Submission
No 51

Inquiry into Services provided or funded by the Department of Ageing, Disability and Home Care

Organisation: Physical Disability Council of NSW and Council on the Ageing NSW

Name: Ms Ruth Robinson and Ms Anne-Marie Elias

Date received: 9/08/2010

Submission to

Legislative Council

Standing Committee on Social Issues

Inquiry into services provided or funded by the Department of Ageing, Disability and Home

August 2010

3/184 Glebe Point Road
Glebe 2037
Telephone (02) 9552 1606
Fax: (02) 9552 4644
Email: Admin@pdcnsw.org.au
www.pdcnsw.org.au

Level 6, 280 Pitt Street
Sydney 2000
Telephone: (02) 9286 3860
Fax: (02) 9286 3872
Email: policy@cotansw.com.au
www.cotansw.com.au

Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales, representing approximately 700,000 residents. PDCN is involved in providing information and education for people and on behalf of, people with a physical disability. Membership of PDCN includes people with a range of physical disability issues, from young children and their representatives to aged people, who live in NSW from the Greater Sydney Metropolitan area to rural NSW who are from a wide range of socio-economic circumstances. PDCN has the background, knowledge and skills to provide input to all levels of Government regarding the needs of people with physical disability.

The objectives of PDCN are : To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available; To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals; To educate and inform stakeholders (ie about the needs of people with a physical disability).

This submission has been informed by the experiences of people who have physical disability, and of the parents/guardians of children who have physical disability.

The Council on the Ageing NSW?

The Council on the Ageing NSW (COTA NSW) is a non government organisation and the peak body representing all persons over 50 years of age in NSW. COTA NSW is a founding member of the national body, COTA Australia.

COTA NSW's core functions include: Social Policy development, representation and advocacy; Initiating and delivering innovative healthy ageing and ageing support community programs such as Grandparents Raising Grandchildren, Positive Ageing, Healthy Ageing Talks, Age Friendly Environments and our Peer Education Programs - Medicines and You and Beyond Maturity Blues; Brokering, referring, collaborating, coordinating, and networking among seniors' organisations and services to seniors; Informing and educating older persons and all those concerned with their welfare; and Representing the needs, views and aspirations of the over 50s to a range of stakeholders.

COTA NSW's role is to advocate for the needs of older people, their families and carers. COTA NSW commends the Standing Committee on Social Issues on this significant and timely inquiry into the quality, effectiveness and delivery of services provided or funded by the Department of Ageing, Disability and Home Care (ADHC).

Scope of Comments

The services provided by the Department of Ageing Disability and Home Care (ADHC) have three major target groups;

- People who are ageing
- Younger people with a disability between the ages of 0-65
- People who informally care for someone who fit into the previous two groups.

The services provided by this department cover a wide variety of needs ranging from accommodation services to services relating to employment, community support, community access and advocacy. PDCN and COTA will provide comment on a range of issues associated with these services. In particular, PDCN and COTA will comment on:

- Funding and the impact of an ageing populating on already high levels of unmet need.
- Variations of service availability in metropolitan, regional and rural areas
- The inflexible nature of funding arrangement that are not person centred
- The power of compliance with the auditing and reviewing process could be used to help potential service users make a choice that is right for them.

It is hoped that comments provided by PDCN and COTA will identify areas of concern, and help provide imputes for change in ADHC, resulting in improvement in service provision.

1. Funding and the impact of ageing on already high levels of unmet need

The concept of dependency has been used in relation to disability and old age. This concept emphasises the loss of control and the association between biologically-based dependency and impairment (Morris, 1999 in National Disability Authority, 2006). This understanding of dependency differs from that of 'social dependency' which is a product of the interaction between the individual's life situation and social structures. This understanding focuses on the role of society in constructing dependency.

