

Bendigo Autistic Advocacy
and Support Service

Co-Convenors
Beck Kelly - Tony Langdon - Susanna Flanagan

Bendigo Autistic Advocacy and Support Service

Public Statement

In response to:

The Parliament of Victoria Family and Community Development Committee *Inquiry into services for people with Autism Spectrum Disorder - Final Report*

and

The 'I am for the 101' petition and campaign by Amaze.

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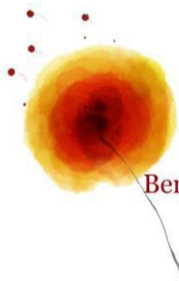
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BAASS responds to the Parliament of Victoria Family and Community Development Committee *Inquiry into services for people with Autism Spectrum Disorder- Final Report 2017* [referred throughout as the “Inquiry” and “the Report” and “Report Recommendations”] and in opposition of numerous recommendations and the ‘I am for the 101’ petition and campaign by Amaze.

The Report contains 101 recommendations in the interests of “inclusion in the community for [autistic people] in consultation with both [autistic people] that are self-advocates and with [autism] advocacy groups.”

There are indeed, many recommendations that we support - that reflect a genuine, meaningful and respectful basis as relate to autistic people. We appreciate the effort and intention behind the Inquiry and the opportunity to contribute and present at the Inquiry.

There are, however, some very problematic recommendations that have the potential to further harm the autistic community or reflect a monetary and/or biased interest or foundation.

The Inquiry Recommendations and BAASS response.

We would like to respond to some Report Recommendations and in some cases, provide our own recommendations with the intention of supporting an addendum to the Report. This is not an exhaustive response, but incorporates the points we feel most poignant.

Report Recommendation 1

•Terminology

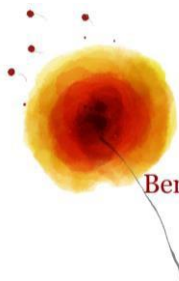
Whilst it is recognised within the Report, that the majority of the autistic community prefers identity first language, the inquiry report then proceeds to use the more offensive of options available.

The majority of the autistic community find the use of “ASD” and pathologising language around autism to be offensive, distressing, devaluing and misinformed. **There are neutral options around terminology that could be used throughout the report and recommendations, that is respectful of the autistic community - encompassing of a range of individual preferences.**

This report and its recommendations are about people - their lives, safety and wellbeing, families and supports. Reducing the autistic community to specimens via medical terminology has made this report - for and about autistic people - incredibly difficult and distressing to read.

BAASS Response and Recommendations

If not using identity first language, we would consider it most appropriate and respectful to at least *use the most neutral*; for example: autism and/or on the spectrum.



BAASS uses identity first language and as such will use 'autistic' throughout our response and recommendations. We would like to explain further why this is the preference of the majority of the autistic community. Autism cannot be separated from every aspect of our being - our experiences, responses, views.

To recognise in the report, that many autistic people and organisations reject the term 'ASD' and find it distressing and/or offensive but to continue using it prolifically throughout the report, is disrespectful and perpetuates further distress for autistic people and misrepresents us.

It is important to note that autism cannot be separated from the person, autism is a part of every aspect of our being- our experiences, perception, function, responses, views.

"We are proud to be called autistic and believe autism positive language promotes equality and acceptance. Identity-first language tells society that we should be respected along with our differences, not in spite of them." (Identity First Autistic).

Lydia Brown, cited on The Autistic Self Advocacy Network website, expresses the importance of language, identity first language and the preferences of the majority of the autistic community:

"Words and language are powerful tools by which an individual can express ideas, whether abstract, actionable, or concrete. As a writer and editor, I know firsthand that language and the meanings we attach to words very much impact, influence, develop, and change the attitudes that we have toward the subjects of discussion."

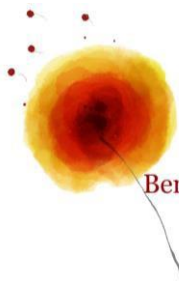
Brown then explains the importance and difference between self - identification and preferences as opposed to non-autistic people and their reasoning for this:

'In the autism community, many self-advocates and their allies prefer terminology such as "Autistic," "Autistic person," or "Autistic individual" because we understand autism as an inherent part of an individual's identity — the same way one refers to "Muslims," "African-Americans," "Lesbian/Gay/Bisexual/Transgender/Queer," "Chinese," "gifted," "athletic," or "Jewish." On the other hand, many parents of Autistic people and professionals who work with Autistic people prefer terminology such as "person with autism," "people with autism," or "individual with ASD" because they do not consider autism to be part of an individual's identity and do not want their children to be identified or referred to as "Autistic." They want "person-first language," that puts "person" before any identifier such as "autism," in order to emphasize the humanity of their children.'

Brown (2011) describes nuances around person-first language as attitudinal and suggesting that autism can be separated from the person "which simply isn't true. It is impossible to separate a person from autism, just as it is impossible to separate a person from the color of [their] skin."

As Brown (2011) aptly extrapolates:

Autism, however, is not a disease. It is a neurological, developmental condition;
... it is disabling in many and varied ways. It is lifelong.
It does not harm or kill of its own accord. It is an edifying and meaningful



component of a person's identity, and it defines the ways in which an individual experiences and understands the world around [them]. It is all-pervasive.

"It is impossible to affirm the value and worth of an Autistic person without recognizing his or her identity as an Autistic person. Referring to me as "a person with autism," or "an individual with ASD" demeans who I am because it denies who I am." (Brown, 2011)

The importance around considering and respecting language is further explored by Brown (2011) in elucidating that:

Lastly, what is most interesting indeed is the shared expressed sentiments that using or not using person-first language is necessary to change and shift societal attitudes toward Autistic people. Returning to the premise of this article, this is the sole reason why this debate continues to be argued and why many people on both sides regularly emerge upset and feel personally attacked. Language *does* play a large role in shaping societal attitudes.

