

Submission  
No 39

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

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**NSW Council for  
Intellectual Disability**

[www.nswcid.org.au](http://www.nswcid.org.au)

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**July 2010**

**Rights • Participation • Inclusion**

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## NSW Council for Intellectual Disability

9 August 2010

Standing Committee on Social Issues  
NSW Parliament  
Macquarie St  
Sydney 2000

Dear Committee,

**Re: Inquiry into services provided or funded by the Department of Ageing,  
Disability and Home Care**

Thank you for the opportunity to make a submission to this important Inquiry. Our submission is structured to address terms of reference a)-e) outlined for this Inquiry.

New South Wales Council for Intellectual Disability (NSW CID) is the peak body representing the rights and interests of people with intellectual disability in NSW. Our Board is made up of a majority of people with intellectual disability, and people with intellectual disability are not only consulted on, but drive the work that we do. NSW CID engages in systemic advocacy and policy development, as well as providing a state-wide information service called ASKCID.

NSW CID is of the view that the Department of Ageing, Disability and Home Care (ADHC, or 'the Department') has delivered many quality services to people with disability in NSW. Many of its programs, or the services that it funds, show innovation and demonstrate quality. NSW CID is also of the view that there is substantial room for improvement particularly in regard to the level of funding provided by the NSW Government to the disability sector, as well as the quality of client focus demonstrated across the board by the Department. We hope to elaborate further on these points in our submission below.

NSW CID would be pleased to have the opportunity to submit oral evidence if required. Please contact NSW CID on [redacted] should you require any additional information or wish to discuss this submission further.

Kind regards,

Carol Berry  
Executive Director  
NSW Council for Intellectual Disability

## Terms of Reference

### a) The historical and current level of funding and extent of unmet need

*Services that ADHC provides.*

The ADHC client population is diverse, and incorporates clients with a wide range of disabilities receiving a correspondingly broad range of services. For example, in the 2007-2008 period the following statistics were recorded about the ADHC client base:<sup>1</sup>

- the most common disability was an intellectual disability (55 per cent reported as having this condition). Physical disabilities (23 per cent) were also common;
- many clients have more than one disability, with 45 per cent of clients having two or more disabilities;
- clients had a diverse range of support needs — 17.8 per cent of clients had high needs, 20.6 per cent had medium needs and 61.6 per cent had low needs; and,
- on average clients accessed 2.1 services from a ADHC operated or funded service. The average number of services received by clients varied significantly on the basis of a range of factors, in particular age and disability type.

The Department of Ageing, Disability and Home Care delivers services, or funds NGOs to deliver services, in a range of areas.

These areas include:<sup>2</sup>

- **Accommodation services**

Some of the accommodation services funded by the Department include large residential centres (over 20 people), medium residential centres (7-20 people), hostels, group homes (under 7 people), attendant care, in home accommodation support, alternative family placement and other accommodation support.

It is important to note at this point that NSW CID objects to the NSW Government's program of constructing or supporting the re-development of large residential facilities (residences of over 20 people referred to above), where international

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<sup>1</sup> The Allen Consulting Group, *Choice and Control*, Draft report to the New South Wales Department of Ageing, Disability and Home Care (DADHC), September 2009, pg 93

<sup>2</sup> Ibid, pg 7

trends demonstrate a need to move in the opposite direction to fulfil relevant human rights obligations – ie. large residential centres are being closed down.

NSW CID is of the view that there are many people in NSW currently living in institutions who could be supported to live more independently in community based settings. NSW CID is strongly supportive of people with disability being supported to live in the community, like everyone else, rather than in large congregate facilities. NSW CID is also of the view that a community based option for many current residents of large residential facilities may be more cost effective. In other words, NSW CID is of the view that a greater number of people could be supported to live in the community if the Government was more creative with the funding dollar.

For example, average service costs vary significantly based on the type of accommodation resided in by clients. Clients in 24-hour accommodation have an average service cost of \$165,544 per annum, whereas clients living in their home have an average service cost of \$32,727 per annum.

