

## Submission to Productivity Commission's Disability Carer and Support Enquiry

### About the author:

Barry \_\_\_\_\_ is 59 years old. Barry has had a typically long history of mental health episodes not necessarily continuously, and generally not causing him permanent or always current disability. However his personality has encountered experiences such as early childhood trauma, and a serious car and motor bike accident at age 21 years which led to him being diagnosed 6 months after 'delayed shock' with paranoid schizophrenia. Overcoming his problems he managed to complete a creative and productive life although suffering on later occasions agrophobia, self-doubt or hardships of life eg Social Security legislation and operations unhelpful to his study, living or way of life.

Barry, unlike many adults with Asperger's Syndrome, has been successful in having a longterm partner, and three grown-up children; two by his current partner and another by an earlier female. Barry has never married and probably would not do so. He has worked professionally in various fields of photography (commercial, fine arts and lecturing) and the sciences but these have been far and between and in hindsight have been thwarted by aspects of his Asperger condition and interfering govt. policies. Barry has had a non-traditional working life and his family has always been a low-income one. Ironically, usually only one working at any given time. This has been due largely due to circumstance rather than a planned one and today Barry has serious doubts whether he could work again. Another feature of his decreased health have been the impacts of the system in his having to deal with his desire to study (research literature indicates strongly that knowledge finding (facts or data) or application serves as a self-therapy for many Asperger's Syndrome people. However for some, their 'obsession with data (not necessarily tangible knowledge)' has little value in everyday living). The system has also hindered his having to prove his health (ill-health) or justification for a disability pension, accompanying issues such as sleep disorders (another strong feature amongst ASD or Asperger's sufferers and his hypersensitivity to a noise eg. dogs barking. Attwood 2007 (*The Complete Guide to Asperger's Syndrome*) claims '70 to 85% of children with AS suffer from extreme sensitivity to specific sounds'.

Because of the second example Barry attempts to demonstrate his experience with local dogs 'nuisance barking' and how his council deemed the prime responsibility for managing them has failed to act appropriately and legally. Instead it has contributed to and produced an apparent latent hypersensitivity problem. Only two programs exist that deal with desensitizing hypersensitivity to noises and neither overseas ventures have adequate validation of success. No apparent program exists in SA, if Australia.

Recently, during preparing this paper he has had a range of difficulties in locating an expert who might support a latent reaction to barking, as opposed to a belief that hypersensitivity is innate amongst ASD sufferer's. As well, some bureaucrats wish to dispute his having late diagnosed AS when it is obvious their sole experience has been with children. However, he may have found an occupational therapist who can perform a 'non-legitimised therapy such as hypnosis and regression' which Barry feels is appropriate to his needs but is not ordinarily covered by Medicare. Barry's original research and experience on adult therapy is hindered by unfair Medicare policies. He is limited to only Medicare subsidized care options and to capped numbers of visits. This short term predominantly 'economic

solution to health care' makes progress slower when the same improved outcome might have been established in a fraction of the time. Many ASD and AS sufferers share multiple and individualized mental, emotional and physical (medical) issues; it can be a nightmare finding suitably qualified specialists who have broader, more open approaches to personal health outcomes.

Barry acknowledges that the web highlights the plight of some Asperger's sufferers who have become housebound by their fear of acquiring their personal hyper-'noises' when they venture outside. Certainly the system ignores human rights, even perpetuating terror or torture regimes on innocent individuals.

Irrespective of his continuing stresses Barry has completed 5 undergraduate degrees and is currently pursuing a Masters degree in Disabilities Studies at Flinders University majoring in Adult high-functioning Asperger's Syndrome. He has been awarded entry into a Fine Arts Masters degree and been given support in pursuing research into changing climate in the sciences. Alternatively, Barry chose a Flinders University option primarily to seek material for his upcoming SSAT (Social Security Appeal Tribunal) but he understands his position is unique in his suffering AS and similarly providing knowledge into a rare neglected area of medical/psychological research. Earlier in his life Barry held solo and group exhibitions of his art around Australia eg. 1975-6 UN " 'Habitat: A Better Way To Live' Photographic Ex", and exhibited in Adelaide, Sydney and Brisbane, and in regional galleries. His longterm goal is to write books, perhaps articles and to produce art; he believes he must give up notions of accepting traditional work and work times because of his need today to be in control of his life and health. The US, UK and European countries have long recognised AS graduates as superior research assistants and actively headhunt them before they leave universities. That same opportunity is not reciprocated in Australian govt and non-govt organizations.

