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My situation:
I have a high-level physical disability and use a powered wheelchair for mobility. At present, I make use of state government-funded medical equipment and personal care hours funded through the National Disability Agreement (NDA). Although the funding is jointly contributed by the state and federal governments, it is dispensed by the Queensland Government and is only available while I reside in Queensland.

I am tertiary educated and currently working in the public service. As a former recipient of the Disability Support Pension (DSP) and a person who knows the day-to-day challenges of living with a significant disability, I believe there are a number of important elements that need to be incorporated into a long-term care and support system so that people with disabilities can make a positive contribution to society through employment and other forms of participation.

The opinions and views suggested in this letter are my own. I am not a member of any political party or writing on behalf of any disability group.

Below, I address some of the issues raised in the Productivity Commission's issues paper. Obviously some answers are applicable to several of the issues, in which case I have placed the answer under the most applicable issue.

Who should be the key focus of a new scheme and how they may be practically and reliably identified?

In my opinion, the focus of a new system should be on people with long-term disability. I believe this should be a disability that is likely to affect the person's core functionality for at least 2, possible 5, years.

This should include people whose disability imposes little or no functional limitations with adequate support and/or rehabilitation. I consider this necessary as I believe a key objective and focus of the a long term care and support scheme should be on improving people's quality of life and limiting the impact of their disability/ies to improve their participation in society. This is best achieved through early intervention, active rehabilitation (where feasible), and adequate support provided with long-term certainty.

Any short term or low level disabilities should be dealt with under a separate disability support schemes. Programs such as HACC and block-funded models are probably well suited to these situations.

Ways of achieving early intervention

In my opinion, early intervention is essential to any sustainable and long-term solution to the current problems with disability support in Australia. This is vital for several reasons, including reducing the demands on disability services in the future, improving the socio-economic status of people with disability and maximising the participation of people with disabilities in employment and the community.

I was fortunate that my parents ingrained a positive attitude in me and my family focussed on the future and the capacities that I had, not what I couldn't do. Apart from the necessary constraints of my disability, I was always treated as just another family member with all of the same expectations as my siblings. This established a 'can do' attitude in me at an early age focussed on achievement and demonstrating to others I could succeed where they didn't expect I could. My family worked hard to ensure the local school had accessible features so that I could attend a normal school, and then packed me off to university. In short, I consider this to have been crucial to getting employment and to participate in the community.

I believe a positive outlook with a focus on the person's abilities, not their limitations, is very important. This may be achieved by proactive intervention whenever a person is diagnosed with a disability. Health professionals (public and private) could be required to refer the person to a central agency for their situation to be addressed. The person would be provided with a case manager to coordinate appropriate support and equipment through the various service providers. The emphasis would be on rapidly securing support and equipment that maximised the person's independence and (where possible) rehabilitation. In addition, emphasis could be placed on providing counselling and other supports to the person and their family/support network to (1) deal with their changed circumstances and (2) embed a positive mindset and 'normal' approach to the situation and their future.

This proactive and positive intervention is needed as too often families of people with disabilities focus only on the negatives of their immediate situation and an intense desire to protect their family member. Disability can easily become the focus of their lives and one or both parents may leave work to care for their loved one in the absence of a proper support system. All too often this can affect the whole family resulting in marginalisation and making it difficult to re-establish a normalised routine even if adequate supports are provided later.

How a new scheme could encourage the full participation by people with disability and their carers in the community and work?

From my own experiences and from discussions with other people with disabilities one key principle is evident but often unrecognised in disability policy – that is the need for *certainty*. People who live with disabilities have a whole range of uncertainties in their lives that most people don't have to consider – *Will this adversely affect my health? Will my support workers turn up to assist me this morning? Where will I find accessible accommodation at the end of my current lease? Will my broken wheelchair be fixed in time for me to get to work?* etc.

To encourage people with disabilities to participate in employment, and society more broadly, disability policies need to overcome some of these uncertainties. Key to this is ensuring that in taking up employment, people with disabilities do not experience additional uncertainties such as the prospect of losing access to subsidised support or equipment that is often 'tied' to the DSP and associated allowances. We need reassurance that we will not be disadvantaged by seeking employment and increasing our participation in society.

