

TO THE PRODUCTIVITY COMMISSION
RE: Long Term Disability Care and Support Scheme
(Anonymous submission)

I am writing this submission because of severe gaps in the present system that need to be rectified. The Assistant Treasurer has asked the Commission to assess the costs, cost effectiveness, benefits and feasibility of a number of approaches. I put it to the Commission that;

1. Long term and essential care and support for the disabled on an entitlement basis taking into account the desired outcome for each person over a life time is mandatory and must have no ceiling. Further – it should not be limited to those with a “severe” or “profound” disability. It should cover all disabled Australians who have restrictions that inhibit the ability to live a decent life.
2. The intention should be to cover all disabilities that are not acquired as a result of the natural aging process.
3. Calculating the cost of long term care and support including management should have no limits per paragraph 1 above.
4. The existing system of funding must be completely replaced, and must not be treated as a “one size fits all” model.
5. Ensuring that a range of support options is available is essential, as is the individualised approach.
6. The idea of a co-ordinated package of care services is prudent and should indeed include accommodation support, aids and support, respite, transport and a range of community participation and day programs for life. It should also include general funding for individual needs consistent with a decent life.
7. Assisting the person with a disability to make decisions about their support is also mandatory.
8. The provision of support for people to participate in employment must be supported by relevant legislative amendments.

I have a big problem with the idea of restricting assistance to those with a profound or severe disability. Whilst covering these people is important, there are gaping holes in the current system that those who are disabled under the relevant legislation fall through. I am one of those people.

I have Asperger’s Syndrome, on the Autistic Spectrum. When the DSM-V is released the whole Spectrum will be classified as Autism. I believe that supports should be available for those anywhere on the Spectrum who have had difficulties in leading a decent life, not just those who are presently classified as Low Functioning Autism and mid functioning Autistics who are isolated from society completely.

Social handicaps exist for everyone on the Spectrum, which inhibits proper functioning. This leads to high unemployment and a poor social life – and consequently severe self-esteem issues. Independent living also becomes an issue under these circumstances. The new system being proposed must include assistance for those in this position. It must include funding for individual need – which can be quite widespread and variable. It would involve special interests, which those on the Spectrum rely upon when everything else is failing.

The system is definitely failing me. I can’t work for the public service after the CMO shut me off with a biased report that I can’t get rid of. I have no faith in the private sector because of the right that exists under current legislation that allows for “unjustifiable hardship”. This is the part that needs to change, to open up the employment market more for those on the Spectrum. For myself – the CMO report has to be removed. It can’t be overruled (I’ve already tried that and failed) because the Department who called for the report won’t co-operate with a review. The fact that the report was in 1997 makes no difference because nothing has changed on the basis the report was written (that I have Asperger’s Syndrome).

As a direct result of this failing, my lifestyle has developed in such a way that the Disability Support Pension is not covering my needs. I can’t work because of this lifestyle, and the only way to turn this

around is with extra funding. This is why I made the comments that I did regarding funding for a decent life. At present I am struggling to maintain what I need.

Accommodation is also an issue. The rules set by the Housing Commission in Victoria does not cater for my needs. I need a large home with plenty of space, but the Department refuses to co-operate without medical back up. I struggled to get onto the waiting list for a two-bedroom home as it is, but the reality is I need three bedrooms. And it has to be within a reasonable distance of public transport, as I don't drive. The public transport must also be of an appropriate frequency and availability, which it isn't where I am for my needs.

Needs for those on the Autistic Spectrum are vast. I just gave myself as an example. There are never any common needs and that's why there can't be a ceiling on the amount of spending required. Further to that, the government needs to enquire further into the issues of those on the Autistic Spectrum. I doubt that your terms of reference would go that far and that's a serious error on the part of the Assistant Treasurer.

In the face of a growing mentality on the Internet (an influential area for those on the Spectrum due to the social issues) that Autism is a disease that needs to be cured, I consider a reaction by government to this challenge to be urgent. We need improvements in the system. I firmly believe that there are many who can contribute a great deal to Australian society – myself included. We need help to break down the barriers that I have spoken of and I for one have been waiting too long (since 1997 when I was diagnosed with Asperger's Syndrome). There are no services available at present for me – having been rejected by the Victorian Department of Disability Services – and this cannot continue.

I plead with the commission to do the right thing from a human rights and civil rights perspective, and recommend to the government that specified funding is needed for those on the Autistic Spectrum. This funding cannot have a ceiling due to the variables that exist, and the government must understand that the Disability Support Pension is not enough. It is certainly not enough for me, and I'm sure the same is true for others in my position even if the specifics vary.

If the Commission wishes to ask me any questions I will be happy to co-operate. Thank you for your interest in the disabled community and I hope you can provide what help you can to push a solution to these issues forward.