16 August 2010

Disability Care and Support Inquiry
Productivity Commission
PO Box 1428
Canberra City ACT 2601

Dear Commissioners

I write in response to your Issues Paper of May 2010. As a person with a disability and someone who has worked in the field of assistive technology for over 20 years, I welcome this Inquiry into the broad aspects of the proposed National Disability Care and Support Scheme. The consideration of a holistic approach to facilitating participation by people with disabilities in Australian society is well overdue. As your issues paper notes, the increasing number of papers and reviews reflecting not just dysfunction but in many cases crisis, indicates the urgent need for more considered action.

I believe the new scheme should seek to be as broad as possible in its focus. Many of the current failings of schemes to assist those with disabilities are due to the fragmented approach. Thus there are over nine mainstream funding schemes for wheeled mobility solutions in Australia, all with different criteria, funding levels and scope of provision. As indicated in your paper, this leads citizens to move jurisdiction (often at different times in their life) in order to maximise their access to solutions they need.

In a similar fashion, the use of diagnostic or similar classification approaches tend to create ‘gaps’ that can mean a person (usually a child) can miss out on necessary interventions and support while another with exactly the same needs but with the requisite diagnosis, is assisted. In 1984 I worked in a voluntary capacity at Royal Children’s Hospital (Brisbane). In one case a four year old boy had functional limitations that made him ‘floppy’ and in need of support during all activities of daily living – including bathing. His functional presentation was similar to cerebral palsy, yet the cause was chromosomal and so he was excluded from gaining access to suitable technology from the then Spastic Welfare League. I thus had to build the bathing unit he needed, based on plans I had sourced from colleagues at the League. In a similar way he was not eligible for the specialised early intervention therapy that may have significantly improved his prognosis. Sadly this situation continues to be repeated around Australia – even to the present when it comes to access to mainstream services.

Many schemes also have set the arbitrary age limit of 65 years. While I acknowledge that access to retirement savings or a pension can lead to different circumstances, some of the functional challenges faced by an otherwise healthy 68 year old following a CVA (stroke) can be ameliorated by interventions (assistive technology, therapy etc) that are known to be effective for a young adult following a traumatic brain injury. I thus favour the creation of functionally orientated services (eg wheeled mobility and seating) that can apply expertise to overcoming disability (in terms of the ICF definition and however caused), and be funded through whatever broad programs are considered expedient for each individual (eg aged care, disability services, workplace rehabilitation etc). Thus the emphasis is on efficiently using expertise, while administratively determining the most appropriate way to allocate and manage funding.

To my mind this enables government and the consumers to judge (and if appropriate regulate) quality and efficiency of services that can focus on delivering outcomes for all clients. Service providers can be encouraged to always be seeking ways to optimise their contribution to achieving desired client outcomes. Thus agencies can work together, facilitating one-stop-shops, be rewarded for proactive intervention that avoids co-morbidity or future delays in service delivery, as well as strategies that further empower users. It also minimises the need for those services to undertake multiple tenders, service agreements and contracts in order to offer the same service to different client groups.

There is strong evidence (as highlighted by the Interim Report and other research work – including our own through the Fremantle Collaboration) that the other facet to effective and efficient use of resources for people with disabilities is a holistic approach. Under the traditional medical models of disability, intervention was based on addressing impairment. It is reasonable to reflect that many of our schemes and approaches still work from this framework. Thus a wheelchair is approved based on its ability to address a particular mobility problem within a limited setting (eg the home). A future scheme needs to build mechanisms that empower the end user to explore and define the *outcomes* they want to achieve from a participation point of view.

The Burwood Hospital Spinal Unit[1] in New Zealand has for some years had an intervention approach that seeks to identify within 24hrs of acute admission, the future employment or other goals of people who have suffered spinal cord injury. Their rationale is that without this client centred focus, the client has no framework or target through which to judge and engage with services or interventions that are offered (or often just applied to them). Few organisations succeed without some aspect of vision or mission that sets goals for future years in a strategic plan. Several children's disability organisations are now using the Life Needs Model[2] to help guide and set longer term goals to enable such structured planning.

Armed with an up to date plan, end-users and their families/carers, as well as reviewing/funding agencies can determine the most cost (and time) effective ways to achieve those goals – drawing on all enablers and services (just as corporations have to plan resources, personnel and targets). It also permits agencies to start some planning of their own. 'Too little, too late' and the Senate Inquiry into the CSTDA (2007) have several examples where needs identified (often with substantial lead time) are not addressed in a timely way and lead to much more costly (and often traumatic) interventions. I liken it to running a car rental company that has no prebooking, only one or two car options, few outlets, and only works on a vehicle when it breaks down (ignoring servicing, cleaning and refuelling). One can only imagine the frustration and anger engendered in customers of such a firm…

Most services are chronically underfunded, but care is needed in simply putting more funds to existing approaches. I note with concern that a long standing, high quality, not for profit mobility and seating service in Adelaide is now in jeopardy because the state operated equipment scheme is now undercutting their service. This arises because emerging system

---

[1] http://www.cdhb.govt.nz/bur/bsu.htm

[2] See for example http://www.novita.org.au/content.aspx?p=528

efficiencies (in the state scheme) have reduced the demand on technical staff, and to avoid redundancies, they have now been reallocated to seating and wheelchair modification. While capable of basic modification, the staff currently lack the necessary skill, and professional rehabilitation engineering oversight necessary to reliably and efficiently complete complex systems and modifications. The service does not recognise the inefficiency it is creating, simply because it takes no account of the labour time (and cost) of their interventions.

