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

Second & Supplementary Evidence

Responding to questions on notice from the NSW Parliament Standing Committee on Social Issues

September 2010

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Supplementary evidence to the Standing Committee on Social Issues Inquiry into services provided and funded by ADHC.

Further to our original submission and following our presentation at the initial hearing on 9 August 2010, NCOSS herewith provides the information requested by the Committee both during the Hearing and in subsequent additional written questions on notice.

Questions on notice from the NCOSS presentation at the Hearing on 9 August:

1. **Disability Institutions**:
   How many people are there in what institutions in NSW?

2. **Self-directed Support Funding:**
   Please provide relevant reading and resources.

3. **Improved use of existing data in ADHC:**
   What data does ADHC have & how can it be used?

4. **There have been criticisms of competitive tendering to provide the best services:** Can NCOSS describe a better way?

5. **NCOSS Networks:** Who belongs to them?

Additional written questions on notice:

6. **Non government service providers are playing an increasing role in the provision of aged care and disability services.**
   Do you think this move has been positive for the industry?
   For example, are service users now receiving a higher level of care?

7. **On pages 6-7 of your submission you discuss unmet and undermet need for disability services.**
   Can you please explain the difference between unmet and undermet need and the consequences both have on people with disability?

8. **Your submission is critical of the increasing rigidity of the various service systems that has resulted in an overall service system that is complex and resistant to change (page 12).**
   Can you please briefly explain this position and offer some suggestions as to how the system can become more flexible and user-friendly.

NCOSS has provided detailed responses with references and where appropriate links to website resources. In answer to some questions, additional relevant evidence has been included.

Should the Standing Committee require any further information or clarification, please contact Christine Regan (Senior Policy Officer) on 9211 2599 ext 117 or chris@ncoss.org.au

1. **Disability Institutions**: How many people are there in what institutions in NSW?

What is a disability institution?

A disability institution contains a large group of people with disability, living on the same site either together or in various configurations, where people without disability do not permanently live but act as staff, or where physical and social access to the local and wider community is restricted. In the vast majority of cases, the resident people with disability do not choose to live there, do not freely and regularly interact with neighbours and do not use/access community facilities, except by organised events in groups. The architecture of a disability institution does not reflect that of the immediate street or local area and the "facility" is recognised or understood by the local community to be "separate" or "other". Traditional disability institutions have been located in 'quiet rural settings', meaning pleasant surroundings but isolated from neighbours, with little or no public transport and few if any nearby public facilities. A disability institution can be one or more old or new buildings on a designated site, or several buildings grouped together in a "village site" often with single access and shared staff.

NCOSS is concerned at the re-development of traditional institutions into smaller disability villages which are still segregated from the local community, have shared staff, and still operate on group rules rather than the needs of the individual person. Australian and overseas research has consistently demonstrated that the outcomes for people who live in these village situations more closely reflect the outcomes of people in large disability institutions rather than the outcomes of people with disability who are integrated into dispersed housing in the community.

ADHC refers to disability institutions as **large residential centres** to avoid the stigma of the term "institution". However, there is over 80 years of experience in NSW and a wealth of respected academic evidence from around Australia and the world to show that people living under the above conditions, regardless of the name/term/definition, consistently have very poor outcomes compared to other people with disability – with similar support needs – who live in a range of small local housing and support options dispersed within the general community. The research supports the finding that size does matter.

How many people live where?

NCOSS said there were 1400 people to our knowledge in disability institutions in NSW. People With Disabilities Australia has reported on a larger number of people with disability who reside in ten government operated institutions and in 21 non-government facilities across NSW in its Special Bulletin in February 2009 (refer to : http://www.pwd.org.au/documents/pubs/EB50.html#pec). All these nominated facilities display the features described in the above definition of a disability institution.

On 26 August 2010, the NSW Ombudsman, Bruce Barbour, reported to NSW Parliament on the closure of residential centres in NSW, indicating that there are 1,600 people now living in disability institutions in NSW.

Here is his media release and link to the Report:

"People with disabilities and the closure of residential centres"

In 1998, the NSW Government announced that all residential centres housing people with disabilities would close by 2010. Today, over 1,600 people with disabilities in NSW continue to live in residential centres, also known as institutions.

The NSW Ombudsman, Bruce Barbour, has today tabled a report that examines this situation and its impact on the lives of people in those centres.

The report draws on extensive work by the Ombudsman in looking at the circumstances of people living in centres operated by Ageing, Disability and Home Care (ADHC), and finds that people with disabilities living in these facilities do not have the same basic rights as other members of the community.

