people with disability

ABN 98 879 981 198

CSI 83   SI 10/60

1 October 2010

Ms Rachel Simpson
Director
Standing Committee on Social Issues
Parliament House
Macquarie Street
NSW 2000

Dear Ms Simpson:

RESPONSES TO QUESTIONS ON NOTICE

I am writing to provide responses to the questions on notice asked by members of the Standing Committee on Social Issues during our appearance at the Public Hearing held on 3 September 2010, as well as to provide responses to the additional questions on notice from Committee members included in the your letter dated 10 September 2010.

Questions on Notice – 3 September 2010

1. **What is your guesstimate as to the unmet need in terms of percentages?**

    PWD is unable to provide a percentage guesstimate in relation to unmet need, although we can say that 98-100% of PWD's individual advocacy clients in NSW are, to varying degrees affected by not having needs met by ADHC.

    Assessing unmet need depends on the parameters of such an assessment. Our submission highlights that there are many people with disability who are unable to access a service from ADHC because their needs are either too complex, too low or their primary diagnosis is not an intellectual disability. There are also many Aboriginal people with disability in NSW who have no contact with the service system, including ADHC although they would be eligible for such services. There are many other people with disability who are eligible for ADHC services who remain on waiting lists, or who are receiving services that are inflexible and don't address whole of life needs.

A thorough assessment of unmet need would require comprehensive research that includes population benchmarking. PWD understands that such research was commissioned in 2005 by the Minister for Disability Services at the time, and completed in 2006 but never publicly released. PWD suggests that the Committee recommend that this report be released so that unmet need in NSW can be better understood.

Despite the lack of public research into unmet need in NSW, there has been increasing recognition that the disability service system throughout Australia is unable to meet demand, it is largely crisis-driven and often unable to respond quickly and flexibly. The view that the system is 'broken' has been a key driver for the Productivity Commission Inquiry into Disability Care and Support, and PWD hopes that this Inquiry will recommend a reconfiguration of the disability support system that will not only address current funding shortfalls but also the lack of control people with disability have over the supports they receive, how they receive them and when they receive them. The latter is more likely to be addressed through an individualised, self-directed support system, which the Productivity Commission has already highlighted as a key outcome of its Inquiry. PWD argues that NSW needs to transition to such a system through *Stronger Together 2* and ensure consistency with potential national approaches to disability care and support.

2. **In terms of silos, can you give us your thoughts on the different types of disabilities that cause silos, the issue of geography, regions, and going from one region to another region there are problems with the services following you or not following you, and the State and Federal silos that cause difficulties so that you may be able to get home care but you cannot get attendant care if you have home care and all those issues that are causing problems with unmet need?**

In our submission, we provide examples of the significant problems people with disability have in obtaining a service or the same quality service if they move between regions within NSW or if they move into NSW from interstate. Service types may be different between regions and States, and State-wide guidelines and policies can be interpreted differently between regions in NSW.

The silos that give rise to these problems and contribute to unmet need are driven by the service system itself. In general terms, the disability service systems throughout Australia have largely evolved from a 'one size fits all' approach based on a person's diagnosis, with an emphasis on ensuring that limited resources can be used efficiently to provide services. More contemporary approaches to service delivery, such as individualised supports, local area coordinators, assessment based on need not diagnosis, have been implemented in varying stages within States and across Australia, so that there are significant differences in service types and approaches, with different assessment procedures and eligibility criteria between States, and often inconsistency and lack of service types between various geographic regions. The outcome is that people with disability need to 'fit' the service system rather than the service system 'fitting' the needs of people with disability.

Recently, the Australian Government identified the inconsistencies and lack of portability between State-based mobility parking schemes that lead to many people with disability facing problems when travelling interstate. While there may still be shortfalls with the new National Disability Parking Scheme established to address this situation, this new national scheme attempts to harmonise the different parking schemes across Australia so that people with disability can be assured of some consistency between these schemes.

