

## NSW Council for Intellectual Disability (Submission No.39)

Ms Carol Berry, Executive Director

*Additional written questions on notice:*

- 1. Evidence provided at the Committee's earlier hearing suggested that there were approximately 460 NGOs providing disability services in NSW. It was debated whether there is a need for such a large number of organisations. In your submission you praise the ability of smaller NGOs to deliver more client focussed and flexible services (page 11). In your opinion is the current number of NGOs viable? And what would you consider to be the 'right mix' of large and small NGOs?*

We are not in a position to comment on whether the current number of NGOs are viable in a financial sense. Where we do feel qualified to comment is to say that smaller NGOs can often deliver a more personalised and community-based service so their importance cannot be under-estimated. We do not believe in mergers simply for the sake of reducing the number of NGOs that exist for efficiency purposes, as quality and personalised service can be compromised in this process. Where there is clear doubling up of services being delivered, there may be a good argument here for reducing the number of NGOs in any particular region for efficiency purposes. However, numbers of NGOs alone may not be the only consideration in determining the availability of quality services across the state. The 'right mix' of large and small NGOs depends on the size (population-base) of the region and how well placed certain NGOs are to delivering the services required in relevant regions or communities.

- 2. On page 11 of your submission you state that your members have reported there are substantial inequities between the quality and diversity of services available in metropolitan, regional and rural areas. Can you please tell us which services and programs you have identified as being delivered inequitably between metropolitan, regional and rural areas?*

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 audit findings were as follows:

- "there is no consistent needs-based approach for determining who gets respite and how much they get" (p3)
- "ADHC and NGO respite centres could be used more efficiently" (p3)
- "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" (p9)
- "ADHC does not maintain data on the occupancy rate of NGO beds" (p3)
- "ADHC does not have a coherent way to prioritise clients" (p12)

The difficulty in gaining access to individual advocacy in rural and regional areas is also problematic. 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, where there may be numerous providers listed in a region or an LGA, but they often they are not operational as they require a minimum number of service users to make it a viable option to deliver services. As such a young person may access Community Service A for 2 years and when they are unhappy with the service there is no-where 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 some-what responsive to this issue 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.

*Also, how could ADHC and NGOs work together to develop a more equitable provision of services throughout NSW?*

Much consultation is undertaken with NGOs, through regional and metropolitan forums, and this has been well resourced by ADHC, however such extensive consultation with people with disabilities does not occur, largely due to insufficient funding.

Further to this, there is little support of initiatives that promote self advocacy and leadership opportunities for people with intellectual disabilities. Good governance mechanisms need to be promoted and encouraged such as the proper supported participation of people with disabilities in the management of organisations. NSW CID is unique in that the majority of our Board have intellectual disability – ensuring that our work is very representative of their interests. The sector should be striving towards this if they are indeed person centred and focused. This would not only contribute to the voice of people with intellectual disability being more valued, but would also assist in the review and monitoring of services – outcome measures would be meaningful to those who actually use the service.

There also needs to be a commitment to capacity building of advocacy networks, similarly to the industry development that is occurring for NGOs. Advocacy agencies and information services will have an increasing role to play in providing essential support for people as the sector moves towards a massive paradigm shift – such as a lifetime care and support scheme and increased self directed options. For self directed funding to be successful people with disabilities will need access to information, practical guidance and peer support. Advocacy agencies will be able to facilitate this if they have been able to prepare - such as providing additional training for staff, creating stronger networks and information sharing between agencies (especially for agencies operating in regional areas), conducting research, and importantly building the capacity for people with intellectual disability to be able to self advocate more effectively. Funding for this process needs to be recurrent and secure to ensure that advocacy is available when needed and future planning can occur.

The Local Area Coordination (LAC) program in Western Australia and the Department of Human Services in Victoria have already developed much learning, policy and practice in the making the shift to self direction and strengthening community and informal networks. In addition internationally much evidence and learning has already occurred in the areas of self direction that address many common concerns regarding assessment, eligibility and safeguards.

3. In your submission you raise concerns that your members often feel exasperated by service providers that do not comply with Disability Service Standards. Also, that the Standards are often expressed in a restrictive fashion (page 15).

The best example of this is that 'duty of care' is often interpreted very restrictively, limiting opportunities for greater flexibility and more responsive service delivery. Staff are often poorly trained in how to manage risk, or how to teach enabling skills. We get many calls from staff involved in service provision who are interested in further training as to how to teach relevant skills to people with disability. They clearly want to develop their practice of teaching skills or enabling people with disability in their relevant workplace but feel restricted in doing so.

Can you please elaborate on this argument and without providing specific details, tell us of any service providers that are not complying with Disability Service Standards? How do you think breaches of Disability Service Standards should be handled?

Members of NSW CID have participated in reviews and consultations regarding service delivery and Standards for many years. Largely the general summary of such consultations is that while the Standards intentions are good, there is problem with their implementation. Comments from people with disability include:

*"Places do not always follow them and there is not enough money to put them into place."*

*"Some people don't know what the standards are or how they even work."*

*"It is hard to complain to the people who are giving you the service."*

Some members of NSW CID, including people who have spent some of their life in institutions, feel strongly that the Standards do not work, one member giving a very clear message - *"if they 'get it' – why is it that people are still locked up – why are people still being abused – why are people not getting the choice they need to have and getting a decent life."* The 'they' being referred to is ADHC and the NSW Government.

Further to this, 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.

Decision Making and Choice (Standard 3) is a standard that members reflect is not being implemented in practice. Whilst some people with intellectual disability report that they are able to make choices about some smaller aspects of their lives there is not much opportunity to make choices about bigger issues – like who they live with or where they live.

4. *Your submission addresses a number of complaints your organisation regularly receives about ADHC provided and funded services. How would you suggest ADHC improve its complaint handling procedures to ensure the best outcomes for people with disability?*

Numerous callers to the ASK CID service express that they are not aware of how complaints are managed, at all stages of the processes. *"Where to start?"* is a common phrase from callers, many not knowing what the process is. Even in the cases where callers have indicated that they have followed the correct procedures, it has been ineffectual - *"I don't know how many more meetings I can attend where things are actioned but no follow up occurs"* and *"I have been through all the hoops – what else can I do other than go to the Minister?"*. At times callers note that they are fearful of making complaints as they believe that it will have a direct impact on the quality of the service they receive.

In terms of specific improvements that could be more, we would suggest the following:

- ADHC website could be improved and made easier to navigate.
- There does not seem to be any readily accessible information on the complaints process on the ADHC website.
- People are unclear what the process is – it needs to be presented simply and clearly – for example, what is the hierarchy when it comes to complaints?
- Easy Read Complaints Mechanisms would be very useful for people with intellectual disability.
- A hotline would be most helpful, especially if it was independent of ADHC and had individual advocacy services were attached to it. This would assist in improving ADHC service delivery across the board.