'People with disabilities are entitled to the same rights and opportunities as the rest of us,' said Mr Barbour. **'This includes being able to live in and be part of the community, to choose the way we want to live our lives, and to participate in decisions that affect us.'**

'However, I have found that this is not currently the case for people with disabilities living in residential centres. The nature of institutional care – including the housing of large numbers of people on one site; segregation of the centres from the broader community; and structured and inflexible routines – restricts fundamental rights and opportunities.'

'The Government's decision to close the residential centres is sound, but progress over the past 12 years has been too slow. This situation needs to change as a matter of priority.'

In June, the Ombudsman and the Disability Council of NSW hosted a community forum to discuss progress in closing residential centres, which was attended by close to 300 people. The report outlines the critical messages from the forum that should inform government planning for closure of the centres and the provision of opportunities for people with disabilities to receive support in, and as part of, the community.

The report notes the clear message from people at the community forum that there needs to be genuine partnership with people with disabilities and their families; and real choice from a flexible and wide range of accommodation and support options.

'I note the considerable work underway by ADHC and the NSW Government in planning for the second half of *Stronger Together* – the Government's 10-year plan for improving disability services,' said Mr Barbour. **'The work of my office indicates the critical need for this planning to include the closure of residential centres, and expansion of**

the range, availability and flexibility of accommodation and support options in the community for people with disabilities.' "

Full report available at:

http://www.ombo.nsw.gov.au/publication/PDF/specialreport/SR_ClosureResidentalCentres_Aug10.pdf

What is appropriate supported accommodation for people with disability?

In describing what would be appropriate living situations for people with disability, NCOSS has joined with a group of disability experts to promote more appropriate forms of supported disability accommodation that reflects the accommodation of others in the general community. This information can be found on the supported living website http://www.supportedliving.org.au/

Other relevant evidence:

On Tuesday 31 August, in response to an article by Christine Regan in the latest *INTERACTION,* the national journal on intellectual disability, NCOSS received an email from a disability service provider who asked to remain anonymous to protect his professional relationships. He has consented to the text being added to this NCOSS evidence: (NB source can be confidentially verified.)

> "I've read your piece in Interaction Christine on institutions.
>
> I've spent a few Saturdays over the past few years writing similar pieces but I never ended up sending them anywhere *for a variety of reasons*. I've had similar conversations with two CEO's who've not experienced what an institution is like. I worked in an institution for a few years in the early 90's. More recently, I've taken people to visit places similar to Peat Island and there is often at least one visitor who says "What a lovely place! Water views, peace and tranquillity....why I wouldn't mind living here myself. What's the big deal? It's such a safe place." Said in all seriousness.
>
> They don't see the realities of institutional living. The large common bathrooms. They don't notice most bedroom doors are left wide open. And then they notice that despite the comments from staff that "there are a range of community living activities for people and that people go out in the community", they do a head count of the people who are walking around and realise that of the fifty or so people who are living there, about 40 of those people are sitting around at the site. This is backed up by data from the 2007 Ombudsman "deaths in care report". They don't see the separation of men and women. The penny drops. Simple questions that are not often considered. Where do people have sex? And with whom?
>
> Some simple lessons I took away from my time there. In an institution if someone is screaming, none of the neighbours poked their head over the fence to ask if something is wrong. When you live in a house in the community, if someone screams for more than 1 minute, there is a better than 50% chance that someone will poke their head over the fence or call the police.

I don't think people realise that segregation does more than effect individuals. Large congregate settings transform the community's relationship toward people with a disability. The normal rules of society are not applied and as people see the discrimination being applied to people's living conditions, they must conclude that there has to be a good [reason] why they are living there. People don't see that as soon as you set people up separately, they are treated differently, and over time, the normal rules fade away.

I could go on. Thanks again for your piece."

This is the ***INTERACTION*** article:

Nightmares and long-held fears *Christine Regan*

Lately I have been reliving old nightmares.

In the very first days of my daughter Erin's life, soon after receiving the diagnosis of her intellectual disability, I developed constant, vivid and vicious nightmares, and daymares, of what her life would be like, and mine.

At the maternity hospital in 1977, the genuinely concerned doctors and nurses were vigourously insisting that I send my baby to a place in the Blue Mountains where she will "receive proper care". The inference being I was incapable and uninvolved. The increasingly persistent advice to my husband was "place the child now before the mother gets attached". Thank goodness times have changed.

The nightmares began. I recall Frankenstein images of gothic halls, sparse dark rooms with locks on everything, large sour faced impatient women in white with no warmth and a will of iron, identically swaddled babies all lined up in rows of peeling metal cots, like mini gaols. Of course I knew that these images were not the truth, but this was the stuff of my deepest darkest fears.