But let's think about what we are doing when we use these terms. When we say "person with autism," we say that it is unfortunate and an accident that a person is Autistic. We affirm that the person has value and worth, and that autism is entirely separate from what gives him or her value and worth. In fact, we are saying that autism is detrimental to value and worth as a person, which is why we separate the condition with the word "with" or "has." Ultimately, what we are saying when we say "person with autism" is that the person would be better off if not Autistic, and that it would have been better if he or she had been born typical. We suppress the individual's identity as an Autistic person because we are saying that autism is something inherently bad like a disease.

Yet, when we say "Autistic person," we recognize, affirm, and validate an individual's identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual's potential to grow and mature, to overcome challenges and disability, and to live a meaningful life *as an Autistic*. Ultimately, we are accepting that the individual is different from non-Autistic people—and that that's not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference.

It is our position that identity first language is the preference of the majority of the autistic community, including ourselves personally. **We do ensure to maintain clarity around the importance of always deferring to the person and accepting personal preferences.**

Future publications and Report Addendum should include neutral terminology in the interests of inclusion of a wider range of community.

Report Recommendation 1.2

This recommendation makes mention of provision of “ongoing, viable and affordable respite care available across the state.”

BAASS Response and Recommendations 1.2

The term and concept around ‘respite’ holds negative connotations and further contributes to stereotypes around disability. The Oxford and Cambridge English Dictionaries define ‘respite’ as “a pause or rest/or relief from something difficult or unpleasant.”

‘Respite’ is a term and concept that further perpetuates stigma and misconceptions around autism and disability in general- it quite literally infers that autistic people are “unpleasant”, cause “difficulty” and in general is dehumanising and offensive in itself. Not only is this concept inappropriate and offensive; it stems from archaic harmful views that disabled people are ‘less than’, are in need of ‘cures’ or aborting, are to be pitied and are a cause of disruption and phenomenal burden.

The recommendation also includes that the Victorian Government ensure that “...families living with ASD are provided proper supports..”

This is both a positive and negative statement. This recommendation is positive in that it recommends that autistic people and their families/carers receive adequate, relevant support.

We acknowledge that this concept originates from a place of desperation resulting from a significant lack of support. It is absolutely critical that autistic people and families have respectful and appropriate support.

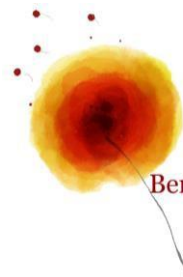
However, as rephrased above, it is more accurate and respectful to consider families and carers not as “living with ASD”, as they are not. They are supporting autistic family/loved ones and **all** people need support in a myriad of ways. Autistic people and their families are classically unable to access relevant, respectful and appropriate supports for their needs.

Supporting autistic people and their families/carers in appropriate, accessible and respectful ways, negates the need for ‘respite’.

Report 2.2.1

Autistic people accessing support through the Department of Health and Human Service (DHHS) under the *Disability Act 2006* such as supported accommodation, personal care and day programs.

The Report discusses the Victorian Government provision of funding for providers to deliver services for autistic people, making specific mention of services such as ‘Aspect’ and ‘Autism Plus’.



We feel this particularly requires highlighting not only due to their inclusion in the final report but also due to serious concerns BAASS has in regards to ongoing abuse reports that have been reported and proven in relation to both of these providers.

Submission 58 to the Inquiry reports a number of witnessed incidents that included restrictive practices, client abuse and poor quality of client care whilst employed at the Aspect Heatherton day service. One of these incidents made national headline news.

This submission was one reporting a “wooden box like structure”, referred to in the press as a “coffin” that was built in September 2014, “was built by staff to effectively lock clients in under the guise of a behaviour support strategy” Clients were also given the task to paint this box, which would serve the purpose of restraining and secluding them if they required “desensitizing”.

Autism Plus is subject to substantiated abuses that have been ongoing for a number of years in one of their residential care facilities of which can only be described as a living nightmare.

In a televised report on ABC’s Four Corners program in March 2017 titled “Fighting the System” Mother Maria told of her nightmare in finding out her non-speaking autistic son was being repeatedly sexually and physically assaulted by another resident of Autism Plus residential accommodation. DHHS were made aware of the ongoing abuse yet the abuser remained at the house where he then went on to rape and physically assault other residents.

In a recent report the Victorian Ombudsman, Deborah Glass stated, “Repeated failures by Autism Plus and DHHS, both by individuals and systemically, contributed to an unacceptable risk of significant harm to other clients, staff.”. Autism Plus were found to have known about the ongoing abuse but failed to notify the families until they were forced by the Ombudsman.

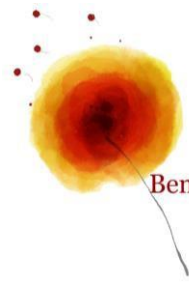
The Ombudsman’s report also stated another man was raped whilst in care in the same facility. His mother, Anne Mallia, said “Lives were being put at risk while the facility remained open.”. For more information on Anne Mallia’s story it is actually Submission 135 of this parliamentary inquiry.

Abuses of disabled people within disability service provision including residential care.

It seems that there has been a critical oversight in regards to the safety and wellbeing of Autistic people living in residential care, supported accommodation or attending autism specific day services, in the final report. It is the feeling of Bendigo Autistic Advocacy and Support Service, that as a parliamentary inquiry into the provisional services for autistic people that these particular services would fall under the scope of provisional services and that this statement needs to be addressed and added into the Report.

We are seeing more and more horrifying stories of physical, emotional and psychological abuses being reported in Victoria. A majority of these reports are being made by individuals living in residential care houses or supported living houses. Some of the complaints are also attributed to Autism specific day service providers.