During late 1990s Barry was awarded an international scholar's award but ironically began a downward spiral due to severe stress. This was caused by his having to travel to Adelaide by buses (previously drove a car 70 km to Adelaide but an accident put it off the road), converting parenting allowance to Newstart with the unwanted *need to look for work* when studying; and Centrelink's failure to acknowledge his unexplained chronic deteriorating physical and mental health. Coincident with these stresses Barry found it impossible to tolerate escalating neighbours' dogs' 'nuisance barking' and began more than 10 years complaining to his council. This proved to be in vain and the neglect has contributed to his hypersensitivity condition. Recently, Barry has begun investigations into the psychological and mental status of this trauma and began trialling another prescribed drug. Some ASD and AS people, in particular, are known to suffer unusually higher reactivities to common drugs with fatal circumstances.

Social Security eventually forced Barry to seek an appeal for their failure to recognize his claimed disabling condition. Barry also had no satisfactory diagnosis at both a personal or clinical position. Although having a life long history of mental or psychological disorders Barry found the system had constructed an elaborate classificatory set of requirements and tables to audit a person's legitimate health and severity of symptoms. A 'disability' definition from a psychiatric and psychological perspective must also affirm strict pedantic criteria amounting to a minimum of 20 points in order to award a Disability Pension. At the initial SSAT Barry won but was rejected and appealed by Centrelink. Although two universities recognized his deteriorating health and provided assistance from their respective

special learning agencies Centrelink forced Barry to seek a higher appeal, the AAT. Again he won immediately prior to the hearing, and consequently had 2 years of financial relief and presumed respite to finish some studies. These legal challenges took up many years of his time. Unfortunately after two years Social Security re-activated its draconian legislation requiring him to repeat procedures to prove his disability had not improved or might show permanent impacts to his 'requirement to work', and resolve him being permanently 'disabled'.

Repeating the need to revisit Social Security's outsourced corporation of independent medical or psychological health assessors testing failed to acknowledge genuine diagnosis or severity. However, Barry had continued to seek an explanation for his condition whilst on the initial disability pension and a recent intervention with a psychiatrist derived AS. Unfortunately, Social Security's testing disputed this or failed to accept his disabled severity. Alternatively, AutismSA a major non-govt. organization reiterate correctly that no definitive diagnostic test exists for AS. Literature supports this finding. This assessment organization continued to resist a positive outcome and attempted to implement its own choice of supplementary assessment tests such as the DASS. Persons who are less clearly differentiated under the ASD are sometimes *branded* as soft cases or 'too difficult' and given the mainstream assessment grade of 'PDD – NOS or pervasive developmental disorder [but] not otherwise specified'. Individuals in this grey box can easily be denied their right to disability pension or services, and sent home to rot or forced to work to the detriment of their health. My partner and I know of at least one family who have lost their mother or father due to suicide as bureaucratic regulations were forcibly and unjustly implemented. Legislation actually makes some service institutions such as Centrelink not capable, or exempt from wrongdoing. Furthermore, many smaller or regional Centrelink offices have no permanent social workers and probably no-one trained in clinical psychology, who might better serve a disabled or unwell, unfit person.

Owing to the severity of his yet undiagnosed condition, the difficulty in accessing an appropriate specialist and waiting times Barry continued study at a slower pace, sometimes aided by prescribed drugs (later shown to be detrimental rather than assisting his fatigue) and hindered by his need to seek yet another SSAT. Fortunately his persistence in determining what his condition was and his need to pursue the Master's degree enabled Barry to present a well-informed case to the SSAT. Barry's exhaustive knowledge on adult Asperger's Syndrome helped him to argue rightfully how so many experts and professionals, even GP's have no or little knowledge of Asperger's Syndrome, less so of the adult afflicted. Certainly no cure is expected in the near future and most of the rare research is aimed at children. No longitudinal study exists for Asperger's and little to no facilities, services exist specific to AS, in particular adults in SA, and probably Australia.

