriginal dollars, reporting on how many Aboriginal clients were supported.
- Aboriginal people always seem to be an afterthought. Despite best intentions, new program and funding initiatives seem to engage with Aboriginal people and organisations last after completing their engagement with the mainstream community. Sometimes resources are exhausted before the Aboriginal component is implemented.
- ADHC are advised to refer to all ADHC staff, not to Aboriginal people separately e.g. "Aboriginal HACC Staff"
- "Competition kills Co-operation". Competition sets providers against one another e.g. local services vying for the same funding
- There seems to have been a reduction in the number of Aboriginal ADHC officers available to work with funded services. Some local Aboriginal workers cannot ask questions for fear of being put down by non-Aboriginal "unwilling mainstream government officers"
- An "open door" is not enough to attract Aboriginal people to use support services; there is a need for culturally appropriate outreach and information.
- Some Gathering members have reported that ADHC has set new unfair service targets for new funding
- "Due to past policies, Aboriginal people are after [want] jobs in HACC and disability services to improve quality of life" of workers, clients and the community.
- Volunteers should not be required to substitute for paid workers, but to complement them.
- The Gathering acknowledges positive progress for Aboriginal participation and usage in some disability services

- Regarding the identification of Aboriginality in client data, the Gathering reports that some providers do not collect data on Aboriginal status, either by not asking or by omitting the question from forms. This problem is further compounded by the fact that approximately 20% of clients do not answer when asked about Aboriginal status.

The NSW Aboriginal Community Care Gathering Committee commends its Policy Statement *Leading Our Way in Community Care* to the Inquiry.

IN CONCLUSION

NCOSS appreciates the opportunity to respond to the Inquiry into Services provided and funded by Department of Human Services, Ageing, Disability and Home Care.

Should you require any further information please contact Christine Regan, Senior Policy Officer, on 9211 2599 ext 117 or chris@ncoss.org.au

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APPENDIX 1

This has been edited from the NCOSS Pre-Budget Submission 2010-2011 A. *Community Services Stimulus Package*.

■ Self-Directed Support for people with disability

Results

- People with disability and families have control in addressing their particular individual needs.
- The disability service system and providers can create long-demanded flexibility necessary to meet individual needs through specific planning.
- An end to perceived duplication or over-servicing in disability services.

Evidence/Rationale

Previously known as individualised packages, the funding method where the person (with or without carers/family) directly receives the funding allocation is now more correctly termed self-directed support.

This acknowledges a critical distinction. Self-Directed Support funding goes directly to a named person with disability who (with or without their family/carers) makes decisions about how the money will best support them. Individualised packages, while separately contracted and monitored, may be allocated to a service provider who allocates the packages according to demand, and who may decide what supports the client needs and then provides them. Self-Directed Support provides a new approach in NSW to sustaining people with disability, which can engage with but does not rely on established service models or systems.

The NSW Stronger Together Disability Plan includes a commitment to explore Self-Directed Support and individualised packages. NCOSS acknowledges that DADHC has commenced action research in this area alongside four pilot programs: *"My Plan My Choice Early Start"* in Met South Region, *"Extended Family Support"* across NSW, 90 self-managed packages in the new *"Active Ageing"* and *"Life Choices"* programs, *"My Plan My Choice Older Carers"* in the Northern Region. These are in addition to the self-managed stream of the Community Participation Program.

Self-Directed Support has been successfully implemented in several other Australian states and overseas for a number of years. The person with disability and their family can purchase necessary supports customised to their specific needs when required from any appropriate source. This approach to supporting people with disability is tailored to the needs of the named individual and does not revolve around service providers or the service system.

Disability service providers, however, can be integral to the support needs of the individual. The effective implementation of Self-Directed Support involves three important components:

1. **Personal Budget.** A funding package adequate to the level of support needed by the person;
2. **Technical expertise.** A qualified disability advisor, a technical expert responsible to the person with disability, is available if needed to assist in developing the tailored package of supports and designing staff activities etc;
3. **Financial intermediary.** This is a person or organisation that, if required, manages the mandatory infrastructure requirements of the funding (i.e. finances, legal obligations, contracting, etc.)

From the viewpoint of the person with disability, Self-Directed Support offers the power to engage the type and level of support they need rather than trying to fit into an established sometimes unresponsive service system. This will also enable the flexibility to address different needs at different life stages as well as cultural issues, especially useful to Aboriginal people with disability and those from culturally and linguistically diverse backgrounds.

The person's specific supports can better engage their strengths, personal networks and resources. NCOSS believes this to be a more effective and efficient way of providing support, instead of fitting often square pegs into round holes in a service system experiencing overwhelming demand.

Actions

That in 2010-2011 the NSW Government provides at least 300 Self-Directed Support packages, on a sliding scale according to needs, to people with disability and their families.

Cost: \$19.5m recurrent in 2010-2011

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