The previous 'welfare-to-work policy' is a pertinent example of a policy response that largely failed to achieve its purpose of increasing employment for DSP recipients because it created uncertainty. I know several people with disabilities on the DSP who were so concerned that if they took up new or additional employment and lost eligibility for the DSP that they would never be able to return to the DSP and the various supports available. The policy simply encouraged these people to overestimate the affect of their disability to remain on welfare – a lose-lose situation for all concerned. A simpler, more-effective policy response to encourage DSP recipients to seek work would be to say that "if you try new or additional employment and it doesn't work out then you can return to the DSP without penalty".

Fortunately, living with a disability forces people to be persistent, adaptable and to tackle challenges head-on - because not only do you have to deal with disability but the uncertainties of disjointed, complex and inadequate array of current disability supports. So, a flexible and personalised long-term support system would remove great uncertainty from peoples lives and would allow us to channel our abilities to making a greater contribution to the workforce and society more broadly.

In short, I believe the design and implementation of a long-term disability support system needs to ask: *will this create or maintain certainty for people with disabilities?*

How to improve service delivery — including coordination, costs, timeliness and innovation?

Currently, there is no realistic means for people with disabilities to move between states. This further curtails the capacity of people with disabilities to improve their circumstances by moving interstate for work, improved support networks or better health outcomes.

I have previously sought employment interstate to maximise my career development and opportunities. However, this was prevented by incompatible state-based disability support arrangements and an inability to transfer my current state-based disability equipment (wheelchairs, etc) and support hours to other Australian states. As a person with high support needs, I would have been unable to cover the costs of this support and equipment from my own income. This situation prevents me from moving interstate to take up career opportunities as financially I would be worse off than being on the DSP.

In Queensland, Disability and Community Care Services within the Department of Communities (DoCs) has a process for transferring personal support hours interstate. However, this is not feasible for two simple reasons (1) the process takes too long, and (2) it provides no long-term certainty to me. To apply to transfer my funding interstate I would need to apply to DoCs for a transfer of my funding to another State, have the application sent to the State I was planning to move to, and then have it approved by that State agency. I am told this may take several months, which is unrealistic given that employers expect prompt decisions from applicants on whether they will accept or reject a 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 12 months I would have to reapply for funding in the new State with no certainty of obtaining adequate support hours. Given my high personal support needs, I cannot risk my recurrent personal support hours to move interstate for employment.

This fragmentation and inconsistent delivery is a recurring theme in disability. I believe that it shows the need to run, or at least coordinate, a long-term care and support system through a national body with funding tied to the person requiring support rather than their locality or service provider. This would achieve greater consistency and ensure people could move to take advantage of better employment, social or health opportunities.

Ideally, such a national body and consistent approach would lead to a consolidation of the multiple different systems, funding streams, bureaucracies and services that current result in so much fragmentation, lost opportunities and cost inefficiencies. The consolidation could allow a significant amount of funds presently being spent on bureaucracy to fund direct support to people.

I believe that such a system could be coordinated by an independent case manager or service provider, chosen by the person with a disability, who could negotiate with government agencies, employers and medical specialists as necessary to coordinate their delivery in a coherent and adequate services in a seamless manner. Providing a case manager would assist people with complex needs to attain or maintain employment by limiting the time they have to spend arranging and managing their support and equipment needs. For me, the burden or having to constantly manage my team of support workers and mobility equipment needs while trying to work is incredibly stressful. If this were able to be managed by a trusted and competent case manager, the burden for many people with a disability would be eased and enable them to work more efficiently and effectively.

Suggested solution: a long-term disability support system must allow people with disabilities to shift their personal support funding arrangements and subsidised medical equipment seamlessly interstate for employment with no loss of benefits or conditions (i.e. tie support and equipment to the person, not their locality or State). Such transfer arrangements should be simple and quick for people with disabilities to arrange. Better still, have a national system and attach the support to the person.

The factors that affect how much support people get and who decides this

In establishing a new long-term support system for people with disabilities in Australia, care must be taken to ensure that people with disabilities are not subject to further uncertainty that the ‘new rules’ will disadvantage them. I believe that a ‘no disadvantage’ test should be applied to the transition from current systems to the implementation of a new system. This would allow a new system to be established, and over time new consistent eligibility criteria and equivalent support levels achieved as people left the system and new people entered the system. This would also ensure community support for the wholesale reform of the disability support system.

How to ensure that any good aspects of current approaches are preserved?