BAASS strongly recommends full investigations into the management and consideration of funding in relation to disability services and residential service providers known to have been involved in the abuse of autistic people and the placement of autistic people into these environments, even after allegations of abuse from that person or from others.



We request the addition of a recommendation relating to addressing the urgent and undeniably abhorrent abuses being experienced by autistic people directly relating to disability services and disability residential programs.

Having received submissions outlining the nature of some of these heinous experiences, aside from numerous highly publicised cases- reflects a grievous oversight in omitting this, as one of **the most** significant and urgent priority in considering supports and services for autistic people.

This must be included as a recommendation, per addendum, to ensure at minimum, these experiences are acknowledged and that recommending immediate attention and overhaul of drastically failing systems be addressed- with predominant consultation being the autistic persons with first -hand experience (based on preferences and consent of each person), families and the autistic community.

In addition we recommend a full inquiry into current Victorian autism specific providers with consultation of autistic led groups and organisations to oversee the inquiry in the capacity of advisors and advocates. It is important that there be significant inclusion of autistic community, advocates and organisations not receiving significant government funding to optimise unbiased authentic input.

We absolutely extend our support in any way possible, in working collaboratively towards services and programs that offer safe, genuine and meaningful supports and contributing to developing guidelines and policy inclusive of diverse perspectives and insights.

It is imperative that the Victorian Government takes a firm stance on this extremely serious problem and takes steps on eradicating any form of abuse directed toward disabled people.

Report Recommendation 3.5

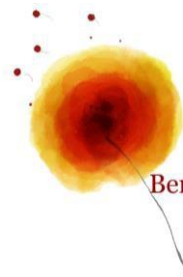
BAASS Recommendation 3.5

This recommendation relates to extensive involvement of the Mindful Centre for Training and Research Development in programs, education, diagnosis, early intervention, monitoring, supporting and Autism Coordinators - as relates directly to autism and therefore requires specific mention of the crucial need for autistic involvement, and a clearly defined expectation around level of involvement and input.

It is *essential and crucial* that development and delivery of all resources, education, programs etc involve minimum 50:50 autistic & neurodivergent people to neurotypical people on any committee/panel etc. relating to autistic and neurodivergent people, to be meaningful and not simply tokenistic.

Undoubtedly, the Mindful Centre has some great programs and provide some positive contributions for the autistic community. The 'Tuning in to Kids' program has cited good results from a positive approach around with Mindful Centre stating research into the program found that "Parents who received the Tuning in to Kids program improved in their ability to respond to children's emotions in supportive and teaching ways. They were also much less likely to be dismissive or critical when their children were emotional...used less punitive measures... and consistent discipline".

Given the Mindful Centre has a significant focus in autism related training and education, it is concerning that the Mindful Centre uses a heavily pathologising basis for their practice and a focus on 'Positive Behaviour Support', and



terminology/perceptions around “managing” “difficult” in relation to hosted training provided.

These factors indicate minimum, if any, input and collaboration with autistic people and what is meaningful from an autistic perspective.

All of these elements are areas that autistic people must absolutely have heavy input into. Many of the autistic community have had extensive and significantly negative experiences around all of these areas and there is an overwhelming lack of knowledge and experience - and in some cases - attitudinal barriers around willful ignorance and dismissal of persons and families.

In considering response in relation to specifically recommended organisations, expanding to incorporate clear minimum standards around meaningful autistic oversight and involvement is crucial in minimising potential or existing bias and vested interests.

Report Recommendation 3.6

The Report recommends the Victorian Government fund the Olga Tennison Autism Research Centre (OTARC) to implement training and establish a clinic around diagnosis of autism.

We have numerous crucial queries around this and challenge this as a singular recommendation involving a singular organisation.

BAASS Response and Recommendations 3.6

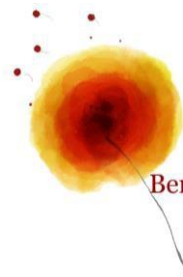
We would like to request further information around why OTARC has been selected as the singular organisation listed within this recommendation?

As recognised in many areas within the recommendations report, autistic people (and we assert that this should also specify that any advocacy organisations involved within autism related programs, guidelines etc.) - should have minimum 50:50 ratio of autistic people vs non-autistic people on the board/committee etc. See also, BAASS Recommendations above.

Whilst there is no doubt that OTARC provides positive and beneficial opportunities for the autistic community, there is some considerable controversy and in many cases- opposition from many of the autistic community- around many aspects of OTARC’s practice and premise.

OTARC has no stated commitment within Mission, Vision, Objectives and Values around meaningful inclusion, collaboration and input of autistic people- despite being an organization heading research and ‘support’ for autistic people. In fact, there is a distinct lack of mention of inclusion or collaboration with the autistic community other than to pathologise. The only mention of autistic people within OTARC’s Mission, Vision, Objectives and Values is as ‘research participant’, ‘participant’ and ‘participant families’.

In fact, primary funding and sourcing of information through organisations such as OTARC and Amaze, is to actively deny



autistic people voices and autonomy over decisions, policy and procedures relating to the autistic community and instead focuses on genetic markers to prevent the “risk” and birth of autistic children. This effectively communicates a desire to eradicate the autistic community.

To recommend OTARC as a singular source is to risk biased and irrelevant outcomes, potentially some harmful to the autistic community. OTARC operates from a perspective heavily pathologising autism and although there is likely some value in the work of OTARC and Amaze, we categorically state that there needs to be considerable change within OTARC with relation to the focus and lack of autistic involvement and input.