Husband and family said the decision was totally mine, so home it was, with not one iota of regret and simply mega-gigabytes of love and joy. Three weeks later, after stabilising her serious health issues, we took Erin home, along with lovely pot plants and several metre long boxes of chocolates that visitors had brought as presents. It wasn't until my son was born that I realised visitors usually brought tiny clothes and baby paraphernalia to congratulate new mothers and welcome babies.

My early nightmares have briefly (I hope) returned because in early March, I attended the "special gala day" at Peat Island on the Hawkesbury River in NSW. Minister for Disability Services, the Hon. Paul Lynch launched "Our Island Home", a warts and all history of this disability institution as a prelude to closure later this year. The beautifully produced book, written by Laila Ellmoos from the Government Architect's Office, contains photos and history, as well as some moving photo-portraits of long term residents.

Completed in 1908, Peat Island has a checkered history as a civil reformatory during the war, then a hospital for male inebriates, morphing into a very large institutional residence for people with intellectual disability of all ages. The

early staff were drawn from the returning military after the war. Accordingly, the approach to managing the people in residential care was highly regimental and strictly disciplined rather than home-like for many decades.

The Peat Island setting is idyllic and picturesque, on the shores of a wide calm river, amid green hills and valleys. But it is an island, near no town or settlement, with the modern Sydney-Newcastle freeway whizzing past. Early staff and residents built the solid crossing that now connects the island to the shore. For me, Peat Island's beautiful rural setting is code for isolated, invisible, secluded, difficult to visit and impossible to commute.

This is a big deal for me because when I was 13 years old, I resolved never to visit any disability institution after a school excursion to a Sydney children's home. There I met a 13 year old girl with intellectual disability who called me "Mum" and begged me to take her home. I didn't, but I have never forgotten.

I decided however that the celebration of the closure of Peat Island was an important event and besides, my curiosity overcame my trepidation. I found a beautiful place with old worn buildings, patched bumpy roads and a large white special event marquee with temporary wooden walkways for wheelchairs and unsteady pedestrians. Large contemporary images of recent residents were artfully hung from the marquee ceiling; these were joyful and respectful, but every smile showed missing teeth. Was it my imagination, or was the atmosphere thick with sadness and ghosts? Several people remarked so.

I cannot remember the trigger for the last time these early nightmares plagued me but this happy event brought it all back like it was yesterday.

I believe the closure of disability institutions is necessary and just. Any that remain open are a continuing threat to my precious daughter's future, and serve only to blight the human rights of all people with intellectual and any other disability. It is very important to acknowledge the mistakes of the past, the terrible treatment and meagre lives of people whose only crime was to be born different. It is critical to remember that sad past, through coming generations. And never, ever to return to it.

2. **Self-directed Support Funding:** Please provide relevant reading and resources.

Effectiveness of individual funding approaches for disability support, July 2010
Social Policy Research Centre, University of NSW,
http://www.apo.org.au/research/effectiveness-individual-funding-approaches-disability-support

This report examined the effectiveness of individual funding of disability support and aimed to inform policy to improve the provision of disability support.

For how self-directed packages operate in Victoria, go to:
http://www.dhs.vic.gov.au/disability/supports_for_people/individualsupportpackages

Disabled People and Direct Payments
http://www.leeds.ac.uk/disability-studies/projects/UKdirectpayments/UKDPfinal.pdf

This report presents findings from a 'four-country' study in the UK exploring direct payments to people with disability and their families.

A report on **In Control**'s Second Phase: Evaluation & Learning 2005-07
http://www.in-control.org.uk/DocumentDownload.axd?documentresourceid=282

In the UK, over 100 local authorities are implementing self-directed support, allowing about 3,500 people from all "social Care groups" now directing their own support. The report anticipates that a new government commitment would soon expand this number of people by "many thousands".

National evaluation of the individual budgets pilot program:
UK Social Policy Research Unit, University of York:
http://php.york.ac.uk/inst/spru/research/summs/ibsen.php

How to Integrate Direct Payments into Self-Directed Support: A Guide: October 2007
http://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=261&cc=GB
2008

Economics of Self-Directed Support
http://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=209&cc=GB

The Costs and Benefits of Independent Living: UK Office for Disability Issues
http://www.sqw.co.uk/file_download/95

This review was conducted to examine the extent to which providing people with disability with more choice and control over the support they need is cost effective.

3. **Improved use of existing data in ADHC:**
What data does ADHC have & how can it be better used?

NCOSS workshopped this issue with the NSW HACC Issues Forum on the 24 August 2010.

NCOSS contends that there is plenty of information provided to and collected by ADHC that is not analysed for indicators of unmet need. Much of this information is provided under a compliance requirement for each funded service and when received, ADHC officers store it against that organisation's information deposit.

