

Family and Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002

Submission to;

INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

To the Committee,

I am making this submission with considerable experience behind me, both in research and in life – and this is not my first attempt to bring to the attention of government the issues of those on the Autistic Spectrum living as adults in Australian society. I have previously participated in the Autism State Plan, and also in the Productivity Commission enquiry into the National Disability Insurance Scheme (NDIS) prior to its trial roll out. On both occasions I am disappointed and dismayed with the effective ignorance of my experiences. I hope this does not come to pass again.

I was diagnosed with Asperger Syndrome in 1997 at the age of 31. Since that time I have been researching the condition and taken in much information from social media of other's experiences – and it is an alarming situation that requires many solutions, both within the support lines and outside them as there are issues are having an effect on the community perception of the Autistic Spectrum.

1. Accessing services and quality of service

For adults on the higher end of the Spectrum, services as far as I can tell are non existent or completely inappropriate. The assumption is apparently made that only those who require a carer deserve any attention. – that is, they haven't achieved independence. Those that have a level of independence are not devoid of the need for services, even small ones. It's very important to note that – in my experience – issues associated with issues such as depression and so forth can not be thrown to the likes of Lifeline, Beyond Blue and so on. They are incapable of coping with the practical needs of those of us who have issues. I for one hate being patronised – or to put it another way, be patted on the head and told everything's going to be okay as though that's the solution to the issue. I find that insulting, and I'm sure I'm not the only one who feels that way. This especially goes for bullying, in particular online bullying where those on the Autistic Spectrum carry most of not all of their social activity to make up for the low levels of it in real life. The ability to pursue special interests for adults is also a service required that doesn't appear.

2. Health services

The health system has serious issues, but they come from outside the Autistic community. Services are being undermined by a fear of the condition. Parents don't want their child diagnosed. There is a stigmas attached. In the old days it was "it's the parent's fault". Now it's "vaccines caused it", "Autistics are inherently violent" and other conspiracy theories designed to make Autism a condition to fear. This leads to a lack of use of services, and this inevitably leads to poor service provision and access. It is imperative that those diagnosed on the Autistic Spectrum and their families be cast iron assured that none of these theories are true. Autistics should be valued members of society. It is also imperative that those who promote these conspiracy theories in Victoria be gagged. Yes, I know about Freedom of Speech and all that, but these theories amount to hate speech designed to make the Autistic community second-class citizens not deserving of the maximum support possible. And that applies across the Spectrum and not just at the lower end.

3. Services in rural and regional Victoria

I'm pretty sure this is an issue across the health system, but virtually all of the existing services that meet even the limited lines are in Melbourne. Very few are elsewhere in the state. Geelong presently hosts the only NDIS home in the state, and I understand that Warrnambool and Portland do okay. But that's all. Ballarat has virtually nothing appropriate (that's where I presently live) and services elsewhere are too general it would appear.

4. Integration across governments and services

This has always been a problem for successive governments and it needs to be better controlled.

5. Disability service providers

As far as I can tell, financial and practical support for special interests that cannot be supported otherwise is non-existent. This is a severe downfall for the otherwise wholly acceptable idea of quality tailored services. Special interests vary infinitely, and many require a higher than normal financial commitment to maintain. I can speak on this personally with my interest in football, particularly in it's statistical history at the local level. I have had to finance it solely on the Disability Support Pension, and it has led to some hardships in appropriate travel and accommodation. There are many other different interest lines that may be even more expensive, especially if they involve travel outside of Australia.

6. Education and housing

Re-skilling is something that has interested me, but the further education sector does not provide the sort of education environment that will allow me to add new skills. When one's social skills aren't up to scratch, bullying begins in the education environment in manners that their codes of conduct don't cover for. Simply laughing at a checking question (which those of us on the Autistic Spectrum need to do to make sure we understand) is a great example of this. It's insulting and they know it's insulting. It's destructively critical, and we are not tolerant of this sort of conduct because we learn nothing from it. So the rules of conduct have to change to include the abolition of this sort of behaviour. Failing that, one to one programs would be the only other solution that I can think of – and that would be expensive to cover.

Housing hits a very strong chord with me right now. I am on the Public Housing waiting list and have been since 2002. I have been on the receiving end of some serious contempt for my needs in housing over the years, to the point that I felt it was needed to take the matter into the arbitration system and ultimately into VCAT under disability discrimination. It failed due to a dangerous precedent – housing that doesn't exist is not subject to discrimination. I am under pressure to stop demanding needs that are common for Autistics relating to housing in order to gain an affordable rental arrangement. This involves isolation – distance from neighbours and in a small town rather than a large city. Autistics are solitary people that need space from others in general. Public Housing does not provide this sort of housing as a general rule, and this has to change. The department is failing in its mission. I even went public on this in the Ballarat Courier in June of 2014, only to have a department spokesperson tell the journalist that I can vary my requirements – meaning eliminating the demand for isolation. It's disgusting and it's contempt for not just my needs, but the social needs of the whole Autistic community. We need space, and we aren't getting it – and I firmly believe that this is a contributing factor to regressions on the Autistic Spectrum.

As an aside, I have noted that the Housing Minister announced on Twitter that \$572 million is being put into public housing in this year's state budget. Not bad, but I think it should have been \$1 billion.

