INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

BACKGROUND:

I am a person with a high-level physical disability (I use an powered wheelchair and have very limited arm movement/strength) in receipt of several hours a day of personal care hours and reliant upon numerous items of medical equipment. I have a tertiary education, have recently submitted my PhD dissertation for examination, and have recently accepted a one-year job.

My situation has exposed me to several major flaws in the CSTDA, particularly the limitations it imposes on personal support hours and people with physical disabilities (PWD) seeking some employment. My submission, below, details the two elements of specific concern to myself: (1) the increasingly onerous bureaucratic requirements associated with personal care and support hours, and (2) the limitations imposed on job-seeking PWDs. I have provided some examples to illustrate these impacts and described possible solutions.

(1) BUREAUCRATIC OVERLOAD

I believe that the current CSTDA is characterised by increasingly onerous bureaucratic requirements imposed on service provider agencies, and subsequently PWDs, by government agencies, particularly at the state government level. While these are imposed ostensibly on the basis of accountability, responsible financial management and the safety of workers and clients, I believe the measures are largely ineffective and that simpler measures are warranted. At the state level, Disability Services Queensland (DSQ) has recently implemented the Disability Services Quality Systems (DSQS) which requires service providers to fulfil a new suite of reporting requirements. It also requires support workers to obtain formal qualifications (TAFE Certificate IV in Disability) by 2008, covering the entire range of disabilities including physical, psychological, and behavioural. In my opinion, its unstated aim is to shift blame and responsibility from DSQ to service providers should a problem arise.

As a consequence of the DSQS one of my service agencies had to employ another staff member simply to comply with the reporting requirements. This shows that funding is being tied up in greater administrative requirements at a time when the need for practical personal support is greater than ever. In addition, the need to fulfil these reporting requirements unduly favours larger but more inflexible service providers while discouraging smaller, more flexible and innovative providers. This negatively impacts upon PWDs, such as myself, who are attempting to maximize their quality of life (employment, social networks, recreation, etc) within the limits imposed by their disability. My previous experience with larger agencies resulted in continually changing support workers, inflexible hours of support (e.g. Blue Care requested that I go to bed before 7pm at night) and uncertainty (e.g. a large agency would guarantee that a support worker would attend at some time between 7am and 10am). These arrangements are completely unreasonable for a PWD undertaking tertiary study or employment – yet these are the very service providers favoured by the imposition of onerous bureaucratic requirements. The smaller service provider I am currently with allows me to select my support workers, mutual agreement on support arrangements and the ability to make direct arrangements with my workers on agreed work times and duration.

The new DSQS requirement for formal qualifications, although a well intentioned effort to improve staff skills, is another example of ill-considered change. I believe that these will result in an unnecessary medicalisation of personal care work, increase staff wages & therefore reduce support hours, and reduce the potential pool of personal support workers. My routine is very straightforward and non-medical, and I mostly employ university students on casual basis. This system works well in that my workers obtain real world employment experience with PWDs which fit in with their study routine, while I have access to flexible staff in non-medicalised circumstances. Everybody benefits. The new system will require all staff to have completed TAFE Certificate IV in Disability qualifications (6 months full-time) if they wish to become a personal support worker. This will preclude me employing university students who are often more highly qualified (often studying medicine, physiotherapy, or public health in paramedics) but do not have the time or career goals to undertake the course for only one or two years of part-time work during their studies. My experience with 'trained' staff is that there is an overly medicalised relationship, which results in a 'worker knows best' power structure instead of a mutually satisfactory relationship between workers and PWD. Staff training is an important consideration, however it should be decided on a case-by-case basis between service provider, PWD and support workers with training relevant to the persons circumstances. For example, for personal support staff working for me on a casual basis there is absolutely no need for them to be trained in dealing with schizophrenia or down syndrome.