There have been some similar approaches or agreements between States in relation to disability service provision, where people with disability who move interstate are allowed to continue funding from one State for a certain period of time until the new State disability service system can allocate services to people. However, this is not a foolproof system when the new State has different eligibility criteria and different and perhaps lower quality services.

A key way of counteracting silos is to reconfigure service systems so that the needs of people with disability and not diagnosis are the focus, supports are identified and controlled by individuals with disability and the service system and supports 'fit' people with disability and not the other way around. Such a system would mean that people with disability, rather than services would be in control of funding and supports, and the service system would need to respond accordingly. In August 2010, a number of national and State disability representative and advocacy organisations developed a joint submission to the Productivity Commission outlining key aspects of such a new system. This submission is available on the Productivity Commission website at:
http://www.pc.gov.au/__data/assets/pdf_file/0003/102756/sub0525.pdf

Additional Questions on Notice – 10 September 2010

1. **Your submission notes that ADHC regions often interpret funding or program guidelines differently (page 10). Is it feasible to expect ADHC to enforce uniformity in service delivery across its services and NGOs?**

   The issue we raised in our submission related to regional interpretations of funding and program guidelines that resulted in different levels of flexible service delivery. A regional interpretation that resulted in a more flexible and responsive service would be much more likely to meet a person's needs, than a regional interpretation that was more constrained and rigid.

   The issue is not that ADHC should enforce uniformity in service delivery across its services and NGOs, as this would constrain the ability of service providers to meet individual needs. Rather, funding or program guidelines should facilitate flexible, responsive and person-centred service delivery aimed at meeting the individual needs of people with disability. ADHC should ensure that regional staff interpret funding and program guidelines in ways that enhance flexibility and responsiveness for the individual with disability.

   In a new reconfigured service system, as discussed above in previous responses, funding and program guidelines would be developed in the context of individualised funding and self-directed supports and would focus on meeting individual needs. This would result in necessary service delivery variations based on individual need, rather than variations based on service-defined regions.

2. **In your opinion, would it be useful to further divide Metro North and Metro South into smaller areas?**

   Dividing the Metro North and Metro South regions into smaller areas may not achieve much if the smaller areas do not contain the necessary services required by people with disability. However, if necessary services are still available within a smaller area then dividing these regions may be one short-term solution.

However, the issue is more about the rigidity of the system: only being able to obtain services within a region regardless of how far away that service is from family and networks; or how close a person may be to a service in another nearby region.

A longer-term solution would focus on enabling people with disability to decide which supports and service locations are suitable for their individual circumstances; and to provide funding directly to people with disability, so they can obtain, control and direct the supports they need.

3. **The Committee has received evidence that ADHC is moving towards flexibility in client funding arrangements and client focused service delivery. Can you please tell us why you believe this change in policy direction is more likely to achieve CRPD rights?**

The CRPD reframes the needs and concerns of people with disability in terms of human rights. It embodies a shift away from social welfare responses to disability to a rights-based approach, which views 'impairment' as an ordinary aspect of human diversity and 'disability' as the result of the interaction of people with impairments with socially constructed attitudinal and environmental barriers. The CRPD articulates how existing human rights apply to people with disability, rather than granting new rights.

For the first time in an international instrument, the CRPD contains in Article 3 a list of general principles that underpin the interpretation of the substantive CRPD articles and provide guidance for implementation. These general principles are:

> "(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
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> (b) Non-discrimination;
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> (c) Full and effective participation and inclusion in society;
>
> (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
>
> (e) Equality of opportunity;
>
> (f) Accessibility;
>
> (g) Equality between men and women;
>
> (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities."
> *(emphasis added)*

CRPD also establishes engagement with people with disability as a central element in achieving human rights. The preambular paragraph (o) states that "persons with disability should have the opportunity to be actively involved in decision making processes about policies and programs, including those directly concerning them". CRPD also enshrines this element within the binding provisions in Article 4 (3).