At this stage, with reference to the very good work of Bob Buckley's submission to the Productivity Commission, Barry wishes to endorse Buckley's 24 Recommendations in 'Disability Care and Support' with a few additional personal notes, and recommendations.

## Introduction:

Bob Buckley's submission is clearly focused upon Autism Spectrum Disorder, ASD, as to definitions and diagnostic parametrics outlined in the DSM-IV (4<sup>th</sup> ed.). It is widely used in Australia but cannot be relied on alone nor with supplementary aids given the diverse, complex spectrum or universe of the AS personality. There is no genetic test. For AS, in particular adults, autistic characteristics or features can be difficult to describe without a detailed history, and interview and assistance from the family involved. Any test should be made by an experienced clinical psychiatrist with workable knowledge of ASD or AS sufferers. Supplementary tests designed in Australia, such as the DASS score for measuring depression, anxiety or stress should only be taken as aids although clinical performance of these factors are nearing better than 70%. Given the smallness of the AS population no reliable assessments are possible. The DSM-IV continues to evolve and by 2012 may have introduced another variable such as 'empathy' into the equation. This new variable may not a 'silver bullet' for AS diagnosis. Some reasons for this are the inherent complexity of AS personality, [recall: no longitudinal study exists], and (as a late adult AS researcher) sufficient evidence suggests the need to introduce better personality tests and different factorials, including 'transpersonal variables', not omitting a more reliable, strong subjective test eg. Rorcharch Ink Blot Test (Mace 2009)

Like Buckley, I endorse his wise note (p3) that 'none of these disorders are a mild form of autism'. To this I posit Lathe, (2007), who advocates that all milder forms of (ASD or) AS never be assumed as mild, and be taken to be more severe in practicality. Buckley writes that, 'outcomes for the two other disorders that are part of ASD are not well known'; mention of PPD has been noted above, and in the case of high-functioning AS and those who have had fame such as Van Gogh (artist), Wittenstein (philosopher), George Orwell (author), Mozart (musician/composer) to name a few, these individuals suffered for their creative works and lived by difficult or troubled relationships. My own has its own irony and different realities to the preconceived normal life style but surely Australians can provide fair and just care and support to people with ASD (and AS) as a matter of course.

The 24 Recommendations and some more. ....

On Buckley's 'eligibility' stance, (**Recommendation 1.**) he is correct to say politicians and bureaucrats having fudged the reasons why the numbers of ASD diagnoses are rising and that the instances of marginalized care might suggest that profound or severe forms of ASD are manageable and receiving adequate care and support. The instances of correctly diagnosing adults with AS must acknowledge that their prior treatments may have been harmful (eg. convulsive electro-'shock' therapy and LSD therapy for wrongly diagnosed paranoid schizophrenia, etc.) at best merely unwarranted, and in some cases, because adults have long learned or conditioned life experiences are requiring 'special' if not otherwise, non-Medicare therapies which cannot be obtained due to limited finances, pensions, etc. The PDD-NOS division of the ASD continuum currently prevents/disadvantages many (a sizable portion of the ASD total population) from accessing due care. Amended DSM parametrics might reduce the numbers of these current disenfranchised ASD sufferers however a new universal health scheme must acknowledge more of these so-called borderline cases.

Buckley advocates the Cth failing to enact human rights legislation. This is of prime importance, **Recommendation 2**. However, recently SA enacted the Cth Discrimination legislation which reportedly betters Victorian and ACT legislation. My own experience with the new SA legislation by the EOC indicates that disability issues are now recognized but my personal experience illustrates how difficult it is to have this legislation enforced and I must provide my situation, which has been touched on earlier.