If this added paperwork and training were shown to improve outcomes and were the most efficient means of doing so, I would be supportive of it. However, I strongly believe that making service providers responsible for both providing services and reporting complaints about their service will not result in improved accountability for poorly run service providers. Assuming that service users who previously were reluctant to report their complaints to service providers, will now feel more comfortable to report their complaints because of the DSQS requiring more regular surveys of service user is ill conceived and naive. Assuming complaint reporting has been identified as a significant problem, the best solution would be to set up an independent complaints agency to whom service users can confidentially report complaints about their service provider. Secondly, people such as myself, who are entirely happy to raise concerns directly with service agencies, should simply be able to sign a service agreement between the service provider, the service user (PWD or their advocate) and the personal support workers agreeing to the general conditions, training, complaints resolution, etc. Such an agreement, based on the principle that any party can withdraw from the agreement or renegotiate it at any time if they are unhappy with the arrangements, would curtail the need for continued and ongoing reporting. This would minimise paperwork and unnecessary bureaucracy, and free up more money for practical personal support. For example, all parties could agree on what training was necessary for personal support workers, and the service provider could arrange for the requisite training to be undertaken.

The other logical step in this process is simply to attach personal support funding directly to the PWD and to explicitly encourage them to move that funding to another service provider if they were unhappy with their service. This market-based mechanism is likely to have a greater influence on service quality than increased feedback forms between service providers and service users (PWDs). The increasing granting of support funding by DSQ to service providers rather than directly to PWDs is antithetical to this and fosters the need for such complex reporting systems.

(2) PERSONAL CARE, MEDICAL EQUIPMENT AND EMPLOYMENT:

My personal care workers are funded through several agencies that are ultimately funded by the Queensland Government. Obtaining sufficient recurrent support hours has been a tortuous and time consuming process of extensive applications and letters – a process that I am in no hurry to repeat. However, these support hours are only available while I live in Queensland. If I were to move interstate to take up employment (where there are a greater range of opportunities given my skills) I would have to face a lengthy transfer process and/or lose this support and reapply within that state. As a consequence of this, I cannot realistically consider employment opportunities outside Queensland.

I am told that Disability Services Queensland has a process for transferring personal support hours interstate. However, this is not feasible for two simple reasons: (a) the process takes too long, and (b) it provides no long term certainty. In short, to apply to transfer my funding interstate I would need to apply to Disability Services Queensland for a transfer of my funding to another state, have the application sent to the state I was planning to move to, and then be approved by that state agency. I am told this may take several months, which is unrealistic given that an employer requires a prompt decision to accept or reject the job. Furthermore, if the transfer was approved, the new state are only obliged to continue to provide funding for a period of up to 12 months, after which you have to reapply for funding in the new state with no guarantees as to attaining adequate support hours. Given my high personal support needs (several hours of personal care per day), I cannot risk my recurrent support funding to move interstate for employment. To confirm this, I direct you to the funding guidelines at: www.disability.qld.gov.au > Support and Services > DSQ Funding > Funding Guidelines > scroll down to Change of Circumstances > Portability Across States and Territories. Adding further complication to this is the fact that already limited personal support funding is typically prioritised by those applicants with a concession card (e.g. DSP). This presents great obstacles to people with disabilities who will require more support hours to shift into employment or who do not have adequate support already.

Similar limitations to employment exist regarding the provision of medical equipment (such as wheelchairs, shower commodes, etc) to people with disabilities seeking interstate employment as it to is funded through State-based programs. As an example, my powered wheelchair is provided by Queensland Health through a scheme called “Medical Aids Subsidy Scheme” (MASS). My wheelchair with its specialised modifications is worth approximately $10 000. However, if I were to move to another Australian State I would have to hand back the chair and its modifications to Queensland

Health. Apart from the obvious question of what I would do without a wheelchair in the interim, I would then reapply in that state and hope that my application was considered speedily. Secondly (and regardless of whether I seek work intra- or inter-state), the subsidy is only available to concession card holders (e.g. DSP recipients) again reduces the incentive for people to seek work as they would have to hand back their specialised equipment and personally fund all their medical equipment and its ongoing maintenance. This may result in a working PWD being financially disadvantaged, making such work an unviable proposition.

I consider that the current CSTDA is woefully inadequate with regards to assisting and encouraging PWDs to seek and maintain meaningful employment. The new CSTDA needs to provide a more holistic consideration of the needs of job-seeking or employed support recipients, particularly in light of the new “Welfare-to-work” policy. My main limitations in regard to employment are requirements for 1) suitable access to workplaces 2) ensuring that DSP recipients who find work won't be financially worse off, and 3) ensuring people with disabilities can move interstate to seek employment. Despite straightforward solutions to these problems, state governments are too parochial, inflexible, and concerned about the minutiae of their financial expenditure without considering the societal benefits; and the federal government appears reluctant to undertake simple, low-cost reforms to improve the job prospects of PWDs. As an example, I have declined to apply for two interstate jobs that I was well qualified for, simply because I could not shift my state-based personal support hours and state-subsidised wheelchair interstate. Fortunately, I have recently obtained suitable employment in Queensland for one year, although the problems with interstate movement of people