It is our recommendation that, to be a meaningful and valid recommendation, the panel consider the following:

- OTARC complies with the acceptable minimum, as determined by the majority autistic community, 50:50 autistic vs non-autistic board members and any persons within development and delivery of autism related materials, programs etc.
- The Inquiry Report recommendations provide an addendum including other organisations with equal or majority autistic input, to work on this with OTARC.
- Recommend within an addendum that the Victorian Government fund autistic developed and delivered programs through organisations with 50:50 ratio or majority autistic personnel.
- OTARC review their values and position in regards to incorporating meaningful positions with significant opportunity for autistic input. Rewrite the narrative of autism as a burden, “risk”, and instead open up to include a holistic view of autism as a way of being, respectful based support and actively countering stereotypes and stigma whilst working directly with the autistic community on an equal level.

We absolutely extend our support in any way possible, in working collaboratively with OTARC and any services accepting of our input, towards developing policy and procedures around authentic and experienced insight - ensuring inclusion of perspectives and insights.

Report Recommendation 3.9

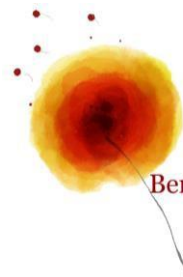
This recommendation aims to ensure autistic children not eligible for NDIS funding, have access to supports by means of Government funding for up to 20 hours of therapy per week. This recommendation also states:

“Ensure their families, carers and service providers are provided with accurate advice, information and support on childhood intervention therapies, including behavioural therapies, that are evidence based.”

BAASS Recommendation 3.9

The NDIS and evidence based therapies.

- NDIA develop guidelines and registration of services in direct and meaningful consultation with autistic people, autistic advocates and organisations that are made up of 50:50 or majority autistic people and professionals.



Therapies and supports should be negotiated as what is most meaningful and supportive for the person, not based on societal expectations and standardised therapies that can be harmful for autistic people.

- That research be funded, as an urgent priority, into the form of 'evidence based therapies' as meaningful and relevant for autistic people and what outcomes autistic people value as opposed to compliance based therapies and those opposed by autistic people.
- That the recommendation of "Evidence based therapies" be reviewed and negotiated with autistic people having experienced those therapies

We absolutely welcome the opportunity to collaborate with the NDIA in contributing to the development and delivery of policy and procedures meaningfully inclusive and accessible for autistic participants.

See also BAASS Response and Recommendations 3.11, 3.12 and 4.12 below.

Report Recommendation 4.8 and 9.9

Building autism specialist schools.

Fund and expand the 'Dookie model' by providing "specialised autism classes".

BAASS Recommendation 4.8 and 9.9

BAASS alongside many autistic led organisations, autistic professionals and the majority of the autistic community categorically and absolutely oppose the development of "autism specialist schools".

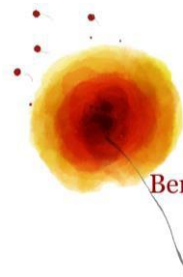
Prioritised focus on development of "autism specialist schools" is segregation in the guise of inclusion.

Note: this response is specifically responding to the recommendation that funding and resources be directed towards developing autism specialist schools and classes.

The **absolute** and **urgent** priority with regards to autistic students and education, is for all students to have access to a safe and meaningfully inclusive learning experience and environment. We fully understand and promote that as looking different depending on the many different needs within our community.

The main point in our response to this recommendation, is the critical need to work on better options to provide a range of non- exclusionary options that are all as inclusive as possible to give parents and students **real choice**. Inclusion does mean a range of things but by creating more 'autism specific' schools/classes detracts from the need to be inclusive overall. There needs to be a range of genuine options, based on diversity of need, and willingness to accept difference.

Inclusion in education is a fundamental human right.



Article 24 of the United Nations *Convention on the Rights of People with Disabilities* (CRPD), General Comment No. 4 imposes that inclusive education is a “**..fundamental human right of all learners.**” And as aptly extrapolated by General Comment No. 13 of the United Nations (UN) Committee on Economic, Social and Cultural Rights; *The Human Right to Education*:

..the importance of education is not just practical: a well-educated, enlightened and active mind, able to wander freely and widely, is one of the joys and rewards of human existence.

Children’s rights around inclusive education and the Government’s duty of care as according to the *UN Convention on the Rights of the Child* (CRC) as ratified by Australia in 1990 to ensure that children receive all rights as outlined in the CRC and as specifically relates to:

- Article 29
 1. States Parties agree that **the education of the child shall be directed to:**
 - (a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;**
- Article 37
 - (a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment.**
 - 1. In all actions concerning children,** whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or **legislative bodies, the best interests of the child shall be a primary consideration.**

The international human rights standards are of relevance for Australia and this response as is declared by the United Nations Association of Australia (UNAA) and the Australian Government Department of Foreign Affairs and Trade (DFAT).

The UNAA states that “Australia's commitment to human rights is enduring: we were an original signatory to the Universal Declaration of Human Rights.”

Australia's clear commitment to the aims and purposes of the Universal Declaration of Human Rights is evident in DFAT’s statement that the Universal Declaration of Human Rights “**...reflects our national values** and is an underlying principle of Australia's engagement with the international community.”

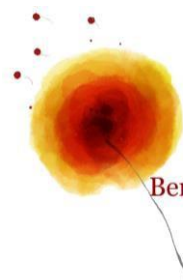
DFAT further states that Australia is a principled advocate of human rights for all and is a “...party to all landmark human rights treaties and **committed to promoting their universal adherence and implementation.**”

The *UN Charter of Human Rights* Article 26. defines the rights to education:

- (1) Everyone has the right to education.
- (2) **Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms.**

The *Disability Standards for Education 2005* formulated under the Commonwealth *Disability Discrimination Act 1992*, outline the responsibilities educational facilities have in facilitating participation of students with disabilities, within environments inclusive to their needs and on the same basis as students without disabilities.

The right of children with disability to attend their local government schools is a right also protected by the *Disability Discrimination Act 1992* (and the *Disability Standards for Education 2005* established under it) which reflects Australia’s international law obligations under *Convention on the Rights of Persons With Disabilities* (particularly Article 24) and the



priorities of the *National Disability Strategy 2010-2020*.