Clients in 24-hour accommodation with low overall support needs have an average total service cost of \$165,713, compared to clients with high overall support needs having an average total service cost of \$170,313. There is very little difference here, and yet people with low overall support needs may not always require 24 hour assistance.<sup>3</sup>

NSW CID is of the view that there are many people currently living in institutions in NSW who could be supported to live more independently in the community, or in smaller, more individually focussed settings. This would be beneficial in terms of the new challenges and opportunities that could be provided to these individuals and may present a cost saving exercise for the Government in the longer term.

- **Support in the community**

Some of the support services provided by the Department in the community include individual therapy services, early childhood intervention, behaviour/specialist intervention, counselling services, regional resource and support teams, case management and other community support such as learning and life skills development, community participation and transition to work, as well as recreation and holiday programs.

- **Respite**

Respite services are delivered by the Department as own home respite, centre based respite, host family respite or peer support respite, as well as flexible or combination respite.

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<sup>3</sup> Ibid, pg 97

- **Employment**

Employment support can be delivered in the context of open employment, supported employment or a combination of open and supported employment:

- **Advocacy**

The Department funds some advocacy services to deliver either individual or systemic advocacy services, information and referral services or a combination of these.

It is possible to identify popular service combinations of those described above. In 2007–08 the top three service combinations were (note: use of advocacy services were not included here):

- respite services and community support services (19.9 per cent);
- community support services and community access services (19.7 per cent);
- accommodation support services and community access services (19.3 per cent).

In comparison, in 2003–04, the top three service combinations for the total population were:

- accommodation support services and community access services (27.0 per cent);
- accommodation support and community support services and respite and community support services (both 23.0 per cent).<sup>4</sup>

The change in popular service combinations suggests client movement away from accommodation services towards respite services and community services. This would seem to be in line with current Government objectives that people with disability be supported to live in their own home.

The *Stronger Together* strategic direction aims to build the capacity of people with disability (their families and carers) through a person-centred approach to disability services that will focus on delivering good outcomes for people with disability.

The aims of the NSW *Stronger Together* strategic direction include a person-centred approach to delivery of public services, underpinned by:

- fair and more transparent access;
- helping people to remain in their own home;
- linking services to need;
- more options for people living in specialist support services; and
- a sustainable support system.<sup>5</sup>

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<sup>4</sup> Ibid, pg 95



*The challenge of accessing services and unmet need in the community*

The impacts of a disability services environment operating well extend beyond outcomes to individuals, their families and government, to include benefits to the community and economy in general. Benefits of a well-functioning disability services environment are participation and employment of service recipients, community and family connectedness, the sustainability of care relationships, the improved quality of services and social equity.

It must be noted from the outset the NSW disability support system is characterised by being a crisis driven system, which responds reactively, rather than proactively, to need in the community. Many families feel that they swing from crisis to crisis, rather than ever feeling in control or appropriately supported by the Government. If greater autonomy, information and power were in the hands of people with disability and their families rather than the Government, we may begin to see some change in this dynamic, however, we note that the solution to this issue cannot be over-simplified. Additional and appropriate funding of the sector would also go a long way to addressing the current crisis driven/reactive focus of the sector.

Prior to people with disability receiving services, an intake and assessment process together with case management services are used to determine the eligibility of individuals for specific formal services and to identify the appropriate mix of services required to meet the needs of a person with disability. These two mechanisms are also used to balance the needs of people with disability within budgetary limitations.

NSW CID regularly receives complaints about the fact that information coming out of the Department about services that are available is quite unclear, and that accessing services or funding that is available can be a complex and onerous process. For example, at present, many people complain that there is a lack of information regarding eligibility for services and service capacity in different areas.

This lack of clarity in regard to clients accessing ADHC services is a major problem, and a great source of frustration for clients.