People with severe or profound disabilities who are currently of working age will often develop increased and complex needs as they age. In 2009 it was estimated that there were approximately 600,000 people with severe or profound disabilities, aged between of 0-64 years living in Australia, with approximately 223,000 having a severe or profound physical disability. [1] There is considerable documentation of earlier onset and higher incidence of Alzheimer's disease in people with Down syndrome. There are also suggestions that people with severe

[1] Australian Government - Department of Families, Housing, Community Services and Indigenous Affairs (2009) National Disability Insurance.Scheme (1. Introduction and Background)
http://www.fahcsia.gov.au/sa/disability/pubs/policy/National_Disability_Insurance_Scheme/Documents/sec1.htm 28/07/2010

physical disabilities such as spinal cord injury and brain injury begin ageing earlier than the general population, and that a range of health conditions worsen with increased duration of disability.[2]

Demand greatly exceeds the supply of funding. A number of pertinent documents such as Treasury's Fiscal Strategy report (Budget Paper No. 6, 2005) the NSW Government's *Towards 2030* plan [3] detail the challenges posed by the ageing of the state's population. In recognition of this PDCN and COTA advocates that Treasury ensure that growth in funding for ageing programs are commensurate with any growth in the ageing population of the State. Proportionate increases in funding to ageing services in tandem with the growth of the ageing population will provide outcomes in line with the government's prevention and early intervention strategy.

ADHC provides a wide range of services to people with an intellectual and developmental disability and some to people with a physical disability in NSW. PDCN and COTA acknowledge that the current levels of funding for ADHC services reflect increases over the last five years, in part because of the *Stronger Together* program. The *Stronger Together* program has worked to increase the amount of accommodation services available, increase respite care and give more children access to early intervention services.

Accommodation and respite

Data indicates that the increase has not been sufficient to address unmet need in the state. For example, in their article "No place for our loved ones to go" Working Carers state that "last year there were 1700 requests from carers already in crisis seeking supported accommodation for their loved one with a disability. Only 112 places were available".[4] This shortage is mirrored in respite care with Australian Institute of Health and Welfare estimating, that in 2005 unmet need was at just under 8000 places. This means that despite the increase there is still a large amount of unmet need for respite and accommodation in NSW.

Services are generally focused on the age group of 1-65 after the age of 65 a person with a disability loses access to disability services and gains access to aged care services. There continues to be uncertainty as to how this will be implemented. The ageing population will have a significant impact on the disability services, particularly in the areas of accommodation and respite care as the informal carers of people with a physical disability get older. This is supported by ABS data which states that in 2003 over 35 percent of carers where over 65. Further, they state that 29% of informal carers fall between the age range of 35-54[5]. The data available suggests that within the next 20 years an increasing number of informal carers will become too ill to care for their children/partner or family member with a disability. In research

---

[2] Australian Institute of Health and Welfare (2000) Disability and Ageing- Australian Population Patterns and Implications P. 39
[3] ABS, 2008, '4106.1, Population Ageing in NSW, 2008', *Australian Bureau of Statistics.*
[4] Working Carers (2009) http://www.workingcarers.org.au/carer-stories/1051-no-place-for-our-loved-ones-to-go-
[5] Australian Bureau of Statistics (2003) *Disability, Ageing and Carers: Summary of Findings*
http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features12003?OpenDocument

conducted by PDCN[6] into the impact of ageing on the needs of people with physical disability, many respondents identified that the ageing of their informal carer was one of their main concerns.

In a study conducted by the Department of Families, Housing, Community Services and Indigenous Australians (FAHCSIA), to determine the most desirable models of care for young people currently living in nursing homes, there was strong support for the need to provide individual and person centred practices, with the flexibility to take into account changing needs of individuals. Additionally it was suggested that individual funding plans needed to be targeted and well structured, particularly for people with progressive conditions as reflected in the following statements: *'Residents are supported to live as independently as possible with continuing community access and choice and control over decisions as long as they are able to do so.'... 'Accommodation should be safe, secure and supportive.'* [7]

Younger people with disabilities with early signs of ageing are often unable to access the services of the Aged Care Assessment Team (ACAT) due to a lack of clarity within the Community Care guidelines. [8] With proposed reforms where only people 65 years or older will be eligible for aged services, it will become even more unclear about the most appropriate service to seek for advice when the person has premature ageing, is less than 65 years and has a disability.[9]

Approximately 12% of people living in cared accommodation (hospitals, homes for the aged including nursing homes and aged care hostels, cared components of retirement villages, and children's homes.) were people with physical disabilities. [10] Aged care residential facilities are not an appropriate option for younger people with disabilities, though they are often the only option available to young people with high or complex support needs, such as people with acquired brain injury.