The general principles make it clear that the rights of people with disability can only be realised if people with disability are free to make decisions and choices, and have individual autonomy and independence on an equal basis as others in society. Article 4 makes it clear that people with disability must be active in decisions about programs directed at them.

In light of this, the more people with disability have control and direction over the supports they receive, including making decisions and choices about what they need, the more CRPD rights will be realised.

4. **There has been some concern that individualised funding may lead to inappropriate use of funds. This was countered by the argument that such abuses already occur in the current system. What protections would you like to see in place to ensure individualised funding is used solely to benefit the person with disability?**

Significant research, policy and practice have been undertaken in relation to individualised funding both internationally and nationally. A number of countries have well-developed individualised funding systems in place with a range of accountability mechanisms and protections, particularly for people with disability in more vulnerable situations.

PWD recognises that their will be risks, including inappropriate use of funds in any system. This is certainly evident in the current system. The issue of concern should be how to reduce risks in a system that provides individual funds to people with disability with the intention of increasing freedom and choice for people with disability in how they live their lives.

In Control Australia, a collaboration involving individuals and agencies around Australia, including PWD, has significant practical and research expertise in individualised funding systems. The In Control submission to the Productivity Commission Inquiry into Disability Care and Support comprehensively addresses the issues of an individualised funding system, including necessary safeguards. PWD supports the views expressed in the In Control submission, and paraphrases and summarises its key points in relation to protections:

- An individualised funding system must operate from the default position that people with disability are trustworthy, and best placed to decide how they should live their lives and obtain supports;

- The system should enable government to fulfil its responsibilities in relation to public funds and protection of vulnerable people.

- The risks and benefits of individualised funding depend on the way in which the system is designed.

- Individualised funding gives control over the planning process to the people planning their own future. They have more time and motivation than, for example, a case manager with responsibility for many clients.

- The person with disability (supported when needed by family, friends, advocates) can decide whether they are getting quality from their support providers. As with commercial markets for other citizens, providers will have business and career incentives to deliver the requirements of each customer.

- A system based on role clarity, with a transparent process of negotiation to decide the amount of funding that the individual will receive, provides the foundation for a relationship of trust between government and individual. Evidence demonstrates that a system that is not perceived to be trustworthy encourages people to adopt behaviours that are wasteful.

For example, if people fear that the government will not increase the assistance they need to match a future increase in their support needs, they have good reason to 'talk up' their current needs and stockpile any money that exceeds their requirements. In a system based on trusting partnership, it has been shown that more people will work to take only what they need. This is not to suggest that breaches of trust will never occur.

- The negotiation to agree the amount of funding establishes a contractual relationship between the individual and the agency distributing funds. The individual receives the money on the basis that they are accountable for its use, with the range of acceptable uses set out in a Support Plan.

- This negotiation also provides an opportunity for the representatives of the funding agency to stipulate additional safeguards – perhaps to require that the funding is held and managed by an intermediary agency, or to require that someone has clear responsibility to monitor the delivery of supports. This does not mean that the funding agency will always be pressing for a reduction in the cost of the support plan. For example, the agency might consider that the individual has under-estimated their need for support, and so offer to increase the allocation to cover more hours.

- In all these tasks and discussions, the person with disability will have access to a range of supports. This may include the involvement of family members and other allies of the person, paid brokers and other sources of brokerage, and other community supports. There will also be a variety of 'secondary support' services that can take on the practical burden of making sure the supports operate reliably – including fiscal intermediary agents to manage the money and support coordination.

- The availability of adequate secondary supports, and the funding required for these, can also safeguard the quality and integrity of the support that the person with disability ultimately receives. This will include assistance with envisioning a future, undertaking person-centred planning, with managing finances that come to the person as a result of their agreed plan, and with the employment, training and supervision of paid staff.

- A well-funded, robust and truly independent advocacy sector is the primary referral point for people with disability for whom the new system is not meeting their needs. Independent advocacy is key to ensuring that people with disability who need support under the new scheme, get access to that support, and that the quality of that support is consistent with the identified needs of the individual. Systemic advocacy can continue to monitor the successes and shortfalls of the new scheme, and provide reports and information to the new Authority, which in turn can lead to ongoing system changes for improvements in support and full coverage in areas of neglect.