NCOSS recognises that this information is neither complete nor superior. It does, however, provide a readily available opportunity, if analysed and mined for information, to improve understanding/knowledge of the indicators of unmet need for supports and services; especially regarding support gaps, flexibility, organisational change, more appropriate support responses and trends in service provision. These elements are critical to a good understanding of unmet need and how to address it.

Data regularly provided by contracted service providers to ADHC includes:

- **MDS Minimum Data Sets** raw data: provided quarterly to ADHC and sent to Commonwealth for collating. ADHC website says:
  > This collection of data occurs on a quarterly basis in line with your funding cycle and provides service user profiles and details of the type and amount of assistance provided. The Australian Government and State and Territory Governments use this information to help plan for the HACC Program.

  Collated results are provided to each state with significant time delays, the most recent report available being 2008-09 for HACC and 2007-8 for disability services. The Productivity Commission uses this data in its *Report on Government Services* released in January each year.

- **Annual Acquittals**: Around November each year, funded services provide a financial acquittal covering their income and expenditure according to the ADHC Funding Agreement. This Acquittal contains important financial and other information relevant to contracts.

- **Annual Compliance Returns**: These are detailed reports that describe, confirm and explain contracted outputs and other details to ADHC.

- **Organisational Annual Reports:** Under the Funding Agreement, organisations are required to provide their most recent AGM Annual Report to ADHC.

- **Monitoring Information**: Until mid-2009, ADHC conducted the IMF or Integrated Monitoring Framework on a 3 year cycle to assess and investigate the level and extent of compliance of funded organisations to the Funding Agreement, schedules of outputs and their agreed service delivery. Almost all funded services completed an IMF within the first 3 year cycle. AS explained in the initial NCOSS submission, this has been suspended pending the development and introduction of a quality monitoring framework for similar implementation.

The HACC Issues Forum also found an abundance of other occasional or incidental information held or collected by ADHC, including:

- Data in Funding Agreement service description schedules, ie schedule 3.
- Research projects contracted by ADHC, Office for Ageing, Disability Council of NSW etc and others; eg 45 & up longitudinal study
- Data from disability and other information and advocacy providers
- ADHC's intake and referral system
- Home Care's Referral and Assessment Centre
- Hunter HACC Access Point
- Data from complaints management processes, including Central ADHC, regional ADHC offices, Home Care Service NSW, Ombudsman NSW, funded services
- Data from local councils; eg annual social plans, development approvals
- Non-ADHC research relevant to ageing, disability and carers.
- Client information systems within ADHC and within funded services
- Annual community planning processes
- Attendance by ADHC officers at community network meetings and occasional stakeholder forums
- Information sent to ADHC by unfunded providers
- Activities undertaken and information provided by peak bodies

4. **There have been criticisms of competitive tendering to provide the best services:** Can NCOSS describe a better way?

NCOSS agrees that competitive tendering is not failsafe and has resulted in several undesirable impacts on the provision of services, including:

- A mushrooming in the number of providers of services under the guise of consumer choice. In reality, the weight of unmet demand usually dictates that the client gets to choose only whether to accept the service as offered, not to freely choose from among a number of service providers. NSW, with more than a third of Australia's population, has by far the highest number of HACC providers in Australia at 1780, compared to the next highest state Queensland (one eighth population) at around 700 providers.
- Due to the potential dollar value of information and/or superior practices in a competitive tendering environment, services are now less willing to share their innovations etc for fear of losing a competitive edge.
- Due to the above, some providers are less willing to participate in local community networks, designed to improve overall service responses and quality of services.
- There is increased pressure on smaller providers to either grow or amalgamate in order to stay competitive
- The cost of continual tendering is disproportionately higher in providers less able to absorb these costs, ie smaller providers, rural and regional providers, providers to specific groups such as Aboriginal communities or people from diverse cultural backgrounds.

Working Together for NSW is an agreement between the NSW Government and community services to recognise and improve this working relationship and acknowledge the role of community services in supporting the people of NSW. Under Working Together for NSW, NCOSS developed a ***Good Funding Policy and Practice*** Paper in 2006, specifically to respond to the then Dept Community Services funding policy. All NCOSS policy officers were involved in the development of the Good Funding Policy and Practice Paper to ensure its relevance to all NSW state government funding programs and departments.

Working Together for NSW: Good Funding Policy and Practice sets out 7 principles for good funding policy and examines all funding models in use by state government agencies. The Paper then outlines the context and most appropriate use of these funding models for the best outcomes for the community and to avoid unintended consequences. NCOSS believes that this provides a much better way than the wholesale implementation of competitive tendering for the purchase or procurement of human services in the non-government sector.