The ageing of the caring population is highlighted in the Auditor- General's report on respite care where they state "ageing carers present a growing challenge for government as their capacity to provide care diminishes over time. At least 13% of carers in NSW, and more than 20% in the Hunter and Southern regions, are over 65 years old."[11] The impacts of this can be seen in the steady increase in the request for respite over 60 nights from 201 in 2006-2007 to 327 in 2008-2009, an increase of 64%[12].

---

[6] Physical Disability Council of New South Wales (2009) *"Impact of Ageing on the Needs of People with Physsical Disability"* Glebe

[7] Australian Government Department of Families, Housing, Community Services and Indigenous Australians 2006 'Helping Younger People with Disability in Residential Aged Care'

[8] Alt Beatty Consulting (2005) Eligibility to Community Care

[9] Council for Australian Governments (2010) National Health and Hospitals Network Agreement

[10] Australian Institute of Health and Welfare, 2003, Disability Series – Disability Trends and Prevalence'

[11] Auditor-General's report performance audit (2010) *Access to Overnight Centre-Based Disability Respite* p10

[12] Auditor-General's report performance audit (2010) *Access to Overnight Centre-Based Disability Respite* p14

In addition to the physical concerns of unmet need there are additional future concerns with how ADHC will meet the needs of clients in the future. As mentioned in the NCOSS pre budget submission around 1700 people with a disability are living in large residential facilities and there are plans to develop more such facilities in NSW. PDCN and COTA oppose the development of such facilities and support the NCOSS position of the development of smaller accommodation options dispersed throughout the community.

The information available suggests that the services that ADHC provides are under extreme stress particularly accommodation and centre based respite. Further, an understanding of the shifting demographics of the informal care sector combined with the upward trend in need for respite and accommodation over the past 3-4 years suggests that the pressure on ADHC will only deepen as more families vie for the specialist disability services that ADHC provides.

Attendant care and therapy services

The increase in need for respite and accommodation is mirrored in increases across other services provided by ADHC, such as attendant care and therapy services. Attendant care is particularly important because, as suggested in figure 4.11 of the 2009 Australian Welfare report, attendant care users have increased 12% over 2006-2007.[13] This suggests that a growing number of people with a physical disability are using attendant care programs to remain independent. Indeed, for many, attendant care is vital for them to live ordinary lives. Use of attendant care enables people with physical disability as it is possible to experience: greater flexilibility in their lives; a more individualised program; more significant contact with staff; easily organized changes to service type and times. What this means in real terms is that people with physical disability if they choose to, are able to live independently, work in regular jobs, fulfil educational goals, attend social engagements and be included in all aspects of life. PDCN and COTA are of the opinion that this steady increase will mean that demand for attendant care will far outstrip supply in the next twenty years, preventing people who could contribute meaningfully to society from doing so.

The lack of services available therapy services is of significant concern to children with a disability and their parents. In a specific issue consultation conducted by PDCN in 2010[14] many indicated that they had to spend in excess of a month waiting for services. One parent of a child with physical disability stated "*we have just managed after 4 years to get Occupational Therapy to start this year*"[15] Another parent stated "*My 7 year old son has been waiting 7 years to see a speech therapist. He has never seen one*"

[13] Australian Institute of Health and Welfare Disability support services 2007-2008 figure A1.26 p124
[14] Physical Disability Council of New South Wales (2010) *Specific issue consultation: " Education for Students with a Disability"* Glebe
[15] Physical Disability Council of New South Wales (2010) *Specific issue consultation: " Education for Students with a Disability"* Glebe