Disability Standards for Education 2005 aims to uphold the rights of students with disabilities to learn “..in an environment free from discrimination caused by harassment or victimisation on the basis of their disability.” (Part 8.2) and the *Disability Discrimination Act 1992* Sect. 22 that stipulates students with disabilities are entitled to an education on the same basis as their peers. The *Disability Discrimination Act 1992* Sect. 22(1) states that it is “..unlawful for an educational authority to discriminate against a person on the ground of a person’s disability.”

Although the *Charter of Human Rights and Responsibilities Act 2006* states that “human rights belong to all people without discrimination, and the diversity of the people of Victoria enhances our community”; we have found this to be far from the case in many instances.

Further to this, the *United Nations Convention on the Rights of Persons with Disabilities (CRPD)*, Article 24 asserts the right of persons with disabilities to access education and countries must ensure that:

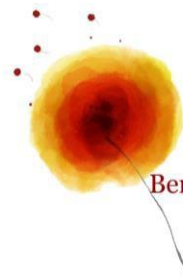
- a. **Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;**
- b. **Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;**
- c. Reasonable accommodation of the individual’s requirements is provided;
- d. **Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;**
- e. **Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.**

The National Disability Strategy 2010-2020 recognises it is imperative for an “inclusive high quality education system” that is responsive to individual needs in order to promote the best outcomes in life and further indicates that “An inclusive and accessible educational culture based on the principle of universality will assist students of all abilities. Teacher training and development is critical to ensure that teachers can meet the diverse educational needs of all students.”.

The Department of Education and Training (DET) states that:

“equal opportunity is a requirement under both Victorian and Commonwealth legislation. In Victoria, the main piece of legislation which makes it unlawful to discriminate is the *Equal Opportunity Act 2010*. Equal opportunity means that every person can participate freely and equally in areas of public life such as in the workplace, in education, or in accessing goods and services. All employees, students, parents, school council members, contractors and volunteers are required to act in accordance with equal opportunity, anti-discrimination, harassment and vilification legislation. We all have a responsibility to ensure department workplaces including schools are respectful, safe and inclusive and free of discrimination, harassment, vilification and otherwise unlawful and unacceptable behaviours.”

Despite the above and the DET *Dignity and Respect Statement* “The Department of Education is committed to providing



safe and supportive work environment where diversity is valued and everyone is treated with respect, fairness and dignity”, the educational curriculum is based on strategies and entrenched culture within an archaic system, requiring conformity and being limited to schedule; including basic human needs, such as toileting, drinking, eating and diet including content/frequency/time. These basic human needs and rights, are essential in a child’s ability to focus, learn and regulate and more so for many (if not all) autistic children and disabled children are often “excluded from local kindergartens and schools, and everyday social interactions.” (Shut Out, 2009 cited in National Disability Strategy 2010-2020).

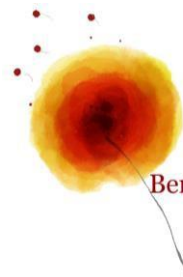
Parents, students, families and communities are fast becoming disenfranchised after the ridiculously difficult effort and measures taken in seeking an unattainable safe and secure learning environment and ensuring their children's needs are met. Many children and families are suffering significantly with many experiencing trauma from their experiences within the education system. Educational Trauma is defined by Lee-Anne Gray (2013) President & Chief Executive Officer, The Connect Group, Co-Founder The Connect Group School, EMDR Certified Clinical Psychologist, TEDx Organizer; as “the inadvertent perpetration and perpetuation of victimization by educational systems against consumers and producers of the system”. Gray explains that educational trauma can affect children, adolescents and adults accessing the educational system, and can have a significant impact on communities in promoting a sense of helplessness and feelings of dis-empowerment. **It is this desperate position that prompts consideration of ‘specialised autism schools’ with the failure of a system that is actively causing such harm to many autistic children. There is no clearer reason, to urgently inject funding and authentic training to benefit all children.**

The National People with Disabilities and Carer Council (2014) reports in the *National Disability Strategy Consultation Report* discusses the education experience of people with disabilities:

Education determines more than a child’s economic future—it is also critical to a child’s social and emotional development, to establishing a sense of identity and a sense of place in the world. It is therefore of considerable concern that 29 per cent of submissions reported frustration with the education system. Most submissions noted that the system has little capacity to meet the needs of students with disabilities. The system was characterised as chronically under-funded and staffed by teachers who received little or no training with regard to disability. Submissions reported widespread ignorance and fear of disability and little or no promotion of the benefits of inclusion. Parents reported particular frustration at their lack of choice of educational setting and the desperate lengths they were forced to go to in order to ensure their child had basic needs addressed. Most sadly reported that they believed their child with a disability was only receiving ‘second best’.

The Australian Bureau of Statistics (2012) recognises that “..many children with autism need support throughout their education..” and states that 95% of autistic students experience “restrictions” in the educational system with 6% of these students unable to attend school due to their disability. It is no surprise that an incredible 86% of autistic students experience having ‘difficulty’ with regards to their school experience (Australian Bureau of Statistics, 2012).

The Equal Opportunities and Human Rights Commission (EOHRC): 2012) also reports that the Commission receives a significant number of complaints about disability discrimination in education and that “..several parents, advocacy groups and members of the Commission’s Disability Reference Group approached the Commission to raise concerns about the experiences of students with disabilities in schools. This included concerns about students being pushed



into part-time attendance or homeschooling..”

The *Review of Disability Standards for Education 2005* (Department of Education, Employment and Workplace Relations (DEEWR) in collaboration with the Attorney-General’s Department (AGD): 2012) found that:

In spite of the intent of the Standards, some reported that ongoing discrimination and a lack of awareness across all areas on education continues to be an extremely significant area of concern for students with disability and their families. Many families reported that, through their education experiences, their children are subjected to: limited opportunities; low expectations; exclusion; bullying; discrimination; assault and violation of human rights.