The Department undertook some work to improve their client intake, assessment and eligibility processes but as far as we are aware this work has stalled. If the Department is genuinely committed to becoming a more client-focussed body in the delivery of the second phase of Stronger Together, this must become a matter of priority.

In regard to helping people to remain in their own home, a number of clients of ADHC have noted that there are insufficient services available for people under the current structure (as reflected in long waiting lists), and that if in-home services are not improved they would have to seek accommodation services for the people in

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<sup>5</sup> Ibid, pg 9

their care. Further, carers have mentioned that more flexible respite services are necessary to assist carers to continue their role, so that the person in their care can remain in their own home for as long as possible.

In regard to linking services to need, many members and service providers alike have highlighted to our organisation that services could be more flexible and better focused on the needs of the person with disability.

Therefore, availability of respite is a major issue for recipients and their carers. Many of our members and people who call our organisation have reported that the inability to access respite can lead to the point where families are so stressed that they consider 'dumping' the person with disability or at a hospital.

In May 2010 the Auditor-General presented a report to the Parliament of NSW titled *Access to Overnight Centre-Based Disability Respite*. Whilst it did recognise that ADHC was providing more respite and managing it better than it has previously, some of the key findings included key points such as:

- there is no consistent needs-based approach for determining who gets respite and how much they get
- ADHC and NGO respite centres could be used more efficiently
- ADHC is increasing the number of people using respite so as to help carers support them living at home. But ADHC targets do not provide guidance as to how the respite resources are to be allocated
- ADHC does not maintain data on the occupancy rate of NGO beds
- ADHC does not have a coherent way to prioritise clients<sup>6</sup>

Aside from the issues with respite, there are other obvious needs in specific areas. There is still major unmet need in appropriate supported accommodation. We receive many calls from the community about this. There are also needs in other areas. For example, many of our members are concerned by the impact of the education system on children with a disability, in particular transitional issues into school and out of school that results in access to less services (for example, a significant drop in access to disability services (provided by ADHC and within the education system) in the time immediately after a person with disability leaves school.

It must be noted that many people with disability are not eligible for ADHC assistance, where families may feel they could substantially benefit from Government support and assistance in this area. This is a substantial area of unmet need which is extremely difficult to quantify. Many families who, from the outset,

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<sup>6</sup> The Audit Office of NSW, "*Access to Overnight Centre-Based Disability Respite*", May 2010

would seemingly definitely qualify for some form of Government assistance, simply do not. This is an issue which a substantial funding investment may begin to address.

NSW CID is of the view that there are many people in the community who feel that the services they currently receive are insufficient to meet their needs, or that they are not currently accessing services they feel they require in order to meet their needs.

There have been clear improvements in the funding level committed by the State Government to the disability sector over the past 10 years. However, unmet need is still prevalent in the community, through difficult to exactly quantify, as we have outlined above.

It is clear to NSW CID that there is significant unmet need in accommodation services, therapy places, respite and advocacy. The Government has had a strong focus on employment in recent times, which is to be commended. Having said this, many capable persons with disability in this state are still either unemployed, or under-employed. There is a lack of reliable data to assist the Government in drawing accurate conclusions in regard to the level of unmet need in the community. NSW CID would draw the committee's attention to the Australian Institute of Health and Welfare report on *'Current and future demand for specialist disability services'*, produced in 2007.

In funding terms, comparatively, NSW commits less in its disability budget to other jurisdictions. This situation should be remedied as a matter of urgency.

NSW CID notes that there is some uncertainty around the level of funding that might be committed to the roll out of Stronger Together phase two by the current Government, and the Opposition at this time has also not made any commitments. This is an issue of concern to people with disability and their families as there is already a substantial amount of concern with the quality of service delivery within current budget commitments, and how effectively unmet need is currently being met and managed.

