Submission to

PRODUCTIVITY COMMISSION

DISABILITY CARE AND SUPPORT

PUBLIC ENQUIRY

BY

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(INDIVIDUAL)

I am the sole (unpaid) full time carer for my 23 year old son. He is totally blind, has autism and a form of epilepsy (controlled by medication) & probably also an intellectual impairment although there are no tests available which give us a definite answer on this due to his combination of other disabilities. In spite of all this, he speaks & has a reasonable understanding of language, is independently mobile, can toilet, shower & dress independently, can & does choose what he wants to do, what & when he wants to eat & drink etc, when to go to bed & has an active social life. He is very keen to be independent to the best of his ability but will always need 24 hour support & supervision to achieve this. He is not able to be left at home alone for any time at all due to safety considerations related to autism as he needs everything to run to a schedule & has no means of coping with unforeseen circumstances (a fire, accident or fall, carer late due to car breakdown etc, someone at the door – could let a total stranger into the house etc etc)

As we live in Queensland & my son has had disabilities from birth my answers to the questions below are from this point of view & based on my experiences with the Queensland disability system.

My son currently receives post school funding which give him 11 hours of support a week & he gets respite for 3 nights once a month. I have no other supports, with no family living nearby. As I am divorced & he can't be left alone this means I am unable to work & forced to rely on the carer payment. I have been trying to get additional funding since he left school but as I am 51 & not considered 'ageing' we are not eligible for anything else. There are few centres in my local area which offer a day program, & of the ones that do exist either they have no vacancies or their idea of a 'day' is between 10 am & 2 pm – not very helpful when trying to get work.

Because of his combination of disabilities we were never able to access any form of child care or OOSH care when he was younger & so I haven't worked for around 15 years now. I was trained as a Pharmacist & should now be earning around $80,000 a year but can't go back to this now as I haven't been able to keep up to date. If the system gave more support so carers could remain in the workforce I would now be supporting myself & my son & younger daughter & would be able to support him in the future through a trust fund or similar. Instead we are all dependent on the welfare system & he will be in supported accommodation at a much younger age than otherwise as I simply can't afford to continue as we are forever.

We recently applied for supported accommodation as a last resort, only to find there are no vacancies in any DSQ run house in our local area. I was told by DSQ employees that the only way to access accommodation through a private organisation (any other than DSQ) is to relinquish him to the state (ie leave him at respite) as the funding for private services is only available if the person is considered to be homeless. The system of paid care should be building on existing family supports but the current system seems determined instead to tear families apart.

I also made a submission to the recent Carers Inquiry but nothing seems to have come of this. Our circumstances have certainly not improved in any way. I hope the government pays more attention this time as many people such as myself are desperate for assistance.

Who should be eligible?

Decisions on eligibility & levels of funding should be made by an independent body of consultants who all have the same training so that across Australia people with the same level of disability get the same level of funding. These decisions should NOT be made by the people who will be providing the service.

Eligibility should be a matter of entitlement. Carers & people with disabilities should not have to beg for funding & services. It should also not be a competition for available funds, with the most funds going to the ones who are best able to put themselves or the people they care for in the worst possible light.

The current system is so inadequate that I feel any new scheme must cater for people with existing disabilities, not just those who are newly diagnosed.

The group that I feel currently is the most disadvantaged is between the time when the person with disabilities leaves school & when their carers are old enough to be considered to be ‘ageing’. This group seems to be the least eligible for funding & at a time when carers should be in the workforce they either are not able to work at all or have very restricted hours, unless they are lucky enough to have sufficient family support. This means that they are forever dependent on welfare. Even when children are at school parents do not have the same options for child care, OOSH care etc that other parents do. By increasing this type of support when parents are of working age would enable more parents to remain in the work force & so be better able to support themselves & the people they care for financially throughout their lives. It would also give carers a life outside of caring & so improve their mental state & stress levels & enable them to continue caring for longer.

Whatever method is used for determining eligibility, it should be as objective as possible & the same system should be used Australia wide & should be flexible enough to allow for all disabilities & combinations.