HACC services

Discussions of the ageing population are commonplace today. Projections of people aged over 65 and 85 are included in these discussions but an investigation of the cultural and linguistic layers of the population of NSW uncovers some interesting patterns. The Australian Bureau of Statistics' *Population Ageing in NSW* Report of 2008 explains that over 50% of people born in 'Hungary, Italy, Latvia and Slovenia' were aged over 65 in 2006. This contrasts strongly with the 12% of people born in Australia who were aged over 65 in 2006. Examining waves of immigration indicates that distinct cohorts of older people are now, or will soon be, reaching an age where they are likely to need age related services such as Home and Community Care (HACC). As the cultural and linguistic diversity of NSW' older population changes and larger numbers of people from China, Korea, Lebanon, India, Iraq and Fiji reach sixty five in higher numbers, services will need to be resourced to respond. Sources from the sector tell COTA NSW that there is a need for additional levels of support such as funding for interpreters and cultural competency training to meet both current and emerging needs. Arguably we are also seeing the ageing of Gay. Lesbian, Bisexual, Transgender and Intersex (GLBTI) communities whose needs are often unmet in a range of aged services settings, including HACC.

In research conducted by PDCN during 2008-2009 of people with physical disability who were over fifty years of age[16] found that Home Care provides about half the assistance for personal care and domestic care (50%) to people with physical disability. Two percent of people reported assistance through the Attendant Care Scheme. A small number of people (2%) reported assistance is received through a residential facility. The use of Meals on Wheels was also reported by 2% of people surveyed.

A recent report[17] by the Men's Health Information and Research Centre at the University of Western Sydney identified a range of access barriers to HACC services by older men in general and vulnerable and frail older men in particular. The report identified that while older men represent 45% of the older population, only one third are HACC service users presenting enormous challenges for services to be more responsive to the needs of men. Older men tend to be largely unaware of services available to them or the eligibility requirements to access help. Men actually feel ashamed to seek help; this is exacerbated by feminised or male unfriendly environments in programs. Ultimately men related better to their peers or other men and the current female domination in community aged care can be a barrier to receiving services.

Home and Community Care program has resorted to compulsory triage assessments and prioritising of clients due to the demand in the community which is so great in some HACC programs that waiting lists of unmet needs have become a standard operating procedure for

---

[16] Physical Disability Council of NSW (2009) *"Impact of Ageing on the Needs of people with Physical Disability"*
[17] "Older men and Home and Community Care Services: Barriers to access and effective models of care". *MHIRC, UWS,* 2009

organisations. For example, essential Health Related Transport (HRT) is booked out in the Eastern Sydney Region and long waiting lists occur on a daily basis. People are refused service simply because there are no more available vehicles and workers available to deliver the service required. People are unable to access HRT for kidney dialysis; others cannot access HRT for chemotherapy. HRT is booked out months ahead, and others are denied access to specialists, clinics and therapy due to the fact that there is no spare capacity.

Recommendations: Funding and the impact of ageing on already high levels of unmet need

1.1 Proportionately increase funding to ageing services in tandem with the growth of the ageing population will provide outcomes in line with the government's prevention and early intervention strategy.

1.2 Increase understanding and awareness of allied health professionals of issues regarding the early onset of ageing on a person already with a disability regardless of age of onset.

1.3 Support existing COAG reforms aimed at relocating existing residents with disabilities younger than 65 years from aged care residential facilities into community based accommodation with appropriate supports. Additionally developing strategies aimed at preventing the premature admission of young people, below the age of 65 years into cared accommodation.

1.4 More funding must be made available for programs that aim to increase awareness of aged care services among CALD communities, and for researching best models for culturally appropriate care

1.5 Conduct research in best models of culturally appropriate care and a call for less competition and more cooperation between service where funding is concerned.

1.6 Conduct research and funding for programs to ensure greater access to HACC services among older men, in particular those who are frail and vulnerable.

1.7 Increase funding for care packages such as EACH and CACPs and greater flexibility exercised within funding service agreements to enable innovative and responsive service delivery. Encourage less competition and more cooperation between services where funding is concerned.

2. Variations of service availability in metropolitan and regional areas

Professional services

In considering the availability of professional services children with physical disability and parents of children with physical disability who have provided information to PDCN have made it clear that the availability of services is highly dependent on geography, especially when the child is a school student. A person who responded to the PDCN specific issue consultation[18] who lives in metropolitan Sydney stated that they were able to access services within 2-3 weeks. In contrast, a respondent to the specific issue consultation[19] constituent who lives in rural NSW indicated that the wait times for professional services was 3 months. These highlight that the adequacy of professional services can fluctuate dramatically according to where the individual lives.