Working Together for NSW: Good Funding Policy and Practice can be found at http://www.ncoss.org.au/hot/compact/Working-Together-good-funding-jul06.pdf and also accompanies this submission.

Other relevant evidence:

At its August 2010 meeting, the NSW HACC Issues Forum also identified a range of issues regarding the application of competitive tendering in NSW, including:

- Inconsistent processing & assessment criteria: the feedback from two ADHC regions on an identical tender was significantly different leading to different tender outcomes
- Community care coordination meetings experience a drop in participation during tendering periods
- Competitive tendering can damage professional and working relationships
- It was reported that in both Broken Hill and the Central Coast, providers collaborate on which organisation/service provider is best placed to tender. This could reduce the unintentional consequences of tendering (thereby enhancing outcomes and relationships) but there is strong concern that this could be considered a restrictive trade practice.
- Planning processes can be affected: there is reduced cooperation where service gaps can be identified but where these also provide an opportunity to approach ADHC for funding. This is a financial disincentive to publicly identify such gaps.
- Competitive tendering can negatively impact an organisation's viability and can adversely affect rigourous planning processes.
- Approved provider status can reduce the tender burden on smaller and medium organisations.
- Conflict of Interest: in some areas, especially but not only regional and rural, local people voluntarily sit on the boards and management committees of several local service provider organisations. The value of commercial-in-confidence information is lost for organisations unintentionally sharing Board members. Conflicts of interest are increasingly reported to NCOSS where a person might deliberately dampen the tender activities of one organisation in favour of another. Action against such people is rarely taken in community services and in ant case the damage is already done. Some of this is a consequence of the escalating responsibility of Board members and the difficulty in recruiting willing and expert hands onto NGO Boards.
- There was significant expressed concern for the future of smaller organisations in tendering processes
- The existing tender processes do not adequately elicit a clear understanding of the passion and capacity of some organisations in the provision of services to eligible people

5. **NCOSS Networks:** Who belongs to them?

Member organisations of the **NSW HACC Issues Forum** in 2010 include:

ACON AIDS Council of NSW
Aged & Community Services Association NSW & ACT
Aged Care Rights Service
Alzheimer's Australia NSW
Bankstown Area Multicultural Network Inc.
Bay & Basin Community Resources Inc
Bega Valley Meals On Wheels Co-operative
Benevolent Society of NSW
Booroongen Djugun Aboriginal Corporation
Brain Injury Association NSW Inc
Burwood Council
Cancer Council NSW
Carers NSW Inc
CareWest Inc
Central Coast Disability Network
Central West Community Care Forum
Centre for Volunteering, The
Coastwide Community Transport Inc
Combined Pensioners & Superannuants Association Of NSW Inc
Commonwealth Carer Respite Centres
Community Care Northern Beaches Inc
Community Services & Health Industry Training Advisory Board
Community Transport Organisation
Council of Social Service of NSW
Council On The Ageing (NSW) Inc
Dubbo Neighbourhood Centre
Ethnic Child Care Family & Community Services
Ethnic Communities Council of NSW Inc
Gilgai Aboriginal Centre Inc
Gnara Kurranulla Aboriginal Corporation
Gosford City Council
GREAT Community Transport Inc
HIV/AIDS Legal Centre
Home Flexi Care & LifeLinks Mid State
IDEAS Inc (Tumut)
Illawarra Forum Inc
Inner South West Community Development Organisation
Inner Sydney Regional Council
Inner West Aboriginal Community Company
Integrated Living
Integratedliving Australia Ltd
Intellectual Disability Rights Service
Interchange Respite Care (NSW)

JewishCare
Kiama Municipal Council
Local Community Services Association
Macarthur Disability Services Ltd
Macquarie University
Manly Warringah Pittwater Community Transport Inc
Men's Health Information And Resource Centre
Mid North Coast Regional Council for Social Development
Motor Neurone Disease Association Of NSW Inc
Multicultural Disability Advocacy Association Of NSW
National Disability Services Ltd NSW
New England HACC Development Inc
Northern Rivers Social Development Council
Northside Community Forum Inc
NSW Community Options Projects Inc
NSW Council For Intellectual Disability
NSW HMMS State Council
NSW Meals On Wheels Association Inc
NSW Neighbour Aid & Social Support Assoc Inc
Orana HACC Forum
Orange City Council
Penrith City Council
People with Disability Australia Inc
Physical Disability Council NSW
Queanbeyan City Council
Redfern & Inner City Home Support Service Inc
RSL Welfare and Benevolent Institution
Shellharbour City Council
Shoalhaven City Council
Shoalhaven Community Options
Southern Community Care Development Inc
Spinal Cord Injuries (SCI) Australia
Sydney Legacy
Wagga Wagga City Council
Wesley Home Care
Wesley Mission - Newcastle
Western Sydney Community Forum
Wollongong City Council