It is abundantly clear that in many situations, the school system is broken and failing students. It is well documented and established that many students suffer profoundly within the school system, and many seek alternatives to the school system altogether.

The Victorian Auditor-General’s Report (2012) *Programs for students with special learning needs* confirms our personal and professional experiences and those of many students with disabilities. The report recognises schools aren’t monitored around the use of funds for disability, nor does it adequately oversee the educational outcomes of disabled students. “Schools are not implementing...policies consistently or effectively. As a result, the quality and type of support provided to students with special learning needs is not equitable.”.

The VEOHRC 2012 *Held Back* report also recognises the deficit within the school systems as relate to students with disabilities in stating that 40 percent of school educators “..were unaware of the [disability] Standards and how these translate into school and classroom practice. **As a consequence, too many Victorian schools, both mainstream and specialist, are failing to provide the services and support that students with disabilities need for a decent education.**”.

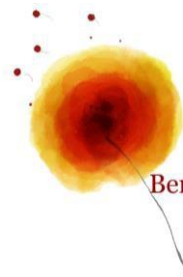
The *Review of Disability Standards for Education 2005*, (DEEWR and AGD, 2012) found that many education providers have little awareness or recognition of -let alone knowledgeable in- the Standards and states that “levels of awareness of the Standards amongst education providers was patchy.” The report also highlights that **attitudes still remain one of the “..main barriers to non-discriminatory access to education and training for people with disability.”**. The review also reports examples of students with disability being “..unable to access and participate in education on the same basis as other students.”

It is astoundingly and horrendously clear that schools are currently failing miserably in relation to meeting mandated obligations around human rights and disability; with a tokenistic ‘tip of the hat’ to inclusion at best; reports of abhorrent abuses and restrictive practices at worst. This is undeniable.

Whilst this remains the case, the focus must be on improving access, educational outcomes, transparency and accountability within the education system. The focus must be on supporting children and families, not restricting their ability to provide a relevant and meaningful learning experience for their children.

Forming ‘autism specialist schools’ will further ‘other’ and segregate autistic students and has been historically proven to be ineffective and often harmful for autistic students.

Segregation is not helpful or appropriate for autistic students and should never take the place of real and meaningful



inclusion in a varied range of inclusive mainstream schools.

Funding should absolutely be provided to mainstream schools to increase their capacity to understand and support autistic students. Appropriate funding for all schools would mean more adequate training and numbers of staff to fully support all students; as most appropriate and meaningful for each student.

As Catia Malaquias (2017) states; “With over 40 years of research evidence overwhelmingly in favour of educating disabled students in the same classrooms as their non-disabled peers and demonstrating unequivocally superior long-term academic, social and economic outcomes, the “special” path, lined by a well-meaning culture of low expectations and outcomes, is too often a sugar-coated path to social and economic marginalisation and exclusion – and serves to further entrench outdated societal attitudes to disability.”

The Centre for Studies on Inclusive Education (CSIE) also reports on research identifying that ‘specialised’ schooling is segregation and is a “major barrier to inclusive schooling and inclusive communities.” The CSIE cites a “..growing body of research findings, personal testimony and experience which support the human rights imperative to phase out segregation in education and fulfill children’s entitlement to fully supported inclusive education based on non-discrimination, equal opportunity and participation as agreed under the UN Convention on the Rights of the Child..” among many others as outlined above.

The CSIE outlines the negative and unforgiveable impact of segregated education:

“Segregated schooling appeases the human tendency to negatively label and isolate those perceived as different. It gives legal reinforcement and consolidation to a deeply embedded, self -fulfilling, social process of devaluing and distancing others on the basis of appearance and ability in order to consolidate a sense of normality and status. Segregated schooling perpetuates discrimination, devaluation, stigmatisation, stereotyping, prejudice and isolation- the very conditions which disabled adults identify as among the biggest barriers to respect, participation and a full life.”

CSIE cites results from research into the impact and consequence of segregated ‘specialist’ schools identified as “depression, abuse, lack of autonomy and choice, dependency, lack of self-esteem and status, alienation, isolation, fewer friends, more restricted interpersonal relationships, bullying and limited lifestyles.”

The *Alana Report – A Summary of the Evidence of Inclusive Education* (2017) research outcomes from over 280 studies over 25 countries concluded consistent evidence that disabled children learning within inclusive mainstream environments not only proves incredibly beneficial for the disabled students but also found positive benefits for all students, including non-disabled students.

Children and Young People with Disability Australia (CYDA with Cologon, K. 2013) report on research findings and outline terms “Macro and Micro exclusion” as relate to education and segregation in the name of inclusion.

“Segregation or exclusion is experienced as a stigmatising mark of being a ‘lesser’ or inferior person. It is a process of dehumanization. Macro exclusion occurs when a child is excluded from mainstream education and segregated into a ‘special’ school or a ‘special’ class/unit for all or part of the day, week or year (or denied education at all).”

Specialised schools are recognised as a form of segregation and exclusion is clear-and yet the Inquiry and 101 Recommendations and Amaze 101 petition recommends specific funding be routed to the development of “specialised autism schools”.

CYDA (with Cologon, K. 2013) further defines forms of segregation, or ‘micro exclusion’ as when disabled students

attend mainstream education environments more on the basis of 'co-existing' as opposed to included with another example being enrolment refusal.

CYDA (with Cologon, K. 2013) also points out that the validity of some research into inclusion can be biased as a consequence of a poor understanding or misappropriation of genuine inclusion.

Further on 'special' education settings, CYDA (with Cologon, K. 2013) states that even the term itself - 'special education', infers segregation and exclusion as opposed to equal participation.

