

## **Inquiry into services for people with autism spectrum disorder**

My name is Janeane Baker, and I am the mother of a 15 year old boy who has high functioning Autism.

I write this submission in the capacity as an individual submission, but also as the founding member of a group called 'Change The Criteria' – a group of parents, carers and friends who are concerned about the lack of accessibility to education support funding for students in Victoria on the autism spectrum.

As a single mother, who works full time, I have had several experiences that I feel cover the terms of reference of this enquiry and I welcome the opportunity to make this submission. I would also welcome the opportunity to speak at a Public Hearing if deemed appropriate by the Committee that I do so.

### **In relation to access to education:**

I attach as Appendix A, the Change The Criteria submission to the Federal Senate inquiry into access to education for students with a Disability (main body of document only, appendices not included)

I and several members of Change The Criteria have completed the questionnaire that formed part of the recent funding review of PSD in Victoria.

There is a major problem with the funding for education assistance within the ASD category of the Program for Students With Disability.

The problem is that of the three criteria that need to be met to obtain funding, one is a significant language deficit.

The reality is that many children at the higher end of the Autism Spectrum, such as my son, do not have what the criteria classes as a 'language deficit'. However, their 'Autistic traits' (for want of a better term) are still extremely strong, making the classroom/school ground/social expectations a veritable nightmare for them to negotiate.

In my own son's case, he failed to obtain ASD funding under the 2013 PSD, despite the fact that since grade Prep in 2006 he had attended the specialist setting, and had never been considered to be an appropriate candidate for integration into mainstream setting. At his mandatory funding review in year six (which I was unaware he was going to be having), I was advised that despite meeting two criteria, he didn't meet the language criteria. Therefore, he would be unable to continue to attend specialist setting in his high school years, and would not attract any support funding at a mainstream high school. At all.

This was literally a horrifying situation to be in.

In the end, I was able to 'circumnavigate' the 'system', and was able to attract funding under Severe Behaviour Disorder. However, in order to do this, I had to advise that my son's 'bad behaviour' was NOT related to his autism (it is).

As parents of children on the Autism spectrum, we spend a lot of time encouraging our children to 'be who they are', to be 'proud of who they are'. I personally spend a lot of time telling my son that yes, he has autism, but that this is not something to be embarrassed or ashamed about.

However, when push came to shove, it was ME who had to deny my son's autism, and on paper have him marked down as a 'naughty boy' so that he was allowed to remain in the specialist setting that he so desperately needed.

As each of my son's birthdays have passed, I have now come to realise that my son is one of the students for which there is 'no place' in the education system.

In relation to socialising, compliance with rules, pragmatic communication, emotional and behavioural aspects of his autism, the specialist setting is definitely the place for him.

In relation to the academic side of his education, he is unable to thrive in this setting due to the 'functional' nature of the curriculum, focusing a lot on life skills.

He is a super intelligent fellow who will probably never be able to reach his full academic potential as there is no place for him in the education system to enable him to achieve this.

Last year I did look into VCAL at mainstream campuses local to me who have concurrent enrolment with two specialist setting schools in the area. Both programs looked fantastic, so I made the calls.

Imagine my sadness when I was asked whether my son had an intellectual disability (IQ less than 70). He does not, and therefore did not qualify for either of these programs.

**This appears to me to be a lack of understanding of ASD and the fact that it is not strictly an Intellectual Disability.** The fact that it is NOT, has precluded my son from attending what appears to be quite a good program at the VCAL level.

The funding criteria for ASD educational assistance MUST be changed. There are too many students falling through the cracks. The consequences of this are massive – not only do these children miss out on a complete education; they do not leave school prepared for the wider world. They do not leave school prepared for the working world. They are destined to end up on welfare, costing the economy millions of dollars. Their families undergo such stress because of there being 'nowhere for my child'. Some of them get turned away from enrolling in school because of lack of funding assistance. Others end up schooling part time. Parents cannot work because they need to be available for the constant calls from school to come and get their 'unmanageable' child.

An ideal situation would be a base room at at least one or two mainstream public schools within each school zone to accommodate children who may not 'fit' into either the mainstream or specialist settings.