Member organisations of the **NSW Aged Care Alliance** in 2010 include:

ACON AIDS Council of NSW
Aged & Community Services Association NSW & ACT
Aged Care Consumer Consultative Committee
Aged Care Rights Service
Alzheimer's Australia NSW
Association Of Independent Retirees
Australian & New Zealand Society for Geriatric Medicine
Australian Association Of Gerontology

Australian Association Of Social Workers NSW Branch
Australian Catholic Health Care Association
Australian Podiatry Association (NSW)
Baptist Community Services - NSW & ACT
Benevolent Society of NSW
Blacktown City Council
Cancer Council NSW
Carers NSW Inc
Centre for Volunteering, The
CEPU Retired Members Association
Combined Pensioners & Superannuants Association Of NSW Inc
Council On Jewish Aged Care
Council On The Ageing (NSW) Inc
Ethnic Communities Council of NSW Inc
Geriaction Inc (NSW)
Healthy Cities Illawarra Inc
Inner Sydney Regional Council
JewishCare
Local Government & Shires Association
Macquarie University
Men's Health Information And Resource Centre
National Seniors (NSW Office)
NSW Meals On Wheels Association Inc
NSW Nurses' Association
NSW Retired Teachers Association
NSW Transcultural Aged Care Service
Older Women's Network
Older Women's Network NSW Inc
Parkinson's NSW Inc
Queanbeyan City Council
Retired Teachers Assoc & Council of Retired Union Members Australia
Retirement Village Residents Association Inc
Royal Prince Alfred Hospital
St Vincent de Paul Society - State Council
Sydney Legacy
UnitingCare NSW ACT
War Widows' Guild of Australia NSW Ltd
Wesley Home Care

Contacts in the 2010 **NSW Aboriginal Community Care Gathering Committee** include:

Aboriginal Disability Network
Awabakal Elders Service
Bankstown Area Multicultural Network
Booroongen Djugun Aboriginal Corporation
CareWest

Casino Neighbourhood Centre
Community Care (Northern Beaches)
Condobolin Aboriginal Health Service
Council of Social Service of NSW NCOSS
Gilgai Aboriginal Services
Greenacres
Indigenous Disability Advocacy Service
Kurranulla Aboriginal Corporation
Macarthur Disability Services
National Disability Services NSW
Ngambaga Bindarry Girrwaa Community Services Inc
Orange City Council
Shoalhaven Community Transport Service
Twofold Aboriginal Corporation
Wagga Wagga City Council
Yinarr Health & Wellbeing Aboriginal Corp

NCOSS is informed by its participation in a number of **Disability and other networks, organisations and forums** including:

Coalition of Supported Accommodation CASA *on disability in boarding houses*

In Control NSW *on individualised & self-directed support for people with disability*

National Council on Intellectual Disability

NSW Council for Intellectual Disability

NSW Disability Advocacy Network NDAN

NSW Futures Alliance *on people with disability growing older*

PADP Community Alliance *on the provision of equipment to people with disability*

Strategic Carers Action Network SCAN *on carers & families of people with disability*

6. **Non government service providers are playing an increasing role in the provision of aged care and disability services.**
Do you think this move has been positive for the industry?
For example, are service users now receiving a higher level of care?

The move to non-government service providers or NGOs in aged care and disability services has been a positive move for service users, the community and the industry for reasons such as:

- NGOs can often be more flexible and immediate in their responses to service users
- NGOs are often created and "owned" within the local community
- NGOs can support people who are distrustful of government due to past experiences ie people from countries with oppressive regimes, Aboriginal people with unfortunate histories of government interventions etc.
- NGOs often provide innovations, are prepared to explore & risk new provision techniques
- NGOs can acquire funding from a number of sources, thereby providing a range of service options and blended supports

NCOSS cannot comment on whether service users receive a higher level of care from NGOs overall. At present, government provided services support people with very high disability support needs in supported accommodation and in specified packages of care (NCOSS understands there are around 20 such disability packages in NSW). Most other forms of disability service provision are provided through NGOs.