PDCN's Specific issue consultation: *"Education for Students with a Disability"* in 2010 indicated that the availability of professional services tends to be focused around specials schools as they have a higher concentration of children that require their services. A child with a physical disability remarked that in his time in an integrated school *"Physio's and OT's (occupational therapists) through the Spastic Centre had partnered with the school to offer students with a disability their services onsite"*[20]. This creates a clear allied health disadvantage for a child attending a mainstream school.

Centre based respite

PDCN and COTA have concerns regarding centre based respite. The NSW Auditor- General's report stated that "for historical reasons, respite centres are distributed unevenly across the state and the chances of getting centre-based respite depend, in part, on where you live."[21] Further, PDCN and COTA have additional concerns about the under utilisation of some respite and other services because the need for personal transport is much more prevalent in regional areas where accessible public transport is not as available. The Audit office also found that carers indicated that distance was a major factor limiting their ability to use respite. Even where a centre is close by, some carers are not able to use it. For example an 82 year old carer may not have a license or the car needed to get his son/daughter to and from a respite centre.

---

[18] Physical Disability Council of New South Wales (2010) *Specific issue consultation: " Education for Students with a Disability"* Glebe

[19] Physical Disability Council of New South Wales (2010) *Specific issue consultation: " Education for Students with a Disability"* Glebe

[20] Physical Disability Council of New South Wales (2010) *Specific issue consultation: " Education for Students with a Disability"* Glebe

[21] Auditor-General's report performance audit (2010) *Access to Overnight Centre-Based Disability Respite* p3

HACC services

Rural and remote communities struggle with minimising and controlling costs. Costs in these communities are considerably higher than metropolitan areas. Whilst rent may be cheaper in the country than in the city; other costs can be extremely prohibitive such as fuel, food and water. If the basic necessities of life in rural and remote communities are higher than service delivery costs are inversely more expensive. Simply put, it costs more in the country to deliver services.

Obtaining and retaining skilled workers and volunteers is difficult. However it has become even more problematic in rural and remote areas. It is a fact that workers are leaving the community sector due to low wages and being redeployed in other industries. There is a lack of younger people entering into the community service industry due to poor remuneration and a lack of an appropriate career path.

As the population ages there it follows that there will be fewer volunteers available and this will directly impact on organisations' ability to deliver services, especially Meals on Wheels and Community Transport, whose volunteer force are ageing. If this reducing number of volunteers is not addressed, services will close and ADHC will have to become the major service provider in the State as not for profit will become unsustainable without workers and volunteers.

Recommendations: Variations of service availability in metropolitan and regional areas

2.1 Recognise and respond to the funding disparity between rural / remote and urban based servicing

2.2 Address discrepancies and gaps between theory and practice of client centered approaches to service delivery through commitment to staff and volunteer training.

2.3 Develop strategies to address the declining pool of volunteers to ensure viability of HACC services into the future

3. The inflexibility of funding arrangements that are not person centred

Older people and people with disabilities have advocated for civic rights and have common concerns in relation to the need for mobility, transport, accessible housing and independent living [22].

COTA NSW recently held a Diversity and Ageing in Action Forum (in conjunction with the Ethnic Communities' Council of NSW, Transcultural Aged Care Services, Metro MRC and Multicultural Health Communication). The forum attracted over 150 CALD service providers to discuss the needs of CALD communities in NSW. The Forum concluded that in order for mainstream services to be more responsive, they need to embrace person centred approaches. The

[22] Priestley and Rabiee, 2002; NCAOP, 2005a in National Disability Authority, 2006)

principle of person centred care is about responding to and meeting individual needs. Adopting person centred approaches would mean responding to the sexuality, cultural, religious and linguistic needs of older people from CALD backgrounds. In a person centred environment even the complex needs of older migrants and refugees who have experienced war and trauma can be met.