**I note the most ironic aspect of the funding issue: since his diagnosis of Autism at the age of four years and ten months, my son has qualified for a health care card. He is not, however, afforded educational assistance for that very same diagnosis under the Victorian Program for Students with a Disability. Instead, on paper, he is a student with a 'Severe Behaviour Disorder'.**

I refer the Committee to the Victorian Auditor General's report of 2012 – Programs for Students with Special Learning Needs - and the recommendations contained therein. Also note this report contains statistics of the increase on students being funded under Severe Behaviour Disorder. There is no doubt in my mind that this is because, like me, families have had to 'fudge the system' in order

to get some kind of funding for their ASD child who does not qualify for ASD funding because of Criteria C. “Whatever it takes” is heard from many parents like me.

### Transport to and from school

My son attends the Lalor campus of the Northern School for Autism.

He catches the school bus to school every day.

At the time he began at the campus in 2013, I was advised that there was no funding for a school bus to travel directly to his school, as technically the Lalor campus is only an ‘annexe’ of the Reservoir campus, and there is no funding available for a bus to an ‘annexe’.

So, every school day, my son gets on the school bus at our allocated bus stop, which takes him to the Reservoir campus. He disembarks from the school bus, and gets onto a ‘shuttle bus’ that takes him to the Lalor campus. In the afternoon, he leaves Lalor on the ‘shuttle bus’ to Reservoir, disembarks from this bus, gets on to what we refer to as the ‘normal travel’ bus, and gets off at the bus stop we are allocated.

This year, however, is a little different.

He gets on the school bus at our allocated bus stop, which takes him to the Reservoir campus **via the Lalor campus where two Reservoir students get picked up, in the driveway, under the portico**. At the time of writing this submission my son is not allowed to get off at the Lalor campus at this point, no doubt I suspect due to the vagaries of funding bureaucracy and associated insurances. Instead, my son still travels through to Reservoir campus, disembarks from the bus, gets on the shuttle bus, and travels BACK to the Lalor campus where he has been not half an hour earlier. The same thing happens in reverse in the afternoons.

Naturally, I have already approached the school about this ridiculous situation.

Why isn’t a bus funded directly to the Lalor campus? My son is not the only student affected by this, there are at least four other students who have to do this travel daily now.

My son, after three days of a new school year, has come home agitated and frustrated at having to make an unnecessary trip on the shuttle bus.

It is only a matter of time before he can no longer handle the frustration and anxiety this creates for him, and we will then be facing school avoidance and higher than normal stress levels, both at home and at school.

### In relation to access to health and community services

As my son has matured into his teenage years, he has developed depression, OCD, anxiety. This is not uncommon amongst teenagers on the Spectrum.

His depression has become so bad that at times he has been suicidal.

As his mother, this has been extremely hard not only to observe, but also to manage.

I am glad to have an extremely supportive employer, where I work full time. They understand that there are times when I am unable to work due to my son’s ‘issues’. But I must say that it does take

it's toll on my working life (through requiring more days off than I would consider 'normal'), and also on my personal health and well being.

I have sought out private practitioners (psychologists, psychiatrists) to assist my son in this, and have had some difficulty in finding the right 'fit' due to my son's ASD. This is because the waiting list for public funded services is ridiculous.

We thought we were on to a good thing, when six months after placing a referral with DHS, we were matched up with a case worker under the Behavioural Intervention Service/Family Intervention Service. I note this was a voluntary referral, suggested by my son's Psychiatrist. It was not the result of a report by a third party to DHS.

A lovely DHS worked by the name of Sharon attended our house and discussed our needs with us. She offered us literature and websites that would assist us.

Sharon attended a second time, it was great to have someone to talk to about the challenges I was facing in relation to my son, his Autism, and his now obvious depression issues.

At the third visit, Sharon advised us that it would be our last visit, as the funding had been ceased and there was going to be a restructure that would result in the program no longer being offered.

As they say in the classics: "Enough said". I'm sure you can imagine my dismay at being told this information. I cried myself to sleep (again) that night.

A referral to the Children's hospital from our GP in November 2014 resulted in an eight month wait to attend a clinic. Originally she had referred us to the Autism clinic at RCH, however with the waiting list there being 13 months long, and knowing that we were in crisis, she referred us also to the Behavioural Sciences unit.