Under the Home & Community Care HACC Program in NSW, funding is proportionally distributed approximately like this:

40% to the Home Care Service of NSW (part of ADHC)
20% to NSW Health (for allied health provision)
40% to NGOs

NCOSS acknowledges that there can be benefits in more standardised service provision from government eg higher wages for government staff, Home Care is well known and is the major provider in some rural areas. However, some of the consequences can include:

- standardised service can be increasingly rigid and does not suit everybody;
- there is significantly reduced local ownership or contribution to local services or supports;
- decisions are made at the centre rather than close to the client or the community;
- bureaucratic processes can defeat flexibility and community engagement;
- political influences can create unconsulted changes;
- very large provision systems can start to negate economies of scale;

- problem solving and innovation can be slow as can cultural shifts to new service supports

The NCOSS position on the mix or balance of NGOs and government operated services is this: there may always be a need for government provided services, especially as a service of last resort for people with very high support needs. NGOs however can be more responsive, less restricted, less regimented, less risk averse (enabling dignity of risk) and more creative, innovative and flexible particularly if using diverse funding sources.

NGOs however must not be seen as the cheaper and easier option or as allowing government to outsource its responsibilities to older people, people with disability and their carers. Government has a clear responsibility to support older people, people with disability and carers, and a clear responsibility to adequately fund, to safeguard and to enhance NGOs to provide appropriate quality services within the community.

7. **On pages 6-7 of your submission you discuss unmet and undermet need for disability services.**
Can you please explain the difference between unmet and undermet need and the consequences both have on people with disability?

NCOSS considers **unmet need** to be lack of supports to older people or people with disability, while **undermet need** is where the person receives some support but it is either not sufficient or inappropriate.

In its *Report on Government Services 2010*, the Productivity Commission says: 'Unmet need' is defined as the extent to which demand for services to support older people requiring assistance with daily activities is not met. (Chapter 13, Box 13.15)

In its report, *Disability in Australia: multiple disabilities and need for assistance September 2009,* the Australian Institute of Health and Welfare explains the meaning of under-met need as "meaning [people with multiple disabilities] received some but not sufficient assistance." (Page 22)

It is necessary to differentiate **unmet need** from **undermet need** for several reasons explained in the scenarios below. People and their carers often approach ADHC for supports which, due to significant undersupply, may not be readily available when needed or requested. ADHC may respond with some remedy in the meantime to carry the person through.

Pressures on the service systems supporting older people, people with disability and carers are driving the imperative to accurately describe and quantify unmet and undermet needs. In trying to offer band-aid solutions to people, ADHC and providers are justifiably trying to alleviate desperate need. It has however led to a distortion in the reporting of service capacity and the extent to which people needs are reported as opposed to actually met.

Consider these scenarios:

1. The family of a person with disability desperately requests appropriate compatible and nearby supported accommodation which, due to undersupply, is found to be unavailable or has a very long waitlist. In the meantime, the person and their family are offered respite care. NCOSS is concerned that the provision of respite in this case may be considered to be a met need. The person and family are considered by ADHC to have their respite need met and may or may not have recorded an unmet need for supported accommodation. If the person with disability went onto the waiting list for supported accommodation, their level of priority may be lowered because they are at present managing. The family may not discover that they are a lower priority on the supported accommodation waitlist due to their respite service until they enquire where they are up to in the waitlist. ADHC could report this family's recorded need as met but the person and their family have significant undermet need.

2. A person with disability requests supported accommodation that is nearby and compatible. ADHC offers the person the next available place which is some distance away and not easily accessible by public transport, explaining that they can move to a more appropriate place when one becomes available. The person's family cannot easily visit the person, creating tension in that relationship. Their priority for the nearby place may be superseded by the immediate need of another applicant. As the person's request for supported accommodation was addressed, their need is

recorded as met. The person and family however would report a significant undermet need due to the resultant strain on the family's relationships.

3. An older person with dementia and his carer wife have been assessed as requiring in home respite on a regular basis. There is no regular respite appropriate to this couple available at present. The couple are offered domestic assistance in the meantime and accept this on the well-intentioned advice of their care coordinator. Due to escalating demand, the care coordinator turns her attention to other clients. Meanwhile, the couple's house is clean and tidy but the wife is increasingly depressed and exhausted. This couple are receiving a service but their need is dangerously undermet.

4. A person using continence aids is finding that the aids run out before their next scheduled subsidised supply becomes available; meaning they receive 9 months of subsidised continence aids when they need 12 months per year. For this person and their family this creates real and actual financial hardship. A creative local respite provider supplements supply from their respite budget in order to assist the person and their family. ADHC determines that the family's respite package cannot be used for continence aids. This result in the ludicrous situation where the person and their family can be offered a holiday but they do not have the continence aids to manage on a daily basis. While technically ADHC is correct and can record the person's respite need as met and the continence supply program can also record met need as the person receives their full (but insufficient) allocation. However, the person and their family are experiencing undermet need causing considerable hardship.

8. **Your submission is critical of the increasing rigidity of the various service systems that has resulted in an overall service system that is complex and resistant to change (page 12).**
Can you please briefly explain this position and offer some suggestions as to how the system can become more flexible and user-friendly.