In meeting individual needs, staff and volunteers need to understand the background issues affecting individuals such as sexuality, religion, culture, grief, trauma, refugee and life experiences, as well as the diversity within each community. Advice can be sought and partnerships forged with other services that can provide CALD programs. There are opportunities for CALD projects to act as an entry point to other community services.

While many mainstream services have adopted person centred approaches, there are still discrepancies and gaps between theory and practice. This can be addressed through commitment to staff and volunteer training. There is a need to highlight good practice examples and transfer knowledge of what works across services.

If ADHC is truly committed to developing a person centered approach in its policies then the client must be enabled to tailor all services (accommodation support etc) to meet their particular needs and goals. This has been accomplished to a large extent both nationally and internationally but the adoption of self directed funding models.[23] PDCN and COTA are confident that NSW could enjoy similar success if it developed services that followed this model. This would require them to:

- Be Culturally –appropriate and socially inclusive
- Be flexible and responsive
- Be supportive and enabling
- Recognise community care as a fundamental part of society that grows and develops to meet the needs of its stakeholders.

Accommodation

In relation to independent living, people with disabilities have advocated for independence from the exploitative relations of care since the 1970s. People with disabilities have also challenged the idea that reliance on others for physical help inevitably leads to loss of choice and control and have called for purchasing power over care through direct payment schemes to change relationships from those of dependence to independence.[24].

---

[23] Community Resource Unity (2009)*"Self-directed Support & Personalised Budgets in Qld"*. http://www.cru.org.au/projects/selfdirectedsupport/selfdirectedsupport.htm
[24] Morris, 1999 in *National Disability Authority*, 2006

In an effort to improve accommodation options of people with a physical disability, ADHC has established a number of new accommodation models. These are detailed in their accommodation support options paper published in January 2009[25]. ADHC suggests that the accommodation models seek to provide people with a physical and intellectual disability with options that meet their requirements for accommodation, and provide greater choice.

The large choice of accommodation options available belies the provider centric overtones to this program as the choices available to the individual are dictated by the services available. An additional issue of concern is the increasing drive on behalf of the *Stronger Together* program to provide grouped accommodation arrangements where people with a physical and/or intellectual disability are required to live together. Indeed, in the high support range the only real difference between the services provided seems to be the type of building the client is in. People With Disabilities Australia (PWD) claim that "Cluster housing models fail to promote independence and personal growth of people with disability, and are instead strongly associated with the loss of skills and the development of maladaptive and antisocial behaviours. They are also far more likely to result in the neglect, abuse and exploitation of persons with disability".[26]

Attendant care

The University of NSW conducted an independent evaluation of the attendant care program for the Department of Ageing, Disability and Home Care in 2008 The evaluation compared three attendant care funding options,: employer model, co-operative model and direct funding model.

The research found that when participants in direct funding are compared with clients in the Attendant care employer and cooperative models, improvements in outcomes are observable and included: . higher average personal wellbeing: a return to a sense of control, managing their own life and maximising independence, choice and activities; better average physical health; higher average satisfaction with physical health and improvements in pain and physical risk management; higher average satisfaction with mental health; higher average satisfaction with personal relationships; active social networks; improved family relationships; control in home – impact on partner and children; less pressure on family; more quality social time with family; improved friendships because of greater flexibility; participation in paid work, study or active in their community; better average prior socioeconomic position than some comparison clients; and higher average satisfaction with feeling part of community [27]

Day Therapy Centres

Whist the value of carers cannot be denied, it is felt that the needs of the person with a disability needs to be considered of primary importance. Services often consider the needs of the carer

---

[25] Ageing Disability and Home Care 2009 *Innovative accommodation and support options*

[26] People With Disabilities (2010) Press release "PWD challenges decision by NSW Government to redevelop institutions"

[27] University of NSW *Attendant Care Program Direct Funding Pilot Evaluation* Final Report *FOR THE NSW DEPARTMENT OF AGEING, DISABILITY AND HOME CARE 2008*

with little regard for the person with the disability. To ensure quality service, service providers need to apply the following five principles when ever delivery a service:

- Provision of person-centered services that enable each consumer to explore individual strengths and goals and work towards achieving the outcomes they desire, with security of support for those who need it.
- Culturally-appropriate, socially inclusive and sensitive to individual circumstances, social context and relationships, enabling the consumer to continue with what is important to them.
- Flexibility and responsiveness to the range of changing needs, interests and choice of consumers.
- Support that enables the positive relationship between consumers and carers to prosper.
- Recognition as a fundamental and valued part of society that grows and develops to meet the changing expectations of consumers, carers, funders and the workforce.