After 8 months we were pleased to receive our appointment time, and I, as the mother, became hopeful that finally after a couple of years of up/down/in/out we finally had a place to go.

We arrived to be told that this 'really wasn't the place for' my son. The lovely doctor still spent over an hour with us, and wrote us a letter that for the first time had in writing that it was obvious that my son had depression, OCD tendencies etc. His suggestion, however, was that really he didn't think it was appropriate for my son to continue attending the clinic, as it was for younger children with behavioural problems, and he couldn't really understand why we had been referred there in the first place. (He got offended when I told him that our GP had thought it was a good option given that the Autism clinic had such a long waiting list – "What? We're sloppy seconds?")

Upon his suggestion we have returned to our original psych who thankfully bulk bills. It seems to be going OK so far, but it has been a long long journey to this point.

More recently I have had a couple of 'late night early morning' meltdown sessions from my son, where I have been concerned about his mental state. During these times, I very seriously considered taking him to the emergency at RCH. What stopped me was the fear of turning up to casualty, and crossing over somehow from the 'Autism' system to the 'Mental Health' system which of course has challenges of its own. I chose to somehow get through (and we did) rather than turn up to a casualty department where my biggest fear was that there wouldn't be anyone there who understood Autism and its associated mental health issues.

My feat for my son's future revolves a lot around a lack of trained professionals who will be able to understand that his mental health issues may not necessarily be conditions 'on their own', but

rather are likely to be a part of his Autism. I would hate for him to be diagnosed as having a mental illness when in actual fact it is his autism that causes him to behave this way.

It would be great if there was somewhere that we could go that specialised in Autism, so that there were no wrong diagnoses of mental health issues over and above the mental health issues that are commonly associated with ASD.

#### Family day and after school care

Although my son is now 15 years of age, I thought it pertinent to write about my experiences when he was younger, which really isn't that long ago.

I have worked full time for the past three years, and consider myself lucky to work literally a five minute drive from home. My son is now capable of staying home alone during the day, although he cannot prepare meals for himself, so thankfully I can dash home on my lunch break and attend to his needs. Even more thankfully, when he is mentally well, he is not a danger to himself.

The story was different when he was younger, however.

School holidays became a nightmare, trying to find appropriate care for him. I no longer have living parents, so this was not an option. I am a single mother, my ex partner while somewhat involved, is not involved enough to enable long term care at times such as school holidays.

It has never been an option to leave my son with friends/family due to his unpredictable behaviour. Believe me, I've tried, and it has never worked.

It was a horrendous experience trying to find school holiday programs, or when he was much younger, family day care programs to cater for someone like my son. I did manage to get him enrolled in both of these things, the access wasn't necessarily the problem (with the correct details supporting paperwork which took a long time to get together). The problem was the obvious lack of Autism specific training that the staff at these settings. My son was 'kicked out of family day care' – which I laugh about now (what else can you do), but which was very devastating at the time. He was also 'kicked out of school holiday program'.

I investigated private, in home care (Nanny), for which the cost was astronomical, but where there WERE a small number of qualified people who were able to work with kids with a disability. I found out that I would have qualified for some money back under the childcare rebate scheme somehow. I found out that I needed to give them at least twelve months' notice that I would require their services because there weren't enough carers to meet demand. A state-funded service such as this would be an amazing help to families.

And once again, I was in the position where no matter how much I wanted to contribute to the community and the economy by working, I was unable to do so to the level that I desired, because I was 'unlucky' enough to be the mother of a child with Autism, who just didn't seem to fit anywhere.

I resorted to paying cash to someone that I trusted enough to leave my son with. She was an integration aide at the time, she is now studying to be a teacher. She still spends a couple of days with my son during school holidays, so that he gets out of the house as much as possible while I am working. I still pay her in cash, she is my only option. I'm a taxpayer, I believe in paying taxes, but I am paying for my child's care on the 'black economy' because there's no other option. Some might say I am lucky to be in a position to be able to afford this. That would be true to a degree. I am not highly paid, and we go without things in order to be able to afford the help that I have from this

person. The alternative is that I do not work at all, so that I can be home during school holidays to care for me son. There's not many jobs that allow you to take the school holidays off!

I note that there ARE school holiday programs for children with disabilities.

There just aren't enough. More specifically, there aren't enough for kids on the Autism spectrum. It's a really special cohort of kids and teenagers that need a certain type of care. From specially trained staff.