NCOSS believes in a diverse industry comprising small, medium and large providers, covering metropolitan, outer suburban, regional, rural and remote locations, supporting diverse communities including Aboriginal and Torres Strait Islander people and people from culturally, linguistically and religiously diverse backgrounds.

For the disability service system:

NCOSS contends that the **universal introduction of individualised and self-directed support funding** will allow the industry to grow and evolve in response to identified need, consequently providing better quality and more responsive services to the eligible person and their family.

No longer will they have to fit into existing service type boxes, receiving services according to artificially unyielding guidelines that reflect such things as data dictionary definitions and bureaucratic contracted obligations.

NCOSS contends that many service providers have been advocating a more flexible approach for years and individualised and self-directed supports will deliver that. This funding distribution method will also deliver improved quality as well as providing incentives for the industry to lift its game.

Effective service providers will benefit accordingly and others will be left behind. Over time, those organisations unwilling to become responsive or with poor quality services will be not be patronized, nor will archaic services/service types that no longer meet people's needs.

The situation of the person and their family will become no less complex, but their lives will no longer be further complicated by the need to learn and navigate a rigid fragmented service system that full-time paid professionals find difficult to follow.

Under individualised self-directed support funding, the person and their family will be encouraged and assisted to make decisions and purchase supports that meet their personal priorities for a good life, supports that reduce disadvantage, supports that more reasonably engage the person in the community that surrounds them. Just as we all expect.

For the HACC service system:

NCOSS has been intensively involved in developing and promoting the **IMPACT** approach in HACC. This approach, which ADHC calls *the enabling approach*, is actively person-centred and involves the person saying what their personal goals/needs/wants are and crafting in-home supports around that person. This reverses the present HACC service system of fitting the person into the system (or not) rather than the system responding to the person.

NCOSS considers the universal implementation of the **IMPACT** approach in community care as the way to unlock the rigidity of the present system and provide

the flexibility and responsiveness required by clients and requested by providers. More in **IMPACT** available at www.impactnsw.com

The NSW HACC Issues Forum regularly discusses its frustration at the increasing rigidity of the HACC service system. The following points outline some of these frustrations, including:

- While referring to positive outcomes for HACC service users, ADHC only counts and indicates outputs in its contracting, monitoring and data collection.
- Multi-service outlets or MSOs, often located in regional areas, were originally established to receive funding under a number of service types to provide a more flexible blended service to local service users. New mandatory data requirements now inhibit this intended flexibility because data is now required under each service silo, thereby unnecessarily complicating reporting and possibly reducing flexibility.
- Data requirements have similarly negatively affected other flexible HACC service provision ie "if you can't count it, it simply doesn't count!" This especially applies to outcomes versus outputs.
- Smaller more local NGOs can be dynamic, take appropriate risks to explore innovation, can be more immediately responsive to individual needs.
- HACC was originally created to maintain and enhance the independence of eligible people (thereby avoiding inappropriate and premature admission to long term residential care). The Forum fears that HACC may have moved away from this worthwhile objective/purpose. The Forum advocates that HACC in NSW re-commits to this important goal and consequently establishes ways to measure and promote this.
- "Contractualism" has adversely affected outputs and service types where the object seems increasingly to be the contract rather than supports to people in the community.
- In home supports as well as neighbour aid and social supports are critical strengths in the HACC program and must be safeguarded and promoted throughout the changes of jurisdictional responsibilities under the COAG HACC split.
- New ways to address bariatric services (services to people who are morbidly obese) and domestic squalor must be established and adequately resourced within the HACC program. At present, the responsibility for and resourcing of both bariatric services and domestic squalor is undetermined, despite constantly arising for certain HACC service types and for HACC clients. This is similarly the case for transport to renal & other health outpatient treatments in some areas, as well as nurse-required insulin injections.
- Ethno-specific services such as day centres can be important supports to people from diverse cultures. However, there is a tendency among assessors to automatically refer people from culturally and linguistically (CALD) backgrounds to ethno-specific services, when this may not be necessary. CALD people should be allowed to use mainstream services, deferring to ethno-specific service only where requested and appropriate. NCOSS is advised that some ethno-specific organisations unintentionally act as information gate-keepers for their clients, inappropriately assuming that their clients will use only ethno-specific services and consequently inhibiting access to other much needed supports for some people.

As promised in Question 4,
The Working Together for NSW: Good Funding Policy and Practice Guide
is attached to the accompanying email.

End of NCOSS Supplementary Evidence

Thank you for the opportunity to provide supplementary evidence to the Inquiry. Should the Standing Committee require any further information or clarification, please contact Senior Policy Officer Christine Regan on 9211 2599 ext 117 or chris@ncoss.org.au