Department level changes desperately need to occur- incorporating real and meaningful inclusion, as taught by autistic adult mentors; mentor programs developed, implemented and delivered by knowledgeable, passionate and dedicated autistic individuals. Currently school systems often do not provide service delivery on a model of inclusion and acceptance. Instead, they commonly stifle enthusiasm, passion and a natural love of and ability to learn; and indeed, quite often resulting in trauma, disengagement, highly compromised mental health and safety of autistic students and families and resulting in a higher need for access to specialised services and public health.

It is abundantly clear that the focus on education as relates to autism, as urgent priority, stands firmly on developing policy and procedures with clear definitions including transparency and accountability around inclusion in education. This is supported by the UN CRPD General Comment 4, highlighting that it is crucial that terms around inclusion, segregation and exclusion be clearly defined.

The need for funding existing educational environments and provision of authentic training in order to fulfill human rights obligations around inclusive education is of paramount priority.

We also note that inclusiveness is hard to define and looks different for many. Involving as many of the autistic community as possible, in the development and expansion of mainstream schooling and alternative options, is imperative to enable meaningful and genuine choice and inclusion. For example, many autistic children, youth and adults may not find the majority of general educational environments inclusive as relates to their specific needs, and would need different options available in order to access meaningful education.

Any training and services provided in schools should be developed and delivered with extensive and majority input from the autistic led organisations, autistic professionals and autistic community. Services and education regarding autism will be meaningless and at times further harmful, if this is not the case.

Report recommendations 3.10, 3.11 and 3.12, 4.12

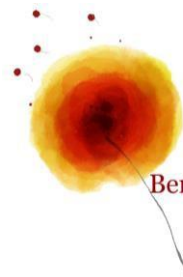
Behavioural and 'evidence based' therapies.

Restrictive practices and Positive Behaviour Support programs be implemented in all governments schools.

BAASS Response and Recommendations 3.11, 3.12 and 4.12

Behavioural and 'evidence based' therapies.

BAASS opposes many of the behavioural based 'management' and 'interventions' employed under 'Positive Behaviour



Support' (PBS) and we are categorically opposed to 'Applied Behaviour Analysis' (ABA) which has many similarities and poses the basis for many components of PBS. and related techniques; as detrimental to autistic people. We question the validity and authenticity of 'evidence based' 'interventions' and fully advocate for supporting autistic children, youth and adults with the most imperative consideration being meaningful, authentic and genuine inclusion and accessibility.

Applied Behaviour Analysis (ABA)

Autism Behavioural Intervention Association (ABIA) describes Applied Behavioural Analysis as "...the leading methodology for treating children with autism spectrum disorder." And is "...backed by nearly 50 years of proven results- it's aetiology stemming from psychologists like Ivan Pavlov, John Watson and B. F. Skinner. The founder of ABA- psychologist Ole Ivar Lovaas, founded ABA as a means to 'modify' autistic children and make them "indistinguishable from their peers.". ABIA proudly reports that ABA is based on Lovaas's behaviourist principles showing that the behaviour of children with autism could be 'modified' and with the aim to "...help children learn how to learn.". According to ABIA, intensive ABA 'intervention' is required at a minimum of 20 hours per week. The Raising Children Network, recommends that ABA interventions involve "critical" intensity in early childhood and should involve more than 20 hours of ABA "intervention" per week. The Children Support Network describes ABA as a range of techniques used to help autistic children "improve" skills, such as play, "reduce difficult behaviour like inattention" and most (if not all) sources of information on ABA, mention positive **and** negative reinforcement.

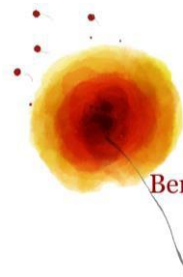
Once again, the language used in relation to ABA and autistic children is deeply concerning and misguided. If the origins of ABA in itself, don't adequately reflect the hideous nature of such therapies, the language in itself should be cause for one to run as far away from ABA and related 'therapies', at previously unrecorded levels of speed.

Autistic children are precious, valued human beings. Autistic children should not be subjected to 'therapies' or language based on 'curing/treating', 'modifying', 'managing', 'intervention' or 'difficult/challenging'. Autistic children have an innate love of and ability to learn and play. These may look different to how non-autistic children learn and play, but are no less valid, wonderful and meaningful. When not coerced or 'intervened' upon to appear normal for the benefit of others.

The Ed Wiley Autism Acceptance Lending Library provides brilliant information and infographics around autism and diversity and in particular stress the importance of letting children be children. "Autistic kids don't need you to make everything 'therapeutic' or a 'teachable moment'! Being autistic doesn't mean that I don't want to have fun and play! My play might not look like you expect, but I need the freedom to explore and discover the world in my own way just like any other kid! Don't take all of my interests and turn them into "therapy". Let me be who I am. Let me do what I love. Let me have fun. Let me be a kid!"

The Ed Wiley Autism Acceptance Lending Library again provides an infographic specifically around the need for respectful and meaningful support and ensuring children have to freedom to play as is meaningful for them. "Autistic children do not play in "inappropriate" ways...Autistic children play, learn and engage in uniquely autistic ways. Don't pathologise our ways of being and how we understand the world around us! Just because it's not your experience, that doesn't make it wrong!"

Dr Bruce Perry of Scholastic Teacher explains that learning is naturally occurring in children - exploring, questioning and discovering as a result of natural curiosity. Dr Perry cites major influencing factors negatively impacting on curiosity and learning as fear, disapproval and absence (absence meaning the necessity of a caring presence and sense of safety). Ally Grace (2016), neurodivergent writer for 'Respectfully Connected', expresses the importance of allowing children the



freedom to learn meaningfully in stating that “..children are born ready to learn; and in possession of innate knowledge about how to go about that.” With respect and trust, children thrive, learn and develop at the pace relevant and meaningful for them. Children “..already know how to learn. They were born knowing how to learn. And they aren’t disordered just because they’re neurodivergent either.” (Grace, 2016).