*[An Expanded Personal AS Tale:*

More than 10 years ago I had the need to report a neighbour's dog barking to my council that manages nuisance dogs under the SA Cat and Dog Management Act. At the time I was completing a take home exam for a degree and continuous barking late evening was upsetting my working. I reported an after hours complaints line supposedly to my council. Since then I understand after hours calls are not even recorded (or are unobtainable via an FOI because many SA councils outservice this responsibility to non-government agents exempt from the FOI ACT) and am told that I must forward a letter ASAP to council before anything will be done. For a Friday night this could have very dire circumstances because a dog might be free to bark until Monday and a letter, even an email might technically not be termed a letter, may not have been received, or the parttime official might be ill, otherwise involved in other work and so do nothing. Following receipt of the letter the official writes and assumedly speaks with the dog owner and warns him/her of the consequences of nuisance barking, and tells one to do the right thing or be fined. Presumably, nothing is done until this repeats itself and you have written another complaint. On this occasion you are told you have to keep a diary for two or more weeks (another added stress on the disabled complainant) and presumably so should the dog owner and surrounding neighbours. Theoretically, council one would assume information would be received that reinforces the complaint but in my area everyone owns a dog and legally up to 3, and all of them own nuisance dogs.

Consequently, no-one will support my complaints irrespective of my explaining on some occasions that dog barking affects my health. Council claims it might patrol more often in order to obtain evidence which should reinforce your complaint or for council dropping it. As it happens council has received letters from one previous dog owner who has threatened to sue me for harassing them, or ignore doing the right thing. Apparently I have been told by a non-govt org. that my council is amongst the worst SA council for managing dog barking but will not provide hard copy statements.

Council has quit the citronella collar which might remedy barking by claiming them to be cruel and has no alternative equipment. A Qld company, Bark Control Australia, specializes in hi-tech bark recording or electric shock collars but legislation does not require councils to use them. One Adelaide council trialed a collar some years ago (April 2007 or 8?) and reported their plan in a newspaper but no follow-up took place. I researched and discovered the trial had been a success but could not determine why the trial took place or why the results were not made public (about 6months later).

Council argued that it has sent vehicles around to observe dog barking instances but these are never on the day the dog offence occurred and although cars are said to wait and observe for 20 minutes I have observed one pulling up only to immediately depart or to cruise past very slowly. On one instance

barking had only just stopped prior to a car driving past. Afterwards barking resumed. Councils need to be more proactive in obtaining evidence and acting whenever random nuisance barking occurs irrespective of receiving complaints.

I have over the years made a number of videos of dogs barking from my house, from the footpath or outside a property. Only twice have I ventured onto vacant land or onto private property but council always says I cannot use video evidence in a court of law. I have utilized legal aid to assist me in my attempts to stop nuisance barking and often times no-one will do me justice over the impact it has had on my health. In 2008, after initial diagnosis with Asperger's Syndrome by accident I discovered that 70 to 85% of ASD (including AS?) suffer from hypersensitivity to noises.

Under the SA Environmental Act 'environmental noise' should include dog barking. Risk to one's health or well-being is similarly exempt from much legislation. SA police do not bother to investigate irrespective of harms incurred to a person's health and so no-one officially can reinforce your complaint. I live in an average country town amalgamated into a larger council with chief administration 30 km away. The local police station is only open some times every few days, otherwise after hours police calls go to the closest permanent police station which is 24 km away in another direction, or to Adelaide 50 kms away. Whereas local police have confirmed nuisance barking because they know my partner and myself and believe they should be more locally active, police will only report to council whereas I receive no police or council statement which can be used in a court of law. On the main, the police say they are too busy or do not bother to write out a report. Police from other stations merely refuse to investigate arguing that dogs are solely a council priority. Bob Buckley has recommended forensic support; more police support must be mandated where human health risk can be justified. Although not suicidal these issues have created a serious deterioration of my health. For me to move away would force me to leave my partner or both of us to sell our property. Many ASD or AS people suffer trauma when their independence is threatened. Trauma has been reduced by my need to have a garden (personal therapy).