**b) Variations in service delivery, waiting lists and program quality between:**

**i. Services provided, or funded, by ADHC,**

In regard to callers to our service, we cannot report that there does not appear to be a clear systemic difference in the quality of service provided directly by ADHC, or by services funded by ADHC, or at least, in our view, there is not be enough obvious difference between the two to draw any useful conclusions. Other services may be able to provide greater detail on the clear differences, if they exist.

The only thing we would be prepared to report on here is that there does appear to be some benefit in smaller NGOs being able to deliver more client focussed and flexible services to meet the individual needs of their clients. This certainly seems to be the case in regard to accommodation services.

**ii. ADHC Regional Areas**

Similarly, there is so much diversity across the board that it would be difficult to draw any useful conclusions here. However, NSW CID has received reports from our membership that where people have more from one ADHC region to another, it has been perceived that better and more accessible services have been received. It seems inappropriate that there should be inequity within the Department's service provision in different regional areas.

There are substantial inequities, as reported through our membership, between the quality and diversity of services available in city areas, and regional and rural areas. This disparity also should be addressed as a matter of urgency.

In regional areas it is often difficult for people to have a choice in services, due to smaller population groups and availability of a workforce. An example of this is the Community Participation Program, whilst there may be numerous providers listed in a region or an LGA, often they are not operational as they require a minimum number of service users to make it a viable option to. As such a young person may access Community Service A for 2 years and when they are unhappy with the service there is nowhere to transfer to, leaving the option of using a service they do not like or dropping out of the program entirely. In some regional areas there are options in providers, but the smaller provider cannot always offer transport or as many hours due to a smaller pool of money being available. Parents often ask why their child is not receiving as many hours as what they had been promised.

ADHC has been somewhat responsive to this area with the Self Managed Model of the Community Participation Program. We encourage the expansion of this program as we believe these initiatives offer more flexibility and empowerment for people with disabilities. The program has enabled people to be more creative and tailor

support around their actual needs. Notwithstanding that the services involved in the pilots of these programs indicate that much could be done to support capacity of individuals to manage such programs as well as making the intermediary process easier or in some instances redundant.

In regard to respite, people living in rural and regional areas complain the services are almost non-existent in some communities and that when travel was involved, a great proportion of the respite care is taken up in travel time.

**c) Flexibility in client funding arrangements and client focussed service delivery**

There is much work to be done by the Department in this area. Whilst the Department is taking steps towards more flexible funding arrangements, such as undertaking a number of pilots where funding has been 'flexed up', further progress needs to be made before the Department can claim to have achieved flexibility in client funding arrangements in any substantial way.

The Department is also exploring ways of being more person centred, therefore more client focused, but progress on this path has been slow and more progress needs to be made in order to bring NSW in line with other jurisdictions, both in Australia and internationally. Much work could be undertaken by the Department to make it a more client-focussed and person-centred organisation.

Internationally, there has been a shift over previous decades in how people with disabilities receive services from governments. In many jurisdictions, the expectation that people with disability will be the passive recipients of services has passed. There is now a recognition that people with disability and their families want more control over their lives, and to exercise greater choice in the services they receive. Many jurisdictions in Australia and internationally have been thinking more creatively about how people with disability can exercise greater autonomy and flexibility in how they participate in service delivery. Whilst the Department is altering its language and apparent focus, NSW CID remains concerned that the Department is yet to make the essential paradigm shift in its perception of people with disability and their families in regard to making funding arrangements more flexible and client focussed.

For the purposes of addressing this particular focus of the Inquiry, NSW CID has assumed that the Inquiry is considering 'flexibility in client funding arrangements' to mean initiatives like 'individualised funding', 'packaged support' or 'self-directed support'. We are also assuming that the Inquiry is including the notion of person centredness when considering the Department's performance in regard to 'client focussed service delivery'.