The best way of ensuring that the good aspects of current approaches are preserved is to let people with disabilities choose what the good elements are. This is most efficiently and effectively by individualised funding that gives people **certainty, flexibility** and a **real say** in their service delivery - certainty that we will not be worse off for working or 'having a go'; flexible support arrangements to make work or participation easier; and a real ability to exert control over our support arrangements. Importantly, reform needs to actively engage people with disabilities in disability policy and program development as they have real daily exposure to these many complex issues. To me, these are critical missing pieces in disability policy at present.

Allocating the support directly to a person allows them or their advocates to choose what they believe is the appropriate supports, and if they are not satisfied with a service or believe they can get a better deal elsewhere then they can move service providers. Such a change will bring short term uncertainty to service providers and some organisations may cease to exist. Governments seem extremely concerned by the prospect of service providers going out of business, but there is no alternative if we really want a flexible and efficient support system that benefits people with disabilities. The alternative is the cumbersome, complex and inefficient systems we have right now.

Getting rid of wasteful paper burdens, overlapping assessments (the 'run around') and reducing duplication in the system

I believe that the current NDA imposes unnecessarily onerous bureaucratic requirements on service provider agencies, and subsequently people with disabilities, particularly by state government agencies. 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 and more cost-effective measures are available.

In Queensland, DoCs has a Disability Sector Quality Systems (DSQS) with the intention of improving the quality of services available. It does this by adding yet more complexity and reporting requirements to an already bureaucratically onerous system.

As a consequence of the DSQS one of my service providers had to employ another staff member simply to comply with the reporting requirements, thereby tying up more funding in greater administrative requirements at a time when the need for practical personal support is greater than ever. Furthermore, the need to fulfil these reporting requirements unduly favours larger but more inflexible service providers over smaller, more flexible and innovative providers. This negatively impacts upon people with disabilities, 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. one large agency requested that I go to bed before 7pm at night!) and uncertainty (e.g. another large agency would only guarantee that a support worker would attend at some time between 7am and 10am). These arrangements are completely unreasonable for people with disabilities undertaking study or employment, yet these are the very service providers favoured by the imposition of excessive bureaucracy and inflexible rules. The smaller service providers I am currently with allow me to select my support workers, allow mutual agreement on support arrangements and allow me to make direct arrangements with my workers on agreed work times and duration.

The other fundamental flaw in the DoCs DSQS is the premise that service providers should both provide services and report complaints about their service. There is no evidence to support such self-monitoring and disability advocates report many instances where poorly run service providers have successfully achieved quality assurance. 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 naïve. To me, a far more rigorous and effective systems would be an independent complaints body allowing service users to confidentially report complaints about their service provider.

The other logical step would be to simply tie personal support funding directly to the person with a disability rather than handing it to service providers to allocate. This simple market-based mechanism would allow users to ‘shop around’ to find a service provider that best meets their needs and aspirations, and would be likely to have a much greater influence on service quality than any ‘feedback’ form or ‘quality’ audit. The increasing granting of block support funding by DoCs to service providers rather than directly to the person with a disability is antithetical to this and fosters the need for such complex and ineffectual reporting systems. Furthermore, it underestimates and stereotypes all people with disabilities as unable to control their own lives or affairs.

Why shouldn’t I be able to transfer my support budget to another agency that offers lower administrative budget and more support hours, or an agency that provides the flexibility needed for me to stay in employment? For example, my support workers and I choose to coordinate timetabling among each other independently as it is simpler and more effective than coordinating it through the service providers case manager. This works for me but yet I still pay the same administration fees to my service provider. With individualised funding I could choose what functions I wanted a service provider to provide and negotiate a administration rate accordingly. This would allow my support funding to stretch further.

Further, why shouldn’t I be able to engage a person with a disability, who manages their own funding package independently, to also manage my funding package? This would provide opportunities for some people with high level disabilities to establish their own micro businesses managing a few funding packages.

Suggested solution: a long-term care and support system should seek to minimise the bureaucratic requirements on service providers and service users. Furthermore, funding should be tied to the person with a disability not their service provider, allowing them to tailor their support arrangements to their needs, maximise their support hours and to move their support to another service provider if they were unsatisfied with their current provider.