On the other hand, a neighbour's dog barking case was recently assessed positively by a barrister however she won't proceed unless I can provide \$4,000 up front. As I cannot work normal hours at a time anymore it is unlikely I could seek compensation or justice. I sought an Adelaide university pro-bono service earlier but they would not take on my earlier requests for lack of funds. I had a State Ombudsman who eventually arranged a meeting with two council employees and myself but he conveniently failed to bring my 3-ringer folder of evidence and no facility had been arranged to view my DVD of dogs barking. Furthermore, no brief had even been given to prepare me for the meeting and although this was only a preliminary assessment I think some authorities (ignorant of the procedures) believe I have had the highest involvement for hearing my grievances, apparently failed, so must be a trouble maker or a liar.

Another major discrepancy is my requirement of providing my diagnosis to council officers to support my health argument against harassing dog barking. These remain at council archives but have not assisted me in any way. Do these people have health or psychological training, I think not? This is unnecessary or discriminatory requirement of the process. There is an unfair management policy and

practice at my council but according to the Equal Opportunity Commission lawyer, "I am not being discriminated against because every ratepayer receives the same level of bogus nuisance dog management." Why do I have no faith in the system?]

According to SA governance and legislation, DisabilitySA, formerly the main State govt. dept. servicing mental health and disabilities was disenfranchised of its responsibilities to legal or some social services. Instead private non-governmental agents were encouraged to fill in the void but these remain funded by the SA govt. which continues to decrease funding. [AutismSA is the major ASD shareholder and is a non-government body. Since 2009 AutismSA have promoted adults AS sufferers a social agenda which now costs \$125/yr to join. This may not be compulsory but either way I cannot afford to pay it]. I have attempted to access two of these non-govt. advocacy groups. One gave me a contract which merely stipulated that 1) they would deal with my issue concerning barking and the impact caused on my health, and, 2) to provide pressure on council. Neither of these were carried out sufficiently primarily because of the nature of the request and secondly because it was outside their jurisdiction and power to do so. At the time I provided a letter of complaint for a new neighbour whose dogs' barking had exceeded 4 hours of loud barking, asking her to edit it, to assist in her dealings with council and to send it on to council. To this day I believe she never sent it or used it. I provide a separate diary for this advocacy agency, see 'MALSSA' document. There is no accountability or reliability for services for a disabled person, in particular for myself with AS. Services appear to imitate a merry-go-round, cyclic incompetency and neglect *ad nauseum*.

Buckley speaks of delays to those seeking ASD/AS diagnosis. This experience is shared in SA. I had to wait about 12 months. Diagnosis by AutismSA was about \$120 and they acknowledged my financial hardship and accepted half price. Today a friend recently diagnosed cost \$400, **Recommendation 3**. A need exists now for multiple pathways into services. Based on individual needs; information above testifies to the extreme divergence of the AS personality. The adult incidence of ASD/AS further compounds the need for screening and diagnosis, **Recommendation 4**. An ASD awareness campaign is necessary from adult diagnostic experience to ensure professionals understand that adults exist with ASD/AS and their needs are as individual as the children these professionals have been limited to in their working lives. This statement does not negate **Recommendation 5** but reinforces it! Adults can be patronized and argued with when they advocate their unique disabilities or experiences. Professionals need to understand that being late diagnosed adults illustrates that they have arrived there lacking assistance, and because they can verbalise their condition doesn't mean they have overcome all of their detriments. It is likely, needs have become more maturer, more deeper, **Recommendation 6, 7, 8**.

Buckley states " ... people with ASD have substantial unmet needs across other key disability service areas including education, accommodation support and employment," **Recommendation 9**. Adults with ASD, in particular, those with own children need family, carer, recreation, finance and other support, **Recommendation 10**. Buckley provides some key facts from the UK Adult Psychiatric Morbidity Survey 2009; he notes 'no increased treatment for mental or emotional problems' which is contrary to another publication, as well as my personal life study situation. Buckley suggests undiagnosis/misdiagnosis

and/or denial of service as common Australian examples. Adults with ASD rarely get assistance p7. The reference to males with higher education qualification having lower prevalence of ASD appears puzzling, and lacking scrutiny, **Recommendation 11**. Consequently ASD research is wanting and requires increased funding. Unfairness is exemplified by my example with the EOC and with Buckley's statement that 'Australian law does not protect people with ASD from discrimination,' p8; **Recommendation 12** is mandatory! Change must be accepted cross the board, **Recommendation 13**; and a disability safety net should ensure ASD needs are met appropriately, Recommendations **14., 15., and 16**. Generic (specialist?) disability services must also be accommodated more fairly, **Recommendation 17** and it is vitally important that a model for diagnosis and delivery involve only 'clinicians with specific knowledge of ASD.'