An individualised approach to service delivery can be defined as the provision of services linked to individual need that may well change over time. This approach also encourages and recognises that people with disability and their families are the experts in their own lives. It assumes capacity, and self-determination as important foundations of this approach. It encourages people with disability to play a significant role in determining the services they receive, and tailors funding packages accordingly. This approach recognises that individuals should be able to access relevant support to assist in planning and management of funding packages. This approach assumes that the person can either manage their own funds, or can elect for assistance through a funding intermediary. It is important that this intermediary be independent of relevant service providers wherever possible to avoid conflicts of interest. This approach also factors in the informal as well as formal supports that

are currently available to a person with disability and how those supports can be sustainably expanded where this is considered a priority.

NSW CID would like to draw the Inquiry's attention to a recently released report entitled 'Effectiveness of individual funding approaches for disability support' which has been prepared by the Social Policy Research Centre (UNSW) at UNSW, and commissioned by the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The new SPRC report has found that individualised funded allows people with disabilities to have greater independence, specifically in regard to accessing support services, which has been found to significantly improve their quality of life.

The report shows that people with disability who have switched to using individualised funding – where a person is allocated a defined funding package to spend on services of their choosing – have been able to meet their life goals by employing their own support workers to help them engage in social activities and by purchasing non-traditional items such as art equipment.

The report also found that most Western European countries and parts of North America are moving towards this funding approach but Australia, with the exception of some states, is still lagging behind. NSW is an example of a state that is lagging behind in this area.

The main benefits from adopting an individualised approach derive from the fact that it is person-centred. This requires a more flexible and targeted approach to the provision of disability services which better meet an individual's needs. At the same time, it can lead to better utilisation of a range of resources.

An individualised approach is particularly appropriate for the NSW disability services environment given that a person-centred approach is one of the key objectives of the *Stronger Together* strategic direction.

#### **d) Compliance with Disability Service Standards**

Compliance with Disability Service Standards is reported by our members and caller to our service to still be a major issue. We would encourage the Committee to examine this issue closely, as recommendations in this area will be particularly important.

The standards are often referred to by parents or carers when they are trying to make improvements to the services their family members are using. Many are often exasperated and express the standards are useless as they cannot be enforced. The sentiment is also expressed that they are used in a fashion that is restrictive rather than which is of course the original intent of the standards.



e) **Adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services**

Clients have reported through our information service that complaint-handling and grievance mechanisms within the Department are poor.

Many of our members and callers to our organisation have systemic complaints about the Department, but the Department seems to have few effective mechanisms and limited motivation to channel these complaints toward improved service delivery.

For example, key systemic complaints include:

- A lack of a client focussed approach, for example, the current intake and assessment process does not allow for people with disability to know the funding level that is set aside for them individually, or to be communicated in a way that they can easily understand (such as service hours, where appropriate). Many clients of ADHC have reported that they find working with the Department extremely frustrating, there appear to be some systemic issues within the organisation that need to be addressed as a matter of urgency, particularly in regard to internal communication, and communication with the client base
- A lack of information, particularly regarding the services that are available and the different methods that could be used (including a person-centred approach) to receive services in a more flexible way
- A lack of planning and management services (including case management). This could be linked with better information this would help people with disability (including their families and carers) to access services that will best meet their needs

NSW CID is of the view that individual advocacy services in this state need to be expanded as a matter of urgency. This would only add to improvements in the system, especially if an agency were funded to undertake individual advocacy and then collate issues into groups to allow for systemic feedback to the Department specifically. This would lead to improved service provision and client satisfaction, especially if the Department also improved its own internal mechanisms in line with advice provided from an independent source.

## **Concluding Remarks**

NSW CID recognises that under *Stronger Together*, the NSW Government has some clear objectives to improve the lives of people with disability in this state. We do not doubt these general motivations, and consider the *Stronger Together* document to be clear in its objectives. However, there are some areas in which the Government's performance has fallen down and needs improvement.

NSW CID is of the view that the work of ADHC could be improved in a variety of areas, as outline in our submission above. In general however, we applaud the Government for its increased funding commitments over the past decade, however, this commitment needs to be expanded and improved.