Nationally there is approximately 140 day therapy centres, with most located in or near aged care homes. These centres may provide a wide range of therapy services such as physiotherapy, occupational and speech therapy, podiatry and other therapies. Fees are charged at some Day Therapy Centres. Over the past thirty years many large disability service providers have stopped providing centre- based adult day care programs, and consequently the need for aged- care day therapy centres has increased. The eligibility criteria for day therapy centres needs to be clarified to ensure access for younger people with disabilities, in a similar way to the provision of ACAT services.

Recommendations: The inflexibility of funding arrangement that are not person centred

3.1 Provide services that are person-centred and enable each consumer to explore individual strengths and goals and work towards achieving the outcomes they desire, with security of support for those who need it.

3.2 Introduction of Individualised Self- Directed Funding.

3.3 Additional and targeted funding should be made available to Community Transport so they can expand their services in areas that are found to have low levels of accessible transport options.

4. The power of compliance with the auditing and reviewing process could be used to help potential service users make a choice that is right for them.

Compliance with the Disability Services Act (DSA) in the community is organic. From a provider's perspective it appears to be a constant balancing act between 'duty of care' and 'dignity of risk'. Monitoring of disability services serves a range of purposes in addition to ensuring legislative requirements are met and funding agreements upheld. Monitoring of services provides a mechanism to ensure clients' rights, welfare, and interests are safeguarded, and that the quality of service is assured.

Compliance and accountability are essential, justifiable and participatory. It's may also be onerous and invasive. The current compliance trend is responsive to funding bodies and governments not to people and communities. Community organisations, particularly ones that are multifunctional centres (more than one stream or type of funding / program), are obviously held accountable to more than one department or level of government and this is the core of the problem. *"Multiple sources of funding from several levels of government adds to the complexity of accountability requirements, which has resulted in wide spread dissatisfaction from Community Service Organisations (CSOs) regarding the burden this creates, with increased compliance costs and fewer resources for service provision."*[28] Organisations already respond to accountability through funding agreements, acquittals, financial audit reports, annual reports,. annual general meetings, regular board meetings, program reports, statistics and other diverse forms of accountability. On top of this, funding bodies and government departments are inventing their own methods and systems of accountability. For example over the last three years a CSO has undergone the following evaluations:

- Ageing Disability and Home Care – HACC Integrated Monitoring Framework for Social Support, Other Food Services, Day Care;
- Transport NSW – HACC Integrated Monitoring Framework for Community Transport;
- Department of Health and Ageing – Quality Reporting for Respite Care; and
- National Child Care Accreditation Council – Quality Assurance for Out Of School Hours Care.

Over all the one organisation has endured six accountability processes, four government departments interrogations, seven examiners, eight days of intensive onsite visits, one surprise compliance visit, six extensive written submissions, client / staff / board interviews, surveys, statistics, comprehensive evidence provision, cross examination and hundreds of hours of preparation work to meet the requirements. It should be noted that organisation passed all these compliance processes.

PDCN and COTA's comments are not related to the auditing processes itself but rather to how the information from the audit is communicated to the service provider and its clients. In general the results of the auditing process are held in confidence between ADHC and the service provider with the provider issued warnings and fines before their funding from ADHC is ceased.

[28] Just Policy. December 2009. Carolyn Wallace & Sarah Pollock. Community Service Organisations Accountability Mechanisms: Reflections of Identity and Mission?

These audits are done to ensure that a quality service is being delivered and that the processes behind complaint management and service delivery are clear and transparent.