Eligibility should not be means or asset tested. It should be based on an objective assessment of the level of disability & its impact on the person’s needs for specialist equipment & services etc & its impact on their ability to care for themselves in an age appropriate manner.

Having a standard Australia wide objective assessment program carried out by trained people who are independent of service providers & state disability groups should lead to a considerately more consistent, fair & transparent system than we currently have. There should also be a means of complaint or objection to assessments with an independent ombudsman or similar who can be accessed if the complaint is not satisfactorily dealt with by the agency concerned.

The scheme should generally not include disabilities that are associated with natural ageing as these should already be catered for by the aged care scheme. However there could be some individual exceptions eg a condition normally associated with ageing such as Parkinsons disease or dementia that appears in a specific person at an age where it would be inappropriate for them to access the aged care system. Also, a person with a disability not associated with natural ageing who reaches an age appropriate for accessing aged care may be better provided for if they continue in the disability sector as aged care facilities may not always be as able to cater for their disability.

Regular review is an essential part of such a system. My son has been receiving Post School funding for 5 ½ years now & although our circumstances have changed considerably over that time (I am now divorced & also have a much better idea of how the system works than I did at that time) there is no real review process & other than CPI increases his funding has stayed the same. However reviews every 12 months such as we have to do for Centrelink for mobility allowance are an unnecessary waste of time & resources. Set reviews at important times such as starting/finishing school plus a means for people with disability or their carers to request reviews if their circumstances change eg wish to move out of home.

Who makes the decisions?

The aim should be for everyone to have individualised funding, with the ability to delegate management of this to an agency if desired.

The person with disability & their carers should of course make the decisions. However there is no point officially having the right to make decisions when there are no options to choose from.

There should be some means for primary carers to pay themselves an income from the funding if they choose to care full time themselves. Perhaps in this case they should be eligible for free training in disability care & also be eligible for super & considered to be members of the work force.

Workforce issues

In spite of the recent pay increase, disability support workers are not particularly well paid relative to the level of responsibility they have. The support workers I have contact with also indicate they have no job security as they are employed only on a casual basis & often are given fewer hours than they want to work. An improvement in pay & better job security would see more people remain in the industry instead of moving on to other things.

Governance and infrastructure

It should be administered by a single independent body which is accountable to the federal government. It should be Australia wide, not administered independently by the states.

There should also be a centralised means of record keeping which would cut out a huge amount of time on the part of carers & people with disabilities & also much administrative time & costs as presently every agency has their own forms which usually have to be redone every year. It would also assist with people moving between states.

At a state level, there needs to be a ‘one stop shop’ where people can find out about their entitlements, what services are available locally etc. This could be a role for the current state disability services, who should already be doing this but aren’t (at least in my experience in Qld). I currently spend half of my time trying to find what services are available, either by phone or internet but you basically have to know the actual name of the service to find it. Just searching for ‘disability services’ gets you very little information.

Implementation issues

I feel that service expansion needs to start immediately, before such a scheme commences. There are nowhere near enough services available for those who would be eligible to access them under such a scheme.

Some priority areas could be supported accommodation (possibly cluster housing or similar rather than the current forced tenancy which is the only option if more than very minor support is required) and centres that are able to offer a combination of group based & one on one or community access type support where the client or carer are able to choose how many hours they spend in which type of care according to their level of funding & other requirements (eg carers need to work).

Benefits

Benefits for people with a disability would include more information available, easier access to services, sufficient funded supports being available to ensure they have access to everything that other people take for granted: a good lifestyle, access to their local community, continued support from family & friends, a sense of empowerment as they have more control over their own lives

Benefits for carers include the ability to remain in or return to the workforce, no longer being forced to live in poverty dependent on the welfare system, able to support themselves & their families & able to provide for their own retirement, no longer isolated but able to have a life outside of their caring role, feeling that they are a valued member of society, the security of knowing the person they care for has supports in place for when they can no longer care for them

Benefits for society include both carers & people with disabilities able to be active members of society, not restricted by lack of supports; knowing that if they or their family members become disabled they will be supported also

Other benefits include a system that is more open and transparent, fewer administrative costs, fewer layers of administration, less doubling up of services, better use of existing resources