7. Workforce issues

There is one clause in Disability Discrimination law that bothers me in relation to Autism. This is the unjustifiable hardship clause, which in my experience is abused by employers. This was certainly the case when I lost my last job not that long after I was diagnosed with Asperger Syndrome. What happens is that employers demand social skills as an inherent requirement in any job, not just the ones where contact with the general public is a compulsory part of the job – such as in sales and hospitality. Social skills in the work place must be a two way street, and if there are issues they should be out in the open where Autistics can learn what's going on and take that information in at our pace, not someone else's. This is an area that also attracts bullying, much like what I mentioned earlier in education. Work place bullying is far harder to control, and there is also the issue of whistleblowers in employment – a common problem that is naturally general.

8. Impact of NDIS

I am aware that there are already funding issues in the current state of the NDIS, and Autism is playing a major role in this poor funding. This angers me because I gave the Productivity Commission notice of the amount of money needed through a study done by AEIOU in 2007, giving an average per year figure of spending within the Autistic spectrum of \$5.8 billion. And they ignored it. It's no wonder the NDIS is in financial trouble. In Victoria, the NDIS is limited to Geelong so its impact has been minimal. And it will continue to be so as long as this underfunding continues.

9. Research into ASD and its prevalence

I have to go back again to the infernal issue of "vaccines cause autism" here. This has to be stopped, and just saying "This is not true" is no longer enough. I have a very firm theory, but it needs checking. In the Diagnostic Services Manual (DSM), the Spectrum is described by several different behaviours – of which a certain number need to be met for a diagnosis. I am of the view that every human being on the face of the Earth has at least one of these behaviours. Naturally not all would have all of the behaviours required, but that's the point. The behaviours exist in every human being. That is the genetic connection. Confirming this will strengthen the genetic argument and undermine the environmental debate over causation – not just vaccines but other theories as well such as mercury, microwave transmissions (such as mobile phones and smart meters) and so on. This rubbish needs to be smashed.

There is also another factor – and that is what can happen when a diagnosis on the Spectrum is in any way treated with contempt. There are various effects but the worst is the violent reaction. This is where the theory that Autism is a violent condition comes from. Violence only occurs when the person on the Spectrum doesn't adjust to their condition and in effect ignores it like it doesn't exist, or demands a cure for it and wants nothing to do with it. If we are to fear anything, it's this. There is a very good example of a person who totally ignored his diagnosis of Asperger Syndrome – and that was Adam Lanza. I think we all remember what he ended up doing at Sandy Hook in December 2012. According to his father, Lanza rejected his diagnosis entirely. He eventually went mad. We can't have that happen again – and there's another one in the bullpen right now (thankfully not in Australia) in Oliver Canby. I hope we don't have one here and we need to re-assure everyone that being on the Spectrum is not the end of the world. It can be made into a

positive. Autistics have the potential to be great contributors to the community, as long as the skills that the condition gives us naturally are utilised.

I am however bothered by those who proclaim they are on the Spectrum without a formal diagnosis. Not that long again Jerry Seinfeld did this. It doesn't help. I have also heard stories that diagnosis results are coming as a direct "consequence" of a vaccine reaction, but then a recovery occurs to the point that the diagnosis disappears. That can only mean that the original diagnosis was wrong, and that has to stop. This needs to be looked into further. We can't have these claims go unchallenged. It's a hard road such is the fear and contempt in the community for Autism.

10. Community participation

I've already mentioned social media as key to the social activities of those of us on the Autistic spectrum. Providers such as Facebook and Twitter are hard to control from Australia – but there needs to be something done to get them to understand that harassment (which is against Facebook's Community Standards) comes in different forms, and not all of them are being recognised. Twitter's tolerance lines are even worse. This leads to bullying and sometimes even anonymous stalking that the police are powerless to control or act against. More importantly it restricts community participation in this regard – a very important area as mentioned.

I am not aware of any real life programs that facilitate participation within the general community, socially or in employment. With sporting programs, given the practical limitation of hand to eye co-ordination, it is very hard to encourage participation in this area. The only time there appears to be an exception is if said sport is a special interest – as is the case with myself in football. Whilst I can't play, I can umpire – and very well if I may say so. Umpiring or refereeing would be a good way to participate where hand to eye co-ordination is not important.

Conclusion:

If I may say so, I consider myself to have a good enough handle on these matters to pronounce myself an expert on Autism, even if I don't have the qualifications of a psychologist or a psychiatrist. My expertise lies in the fact that I am on the Autistic spectrum. We should be heard. For the committee's additional consideration, I have written several articles on my website on the subject of Autism and I think they are worth reading. Some of them are somewhat emotional, but then this is emotional subject.

<http://www.philgluyas.com/as/articles.htm>

Some of the articles touch on matters that I have already brought up in this submission.

To conclude the highlight points for action are;

- Eliminate the fear of the condition through proper and full counters of conspiracy theories
- Improved access to services in as many regional centers as possible, with a focus on Ballarat, Bendigo, Shepparton, Mildura and Traralgon
- A grants structure for funding of special interests
- Appropriate housing options to gain independence and retain functioning levels
- Options to punish bullies on social media such as Facebook and Twitter as well as in the education system and in the work place

And above all else, we need to be treated as human beings by the community – not brain damaged second class citizens who should be restricted. That is hate speech and should be treated as such.

I am happy to talk to the committee about my submission should I be invited to do so. In fact I would hope the committee would want to pick my brain on the subject based on my articles and my life experience.