PDCN and COTA believe that keeping this information confidential between ADHC and a service provider runs counter to the intentions of the audit. Indeed, past instances of the negative impact of secrecy in the audit results can be NCOSS Submission to the Public Accounts Committee Inquiry into the HACC Program where they state that "NCOSS cannot assess any improvement in HACC practices etc because there has been no public reporting against the Performance Review recommendations."[29] This illustrates that historically making audit and review results private hampers the ability of stakeholders to make informed decisions about a services.

PDCN and COTA are of the belief that the results of an organisations audit should be made available to their clients. This would better inform clients on how their service provider is going against the standards set by the National Disability Standards and how they are performing against other service providers in the area. This would also provide clients with a way of objectively measuring the services they receive and give them the ability to make choices regarding the service providers that they engage.

There is a need to establish an independent body to oversee and monitor the quality assurance process, and replace the current practices with a more accountable system of review and evaluation. Independence from government and community is essential. Without a robust and comprehensive monitoring framework the risk to people with disabilities is profound. There has been a systemic history of abuse and neglect; accountability must by regular, transparent and rigorous. It must be client focused, outcome driven and enforceable. The independent body must have the power to enforce its findings. Without this power there is no validity to the process

PDCN and COTA are committed to openness, transparency and accountability. The Ombudsman has traditionally had the funding and power to investigate an agency they watch over to ensure that they are functioning properly and improving delivery of services to the public. This involves acting on the complaints of the public or an employee of the agency and then making recommendations based on these findings. These recommendations were legally binding on the agency and the agency was reviewed at a later date to ascertain their compliance with the Ombudsman's recommendations.

The Ombudsman's office has undergone significant reform in recent years these reforms included: A reduction in Budget[30], a reduction in the legal powers of the Ombudsman to compel

[29] New South Wales Council of Social Services (2006) *NCOSS Submission to the Public Accounts Committee Inquiry into the HACC Program* p8

[30] Alexandra Smith (2009) *Budget cuts killing Ombudsman role* http://www.smh.com.au/national/budget-cuts-killing-ombudsman-role-20090821-etsu.html

agencies to adopt recommendations, and the absorption of other similar organisations such as the Community Services Commission

This has forced significantly cut back on the amount of complaints the Ombudsman's Office is able to process whilst expanding their role. This has its own risks in relation to the openness, transparency and accountability of all agencies watched by the ombudsman and particularly for the handling of complaints by the public. The reduction of the ability of the Ombudsman to handle complaints is of significant concern to PDCN and COTA as it is the primary means of ensuring the openness, transparency and accountability in the disability sector since the discontinuation of the Community Service Commission and replacing it with the establishment of a Disability Branch within the Office of the NSW Ombudsman in 2002. As such, PDCN and COTA fear that the Office is unable to give the disability sector the focus /attention that it requires.

There is presently not enough funding for advocacy services in NSW to perform the tasks that they have been funded for, there needs to be a commitment from the NSW Government and ADHC to Peak Bodies across the sector, particularly in relation to systemic advocacy. There are systemic problems with the current complaint handling and grievance mechanisms. Over recent years there has been a lack of organisational funding to community advocacy services, severe over demand for these services, poor recruitment and retention of advocates both employed and volunteers, and a lack of clarity to the NSW Ombudsman's role, purpose and investigative powers in regards to government services. These issues must be addressed and rectified.

Recommendations: The power of compliance with the auditing and reviewing process could be used to help potential service users make a choice that is right for them.

4.1 Establish an independent body to oversee and monitor the quality assurance process, and replace the current practices with a more accountable system of review and evaluation

4.2 Increase the powers of the Ombudsman to allow them to investigate complaints more fully and legally compel organisations to adopt their recommendations.

4.3 Provide results of auditing of ADHC service providers available to the clients of the service

4.4. Increase funding for advocacy services in NSW to enable them to adequately perform the tasks that they have been funded to perform.

The services provided by ADHC are exceptionally important to people who are ageing, and people with physical disability of all ages, throughout NSW. It is hoped that PDCN and COTA's comments will help this inquiry make the reforms to ADHC services to ensure that ADHC can better meet the needs of people now and in the future. For additional information please contact Anne-Marie Elias (Policy and Communications Manager) from COTA on 9286 3860, or Ruth Robinson (Executive Officer) from PDCN on 9552 1606.