- A strong, complaints handling and monitoring body, with powers to intervene in service and support contracts, and to compel the cooperation of service providers, in order to arrive at swift and effective resolutions must be established.

PWD recommends that the Committee review the full In Control submission to inform its understanding of individualised funding systems and how they can operate in Australia with necessary safeguards and protections. PWD can provide this submission on request. The In Control website is http://www.in-control.org.au/

5. **Your submission raises concerns about the use of abusive behaviour management practices (page 17).**

   (a) **Without providing specific details, can you please tell us of any occasions where abusive behaviour management practices have been used?**

   There are many instances where abusive behaviour management practices have been used in ADHC provided or funded services. These practices may not be intentionally applied to cause abuse. They are more often legitimised through policy as restrictive practices employed as a means to bring about a change in behaviour or to prevent serious harm to the person or others. However, they cause physical pain and discomfort, deprivation of liberty, prevent freedom of movement, alter thought and thought processes, and deprive persons of their property and access to their family.

   Without providing specific details, PWD can provide the following examples:

   - A Deaf-Blind person was placed in a group home but communication needs were not addressed, which resulted in significant isolation for the person. The person began to withdraw from others and after a period began to hit her head against a wall. To prevent serious harm, the person was required to wear a helmet.

   - A person with disability who had aggressive behaviour was kept in a secure unit. The behaviour management plan required the person to be physically and chemically restrained when they were displaying aggression. Physical restraint was applied by four staff members sitting on the person until they calmed down. The person was given large doses of medications, which resulted in the person being immobile for long periods of time. This person had lived in the secure unit with these practices for many years of their life.

   - A person with disability living in a group home was obsessive about food, which was creating concerns about the health of the person. An approved behaviour management plan included a measure to keep the refrigerator locked at all times, and for support workers to provide food to the person at certain times. This not only impacted on the person but all people with disability living in the group home, who were also unable to access food.

   - A person with disability may be given large doses of medication to reduce sexually active behaviour, whether appropriate or inappropriate, within residential settings so that this behaviour does not impact on other residents.

   - A person with disability who may be at risk of coming into contact with the criminal justice system are authorised by Guardianship legislation to be placed in a secure accommodation facility under ADHC's criminal justice program and related initiatives. This amounts to civil or preventative detention.

   (b) **What alternative behaviour management techniques would you recommend in these circumstances?**

   Restrictive practices should be replaced by evidence-based positive alternatives. There is a range of evidence-based research for ADHC to draw upon in this regard.

   Behaviour management plans and programs should be consistent with evidence-based practice and achieve desired behaviour change with positive, person-centred strategies that are underpinned by respect for the individual's human dignity.

Disability support staff and families should be provided with information and skills development about positive alternatives.

In the examples provided above, positive behaviour management expertise could identify positive alternatives, but PWD suggests that such alternatives could include, but not be limited to:

- Identifying and addressing the underlying cause for behaviour – facilitating communication and engagement with others (first dot point);

- Identifying suitable medication that would enable the person to control behaviour but still engage in daily living instead of chemical restraint; and establishing a positive skills development and behaviour program for the person (second dot point);

- Establishing a positive skills development and behaviour program for the person that does not impact on other residents (third dot point);

- Providing sexuality and positive relationships training to people with disability and identifying how the person may wish to express their sexuality positively (fourth dot point);

- Establishing a positive skills development and behaviour program; providing social supports and facilitating meaningful community engagement (fifth dot point).

In addition, PWD strongly believes that negative or challenging behaviour can be a result of the environment in which people with disability are required to live. In the examples provided, some of the behaviours could have been avoided or alleviated by ensuring people with disability live in the community, within their networks and supported by family, friends and other supports. Group homes may achieve this, but in many cases people with disability in group homes are still expected to live with people they do not chose as co-residents and they are restricted by their co-residents' behaviour plans and can then develop negative behaviour responses as a result.