I further note that, in relation to the bus issue I have mentioned above, discussions with the school have resulted in a warning that my son may not be able to get off the bus when it gets to Lalor in the morning as there is no before or after school care available within the specialist setting.

**I believe that before and after school care for students of all ages in specialist setting is a 'must provide' option for families that require this service. We cannot place our children into mainstream before and after school care programs – we need programs that are autism centred and specialised. Or, we need specially trained staff at mainstream programs to care for our children.** I have never heard a parent of a child on the autism spectrum talk about their child being in before/after school care. I suspect this is because, as was my experience, there are none available.

#### **In relation to the NDIS, employment and housing**

As my son is still in his teenage years, and my area will not receive the NDIS for some time, I am not familiar with the processes involved in this scheme as yet. I hope, however, that it is easy to navigate, and that people are treated as individuals, not numbers.

In relation to employment – I have big fears for my son, who at this point in time is showing signs that it will be quite difficult for him to obtain employment and if lucky enough to do so, to remain employed for a significant length of time.

My biggest fear in relation to my son's future, is that similar to the education funding at the moment, he will not qualify for assistance due to a criteria that deems him 'able to find work'. I do listen to parliament on a regular basis, and note that recent discussions around the DSP in the House of Representatives saw both major parties supporting a 'crack down' on the DSP and how people will qualify, receive it etc. I hold the same fears in relation to qualifying for assistance under the NDIS (although I admit that at the moment my fear is based on not being fully informed of how the scheme will run).

If my son finds himself in the situation of not being able to gain employment, or sustain employment, I do not want him to receive unemployment benefits. If he NEEDS government support, I want it to reflect the reason WHY he cannot work – because he has a disability that prevents him from being effectively employed. It might sound bizarre, however the services one receives on disability support are different to those that a person receives on employment support. If my son finds himself in the situation of not being able to work, the training programs that are provided under employment support will not assist him. However, he will need access to medical services, psych services, and employment training programs that have disability in mind. Writing a resume will not be what he needs to be trained in. As an adult, it is highly likely that he will still need further training in how to communicate effectively with neurotypical workmates, how to understand employment contracts, how to get to work, self care so that he gets a job, how important it is to shower daily so that you can present well at work, how to turn up on time etc. All the things that people like you and I already know but that HE is likely to always need to be guided on.

**Thankyou**

I would like to take this opportunity to thank the Andrews Government for the action it is taking in this area. Change The Criteria was pleased to be invited to attend a round table discussion with Daniel Andrews and James Merlino at the time that the ALP was in Opposition. It is encouraging to think that this meeting, in part, has contributed to this enquiry, and to the recent PSD Funding Review. From little things...big things grow.

Janeane Baker

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## **Appendix A: Change The Criteria – Submission to Senate Enquiry, 2015**

### **Submission to Senate Inquiry:**

**Inquiry: the Current levels of access and attainment for students with disability in the school system, and the impact on students and families associated with inadequate levels of support.**

My name is Janeane Baker, I am the mother of William Baker, aged 15.

William suffers from high functioning Autism, diagnosed at 4 years of age.

Since prep (aged five), William has attended the Northern School for Autism, and had never been considered an appropriate candidate for mainstream schooling on any level. Despite a 'good' level of verbal skills, his pragmatic language had severe deficits, and his 'autistic deficits' (behaviour, social, communicative) have always been large.

In May 2012 I was devastated to be advised by his school principal that he had failed a mandatory funding review (mandatory in Victoria when a child is in grade six or equivalent) and was at great risk of being thrown into the mainstream system for his high school years, WITHOUT an aide of any sort.

The reason for this was the criteria that is used to procure funding for students with ASD in Victoria – three criteria must be met, one of which is a severe language deficit, which William no longer has (due to extensive efforts on my part and the part of his teachers to work with him on this)

The outcome of our situation was that we had to apply for funding under 'Severe Behaviour Disorder', which we subsequently received and were able to keep William in the specialist setting that he needed.

However, in the process, I had to DENY that my son's autism has anything to do with his behavioural issues (see Appendix A) and on paper he is now funded because he is a 'naughty boy', and NOT because he is autistic.