As I understand, the current CSTDA only affects point 3, above, relating to directly national reform could be achieved and provide genuine incentive for DSP recipients to seek work. The simple solution to this is based upon the revised CSTDA attaching support and equipment to the person rather than where they currently live! In its present form, the current CSTDA requirements represent a form of apartheid by restricting the movement of PWDs around Australia – a situation which does not apply to people who aren’t reliant upon state-based support hours or equipment. This presents a very real disincentive for people like myself trying to further my career prospects. I have endeavoured to bring these matters to the attention of the major political parties in recent years without success. The negotiation of the new CSTDA in 2007 is an opportunity to achieve meaningful reform, which would present significant personal, state and national benefits.

KEY CONSIDERATIONS AND SOLUTIONS

The issues that I have outlined above represent very significant obstacles and disincentives for people with substantial physical disabilities. I am highly reliant upon both my personal support hours and my subsidised medical equipment for my daily existence. I believe that the current CSTDA arrangements and responsibilities between the two levels of government are too complex and result in no agency taking responsibility for outcomes for people with disabilities. Ideally, I believe responsibility for all elements of support for PWDs should be brought under Commonwealth jurisdiction to ensure equal arrangements nationwide and to enable people with disabilities to freely move interstate.

If the CSTDA is to remain then it needs to be substantially reformed and based upon a cooperative federalism model with the Commonwealth providing financial incentives to States to improve outcomes for PWDs (e.g. more hours of support for PWDs, more appropriate support, support for more PWDs, more incentive for PWDs seeking employment, minimal bureaucracy). This must also consider These arrangements must include the following elements:

- A streamlined arrangement to allow people with disabilities to seek employment interstate with the assurance that their personal support funding arrangements and subsidised medical equipment can be seamlessly and immediately moved with them if they are accepted into a job (i.e. the support and equipment would be tied to the person, not their locality or State). Employers WILL NOT allow people to delay accepting a position while State bureaucracies to make up their mind about transfer arrangements.
- The new CSTDA should either remove the need for a concession card from application requirements from personal support hours and medical equipment, or allow people with physical disabilities to retain their concession card so that they are not disadvantaged in applying for (and/or receiving) personal support hours and/or medical equipment that are contingent upon concession card status). As a PWD with limited savings I have no means of personally funding this equipment (approximately $10 000) or personal support ($20 000 to $30 000 per year) from my wage.
- These issues are at the very coalface of providing greater incentives for people with disabilities to work. In making these relatively straightforward changes, the participation of PWD in the workforce would be encouraged, and as a largely bureaucratic measure would be more about flexibility in funding rather than additional expenditure. I require this equipment and support regardless of whether I am employed or not – although reducing the complexity and delay would greatly assist my job prospects. Just as tax cuts are considered necessary to provide workers with incentive to take on additional work, people such as myself need to reassurance that they will not be further financially disadvantaged by seeking employment.
- Minimising bureaucracy where possible should be emphasized to reduce the cost of bureaucracy and maximize money available for practical personal support.
- One-size-fits-all approaches should be replaced with greater emphasis on tailoring arrangements to PWDs needs. While this may entail slightly greater time in the earlier phases, in the longer term it would significantly reduced onerous reporting requirements, prevent unnecessary staff training and lead to improved outcomes.
- Government, particularly at the state-level, must consider the broader social and economic benefits of PWDs participating in society. Improving this participation requires more flexible arrangements and tailored responses to individual needs

and aspirations, and a retreat from one-size-fits-all measures and current focus on immediate economic costs.

The issues above are presently poorly addressed under the existing CSTDA. Given the substantial changes of “welfare-to-work” measures and the need to remove disincentives to PWDs seeking or in employment, the revised CSTDA must move from parochial and inconsistent state-based systems toward a more flexible national system that does not discourage effort on the part of PWDs.

I would welcome the opportunity to present the above ideas to Senate hearings on the CSTDA should you require further details on any of the above elements of my submission, further examples or personal experiences and/or further details on my proposed solutions from the perspective of a person with a disability.

Yours sincerely,

Ben Lawson