Buckley is correct when he posits accommodation services and support for adults are in crisis. A truly comprehensive universal health scheme MUST address the anomalies current in the system which prevent essential services from meeting the needs of ASD and AS people, and all those with disability related health problems. Behavioural services are abusing those in need by professionals and bureaucrats who have vested interests and / or philosophies / political views counter to correct diagnosis, fair treatment, service delivery and complaints. Clearly, the current service model is unsatisfactory and unworkable, **Recommendation 18**. It would be wise to suggest many, if not most ASD people might require life support services and in the case of AS changing circumstances, eg. aging might require newer or alternative effective programs, **Recommendations 19., and 20**. Buckley highlights the "efficiency dividend" constraint or the government's practice of persistently cutting funds when no effective review justifies these impacts, **Recommendations 21., and 22**.

My own example helps illustrate that services are often non-existent, are encumbered by unnecessary complexities of bureaucracy or poor knowledge of the needs, networking of professional affiliations or lack of research. An on-going R&D mentality would assist in cutting cost and delivery. Secondly, ASD services should revolve around individualized person care; my own research has suggested integrated life practice methodologies for all. Mainstreaming has a place but should not be an economic nor social imperative for some institutions. Specialised one to one delivery might better ensure some self-improvement; eg. 'mindfulness' therapies could assist in elevating ASD people, their carers, and families' everyday lives however, only able-minded persons should participate. The current omission of many AS sufferers from the Government's disability costings and service delivery audit is criminal neglect, **Recommendations 23., and 24**.

**Recommendation 25**. Improved communication and shared experiences dialogue.

Given my deemed late diagnosis adult AS perspective, I might add that an intervention program might be set up where adults with AS could provide talks, or advice on their successes in life. AutismSA has only recently begun a social network for its increasingly identified AS males and female members. AS people help organize these events and for those more financially able to participate experience social bonding and recreational pursuits. In SA, males and females with AS have previously been separate from each other but recently joint events have enabled each communities to collaborate in games, BBQs, films or day out activities. Many adults are independent enough to parttake of these events however



their carers or family members supervise the less abled. Ages range from teenagers to midlifers; it is an obvious advantage for younger members to meet and gain a realization that their older colleagues have produced positive lives. Similar intervention might also be undertaken in primary or secondary schools, or at tertiary institutions so that children and parents of ASD or AS students can gain constructive advice from these adults with experience. Admittedly, one would hope councillors have acquired adequate training in ASD.

**Recommendation 26.** Raise the general community awareness of ASD.

Allied and Official Health Department/Organisations to sponsor people with ASD through schools and tertiary education. Specially funded art exhibitions for ASD and AS people.

**Recommendation 27.** Raise employment options for AS or for high-functioning ASD graduates. AS adults have superior 'researching' skills, originality and ideas. Although special niches may be needed for some to function in a traditional work culture, the benefits to the employer, AS person and to the larger society are obvious and cost-effective therapy in the longterm.

Thankyou for the opportunity to take part in the *Disability Care and Support Enquiry*.

Re- Barry /13 Sept. 2010.

# CASE CLOSURE LETTER



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MALSSA  
INCORPORATED

Dear Mr B

It appears that your case about dog barks in your area that have attempted to help you with can not be pursued further. As explained earlier to you via email that your issue could only be resolved in the long term through policy or legislative change.

Please telephone us on 81222714 if you need help from MALSSA in the future. We wish you all the best.

.....  
Individual Advocate  
On behalf of MALSSA.

31.05.2010