The stress that this whole process placed on myself as a single mother back in 2012 is still being experienced by families in Victoria 3 years down the track – the funding criteria has not changed. Many children will be slipping through the cracks, many families will be feeling the pressure of having to take their children out of the specialist setting and put them un-supported into the mainstream setting. Those families who choose to educate their ASD child in the mainstream setting are finding themselves and their children unsupported.

**A parent's right to choose where and how their child is educated is often taken away because of the lack of support available for students on the Autism spectrum.**

As a result of our funding challenge in 2012, I set up a group called 'Change The Criteria'. This is a Facebook based support group, made up of people who are affected by the funding issues (particularly with ASD funding, but more often now we are also seeing people who are affected by funding under IQ, where their children are just missing out on much needed support because the 'line in the sand' for this funding is also ridiculously prejudicial). There are currently 379 members of the group, as it also includes people who know people that are affected, and recognise how stupid the funding criteria is in this state.

Within the group we constantly see the results of children not being funded to receive much needed educational support. From children who constantly require early collection from school because they or the staff can't cope, to teenagers who are now avoiding school altogether due to high anxiety that results from not being supported within the mainstream school system.

We see/hear about family breakdown as a result of the stresses that an unsupported education places on the ASD student, family, carers and friendships.

In one case, a mother chose to voluntarily place her child into state care because she was unable to cope with her son, who had been rejected from several school settings due to the fact that he was unable to attract support funding because he didn't satisfy ALL THREE criteria (he was verbal). While the issue of this boy's education was obviously not the only issue in that family's world, it significantly contributed to the general angst that the family went through as they tried to find some kind of school setting for the boy they loved so very much.

In September 2012 the Victorian Auditor General's Office (VAGO) released a report into the Program for Students with Disabilities in Victoria, the funding criteria and recommended changes (as part of this submission, see attached the Change The Criteria official response to this report, Appendix B).

One of the most disappointing findings was that there appeared to be little or no accountability by the Department in relation to keeping track of the outcomes of individual students who had been funded.

Therefore, it follows that they would not know whether previous funding helped an individual student or not, but rather they simply base their funding criteria at the mandatory year six review on a 'blanket' scale, as a result of which so very many students fall through the educational cracks.

**This is not just an educational issue: it is a social issue, it is a families issue, it is a mental health issue (many students with ASD will also suffer mental health issues such as anxiety/depression), it is a communities issue.** It is also an economic issue – for the money that is invested in our students now is saved down the track when they ARE able to get a job and contribute to society in a meaningful manner. **With little or no support during their school years, ASD students enter the adult world as fragile, unprepared individuals. They are at major risk of becoming adults who are entirely dependent on welfare.**

**This is also a human rights issue: we all have the right to achieve our full potential, and to receive an education that is relevant and accessible to us. In the state of Victoria there are too many ASD students who are denied this right, due to the prohibitive funding criteria they need to meet.**

**The irony is that many children who are on the higher end of the Autism spectrum are extremely intelligent, but are unable to utilise this intelligence due to their autistic traits being so strong. With the correct supports in place, these children could achieve so very much – without the support, their intelligence is wasted. We are potentially losing some of the future professionals who could help put Australia on the map as the smart country. Somewhere out there we may have the person who finds the cure to cancer, or discovers something amazing about the Universe, but we may be letting them slip through the educational cracks when they are 14 years old.**

Successive Victorian governments have talked about how funding for these students has increased; how money has been spent on new ASD specific schools (it has), and programs to make mainstream schools more ASD friendly (it has). But 'autism friendly' schools, while helping somewhat, do not prepare a child for the real world. These students need individual support, to teach them how to exist in a community, while working with their individual conditions.

It is irrelevant if the 'money is there' when students who need this money spent on them **cannot access it due to the restrictive criteria that is in place.**

The Victorian State government has recently announced a review of the funding criteria used under the Program for Students with Disabilities. We will also be making submission to that committee.

As a group of affected parents, carers, grandparents, family and friends, Change The Criteria desperately hopes that funding changes occur, so that future generations of students with ASD do not go through the

anxieties that our own children have; and so that families do not have to suffer the unnecessary stress of seeing their dearly loved children struggle in a world that is already difficult for them.

--end of Appendix A--

-----END OF SUBMISSION-----