Effective review and audit of the most cost effective approaches to delivery of services is imperative initially and then on a regular basis. This would enable monitoring and strategies to ensure the quality of service, that it is capable (on a national basis) of meeting all levels of need (including the most complex), and at locations that facilitate consumer access (including rural and remote service delivery and support). Appropriate multi-disciplinary review teams (involving professional bodies and skilled end-users) drawing on agreed evidence based guidelines and good practice approaches would be more effective than simple administrative reviews. Such review teams would also become aware of innovative practice that should be considered for broader application.

Finally I believe the new scheme needs to be underpinned with two key facets – enhanced user/consumer leadership and a broad research agenda.

Many services lack skilled and effective participation of people with disabilities in their governance or service delivery systems. While agencies are often happy to engage select consumers on ‘reference panels’ and the like, they are generally *reducing* the number of people with disabilities involved claiming they lack sound governance and leadership skills and often have conflicts of interest. Sadly very few organisations then actively work to address this limitation. People with disabilities should not be token players in leadership. The scheme, in partnership with other government and industry programs, should facilitate talented and capable people with disabilities to gain the necessary skills to take a much more active role in the leadership and delivery of services in the sector. Targets should be set (without watering down any expectation of sound governance or performance targets) for Boards, government agencies and others to increase the percentage of people with disabilities in their leadership structure and service delivery streams.

In the same way, research relating to disability, assistive technology, therapeutic intervention, universal design, caring etc is mainly done ON people with disability, and rarely BY people with disabilities. Further, there is no specifically allocated funding from any source that targets research focused on disability, assistive technology and related areas (perhaps with the exception of some telecommunications access funding out of Dept of Broadband, Communications & the Digital Economy, and some philanthropic funding schemes). Although research funding is supposedly part of the National Disability Agreement, I have never seen it allocated competitively to projects apart from improving internal administrative arrangements. Major funding schemes (eg ARC, NHMRC) often dismiss proposals from the disability sector on grounds of lack of commercial return, or insufficient numbers of the population (thus not achieving sufficient ‘significance’).

Internationally some centres (and national funding schemes) are actively seeking to address this failing. The Toronto Rehabilitation Institute (with partner bodies – including industry) has several scholarships for higher degree research that are competitively awarded to highly skilled students with disabilities. Canada, the USA (NIDRR) and several European countries (as well as the EU itself) have specific, ring fenced, funding available to investigate issues relating to a range of applied (and sometimes theoretical) aspects of enablers and issues in disability.

Several of these schemes include funding to not only undertake University or pilot project work, but also to translate the findings into useful and applied action for service providers or users. The Australian disability research sector is littered with highly successful pilot projects and research work that is then wasted because no agency or system exists to consider adoption of the findings more widely. Consumers and professionals regularly complain that they give and give to surveys, researchers and others, yet rarely get feedback or a relevant report, let alone see changes in line with the recommendations or findings. The net result is researchers abandoning the sector (or doing it in their spare time through lack of ongoing funding), and consumers in particular, unwilling to participate in any further research activities.

While I concur with the general suggestion that the future scheme should be supported in a similar fashion to the Medicare levy, I suspect others are best placed to comment on the simplest, most equitable way to incorporate the financial aspects into the taxation/welfare systems. I do believe though that many of the changes needed can occur relatively quickly and result in improved service. A broad plan that sets the goals and expectations should be established and agreed. Then an appropriate schedule and targets set to bring all the elements into place, where possible targeting strategies that (while a part of the whole) can demonstrate positive change quickly (early ‘wins’). I suspect with some careful detective work, there will be several elements (perhaps the majority) for which the most effective way forward has already been described several times in reports and inquiries over the years. Our challenge will be to move people with disabilities, their carers/families, and the sector generally away from the current ‘poverty’ mindset (where anything is better than nothing) to setting ‘broad hairy audacious goals’ in line with the UN Convention on the Rights of People with Disabilities. Then real, lasting and cost effective change is possible.

I would be happy to respond to further questions of the Commission relating to the place of assistive technology and research in empowering people with disabilities, and I look forward to your interim report.

Yours sincerely,

Dr Lloyd Walker.