How to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future

I believe the new system should consider ways in which the additional taxes and welfare savings of eligible PWDs who gained work are directed back into the support system..One element of the system could be a change to government policy so that where a person with a disability required extra support (equipment, support hours, etc) to attain or increase employment, necessary funding support could be made available up to a total equal to the gains in taxation from them working and the savings from their welfare. The present Work-based Personal Assistance program, with broader eligibility and support levels, could provide the basis for such a system. Although for people with high support needs the government may receive no net financial gain from some people with a disability, the positive signals this would send to people with disabilities, potential employers and society could be substantial.

Further, this would create a real incentive for policy makers and administrators to provide the systems, certainty and flexibility required to increase the participation of people with disabilities. Such incentive is not present in the structure of the current disability system has responsibilities and funding divided between Commonwealth and State Governments. This fundamentally flawed as the Commonwealth funds welfare (e.g. the DSP) and typically bears responsibility for employment figures, yet the States deliver key support services and equipment with no real economic incentive to improve the employment of people with disabilities.

The practical aspects of a scheme that will make it work, such as how existing arrangements would fit into a new scheme, how to manage risks and costs, and ideas for attracting people to work in disability services

In Queensland, DoCs has a Disability Sector Quality Systems (DSQS) which requires service providers to fulfil a new suite of reporting requirements and required staff training. The emphasis is on support workers obtaining formal qualifications such as a TAFE Certificate IV in Disability covering the entire range of disabilities including physical, psychological, and behavioural.

The new DSQS emphasis on formal qualifications, although a well intentioned effort to improve staff skills, is another example of ill-considered change. In my opinion, its unstated aim is to shift responsibility from DoCs to service providers should a problem arise. I also fear that it is resulting in unnecessary medicalisation of personal care work, inflated staff wages and ultimately reduced support hours, and a sharp reduction in the potential pool of personal support workers. This is presumably viewed as some sort of panacea to poor quality services, when in fact it may entrench rigid agency focussed attitudes in support workers and exacerbate difficulties in people with disabilities engaging support workers who meet their needs.

My routine is very straightforward and non-medical, and I prefer to (and currently do) mostly employ university students on a casual basis. This system works well as my workers obtain real world employment experience with a person with a disability and which fits in with their study routine, while I have access to flexible staff in non-medicalised circumstances. Everybody benefits. The new TAFE certificate requirement will preclude me from employing university students who are often more highly qualified (often studying medicine, physiotherapy, or occupational therapy) because they do not have the time or career goals to undertake a TAFE course in disability for 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 and equal relationship between workers and the person with a disability.

Staff training is an important consideration, however unduly prescriptive and irrelevant training is detrimental to all concerned. Instead, training should be decided on a case-by-case basis between service provider, the person with a disability and support workers, with training tailored to the person’s 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’s syndrome.

This demonstrates the fundamental problems associated with so much disability policy of (1) a measure employed to solve a problem [in this case, service quality] exacerbating problems elsewhere [finding suitable workers and normalising PWDs lives], and (2) creating unnecessarily complex and inflexible bureaucratic systems. This underlines the need for a long term care and support system to minimise the complexity of systems, maximise the flexibility of those systems and to give choices to people with disabilities not bureaucrats wherever possible. As stated elsewhere, I believe at the core of this is tying funding to the person not a service provider and allowing the person to move to another service provider if they are not satisfied.

Conclusions

Despite a generation of equal opportunity, anti-discrimination legislation and high economic growth in Australia, the economic circumstances and social attitudes toward people with disabilities still lags behind. This is exacerbated by relatively low participation in the workforce and social institutions. The implementation of a long term care and support system should be the catalyst for new approach to disability policy that supports, encourages and provides added incentive to people with disabilities to participate in employment and society more broadly.

In considering a model for an insurance scheme, I encourage you to consider program designs that will give people with disabilities greater independence and flexibility. To this end, despite the imperative to minimise duplication I do not believe such a scheme should simply ‘top up’ state-based programs – especially those that are not ‘best practice’, such as the regressive especially block-funded models such as that favoured in Queensland.

It is imperative that disability moves away from measuring outcomes based simply on the numbers of people services are provided to (e.g. current HACC based programs), which simply results in support being spread thinly and a churning of people across different services. Instead, what are needed are meaningful, integrated and simplified systems that bring improvements to the socio-economic opportunities of people with disabilities across Australia.