Residential facilities that congregate people on the basis of challenging behaviour, such as the current Lachlan Centre and proposed redevelopment, are not conducive to providing a positive environment that would facilitate positive behaviour change. This is supported by evidence that demonstrates the skills development and positive changes to behaviour that occur when people with disability are moved from such facilities to genuine community living and housing options. Such changes have included the development of communication and independent living and employment skills, the reduction of obsessive behaviour related to food and the establishment of meaningful social relationships.

(c) **How would you recommend the ADHC ensure abusive behaviour management practices are not used?**

ADHC has established an Office of the Senior Practitioner to oversee behaviour management practices, and also has policies and procedures related to behaviour management practices. However, this Office is contained within ADHC without a legislative framework or powers.

PWD believes that the regulation of behaviour management practices and safeguarding of people with disability who are subjected to these practices should lie outside the control of ADHC and be in line with the CRPD obligations, in particular:

- Article 15, Freedom of torture or cruel, inhumane and degrading treatment or punishment; and
- Article 16, Freedom from exploitation, violence and abuse.
- Article 17, Protecting the integrity of the person;

In our submission, we have provided four comprehensive recommendations that outline the legislative and institutional framework required in NSW, including the enactment of specific legislation and the establishment of an independent, statutory Office of the Senior Practitioner. In addition to these, we also now recommend the following:

- Guardianship legislation ought to be amended to explicitly provide that in no case may a provision in the Act, or an authority provided under the Act, be used to authorise a restrictive practice that amounts to civil or preventative detention of a person for the primary purpose of protecting others from harm.

- NSW legislation ought to provide that all forms of restrictive practice not prohibited must be subject to explicit approval, monitoring and review arrangements. They must be subject to the principle of the 'least restrictive alternative;' and the active promotion of positive alternatives. Moreover the legislation ought to require that any use of restrictive practices must comply with human rights related standards and be for the purpose of fulfilling a human rights related goal.

- Under the legislation evidence that the a restrictive practice has been used contrary to a direction of the Senior Practitioner ought to be designated prima facie proof that the practice is unlawful for the purpose of civil and criminal proceedings.

6. In their submission, Spinal Cord Injuries stated that "there is clear potential for ADHC funded advocacy service providers to not 'bite the hand that feeds them' (whether real or at least perceived) at the expense of a clients' ADHC related issue leading to a conflict of interest" (page 10). How do you suggest this potential conflict of interest for ADHC funded advocacy services be managed?

There are a number of key factors that can alleviate conflicts of interest such as the one stated in the submission made by Spinal Cord Injuries. PWD recommends the following:
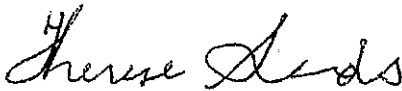
- **Funded advocacy services must be independent from government and service provision.** While this is generally the case in NSW, there are some advocacy services located within agencies (such as Spinal Cord Injuries) that also provide support services to people with disability, including accommodation services, respite, community transport etc. This is a direct conflict of interest as advocacy will be required by many people with disability in relation to the services they are receiving from the same agency.

- **Funding and regulation systems for advocacy services must be designed to protect the independence of advocacy.** For example, funding agreements and reporting requirements must not constrain the 'voice' or role of independent advocacy or confine advocacy to protecting or fulfilling government policy directions.

- **A key element to support a system of independent advocacy would be the establishment of an independent statutory body to fund and regulate advocacy**

supports in line with CRPD. This would ensure advocacy was not funded by the government agency that provides and funds service provision; and would enable funding, accountability and regulation not to be compromised by government agendas.

- **A new independent statutory body should be governed by people with disability, their representative organisations and their chosen allies.**

Thank you for the opportunity to provide responses to the additional questions required by the Committee. Please let me know if you require further clarification or information.

Yours sincerely

THERESE SANDS
Executive Director, Leadership Team