Grace (2016) further expands on meaningful learning and support as opposed to goals around ‘normalising’ autistic people to appear more like their non-autistic peers. “Most of the opinions I hear surrounding neurodivergent people, centre around the idea that they should be functioning, living and acting like a neurotypical person would.”. “Neurodivergent people carry this name (neurodivergent) because their brains function in atypical ways. This means that, statistically, they are in the minority. There is nothing inherently logical or ethical in aiming for the neurodivergent to seem more typical. It is simply based on numbers. The base reasoning is that the type of brain that appears the most when you randomly gather humans together; must be the ‘right’, best kind of brain.”. This accentuates our avid belief that all autistic people should receive meaningful, **respectful** support, based on nurturing and accepting differences.

As succinctly expressed by Ed Wiley Autism Acceptance Lending Library (n.d), “Autism acceptance does not mean no help or therapies. What it does mean is finding supports and accommodations that are respectful of my neurology. Supports that I need do not force compliance or indistinguishability. Those things actually make my life harder. Supports that I need don’t make me less autistic, they just help me to navigate a world that can be very unfriendly to my kind of brain. Support me, but don’t try to change who I am.”

There is a plethora of writing on the experiences of adult autistic people having been subjected to Applied Behaviour Analysis (ABA) techniques and ‘therapies’ all of whom vehemently oppose ABA as assimilation training and focusing on indistinguishability, being abusive and a cause of significant trauma with life-long effects.

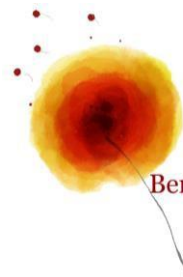
Devita-Raeburn (2016) acknowledges that a “fiercely articulate and vocal community..” of autistic adults of which many have been recipients of ABA, “say that the therapy is harmful.”.

“They contend that ABA is based on a cruel premise- of trying to make people with autism ‘normal’, a goal articulated in the 1960’s by psychologist Ole Ivar Lovaas, who developed ABA for autism.”. A 2008 survey of leaders and scholars in the field of ‘positive behaviour interventions’ – found that “..one quarter of these experts regarded electric shock as sometimes acceptable, and more than one-third said they would consider using sensory punishment - bad smells, foul tasting substances or loud, harsh sounds, for example.”. (Devita-Raeburn, 2016).

Lovaas’s first experience with the concept of behavioural based concepts as therapy and ‘treatment’ was as a student of behaviourist, Sidney Bijou - who had been a student of “...the legendary experimental psychologist B.F Skinner...” who used behavioural methodologies to train rats to perform tasks using positive behaviour rewards. Lovaas developed his ‘therapeutic’ intervention based on making autistic children appear as ‘normal’ as possible, “indistinguishable from their peers”. (Devita-Raeburn, 2016). Sequenzia (cited in Parker, 2015) relates ABA as “..defining success as behaving like a non-autistic person..” and is “..unethical and abusive.”. Sequenzia elaborates “They refuse to acknowledge that being trained to obey, and to force our brains to do things in a way they are not wired to do, causes long lasting pain or makes autistics learn the ‘correct’ answers and ‘behaviours’ while keeping their autistic essence buried and unexplored.”.

Devita -Raeburn (2016) reports that adult autistics/advocates instead call for neurodiversity to be accepted, rather than the theory that autistic people are “abnormal and needing to be fixed.”.

The Autistic Self Advocacy Network (ASAN) (n.d) relates within their position statement that “many therapies for autistic children and adults are helpful and should be widely available. However ASAN opposes the use of behavioural programs that focus on normalization... One of the guiding principles underlying the United Nations Convention on the Rights of



Persons with Disabilities is respect for the right of children with disabilities to preserve their identities. Autistic children should not have to grow up constantly being told that their natural behaviours are wrong and that they cannot be accepted as they are.”

Dawson (2004) aptly raises the concern around consent and points out that “Societies and scientists have historically made serious errors in determining which kinds of people are acceptable and which behaviours should be aggressively treated. People with differences have been ostracized then forced into mandatory treatments for their own good: left handed people, and homosexuals, and many others. Societal and scientific assumptions about what constitutes freedom and integrity for disabled people have often been wrong.”

Positive Behaviour Support (PBS) and Early Intervention

Our first request around this specific component of the recommendations, is that an addendum include clarity by way of specific description of Positive Behaviour Support this report references.

To be clear, there are some ‘positives’ to this approach but there is still a heavy focus on negative terminology, blame, imposing non-autistic expectations onto autistic people and deficit based, harmful concepts around ‘management/management plan’, ‘intervention’, ‘bad/challenging behaviour’, ‘function’, indicating a poor understanding of autism and autistic needs. None of the following ‘Positive Behaviour Support’ sources clearly prohibits restrictive practices but mention ‘reducing or minimising restrictive practices’.

Our response is based on Positive Behaviour Support as described by the below sources, which are not exhaustive:

Autism Spectrum Australia (Aspect)

Aspect offers information and training in ‘Positive Behaviour Support’ (PBS) as an ‘evidence based’ approach for autistic children. The frequent theme and concern throughout this methodology is for the parents and people around the autistic person. “The most frequent complaint of most parents of children on the autism spectrum is that other people don’t understand why their children do what they do.” Aspect then goes on to explain commonly termed ‘challenging behaviour’ which immediately views the autistic person through a negative lens, as is the defining purpose for ‘Positive Behaviour Support’. The autistic person exhibits “challenging behaviour” which is defined as such and “is ‘challenging’ because it challenges everyone who supports the person to understand why it is happening and to work together to find a solution.”.

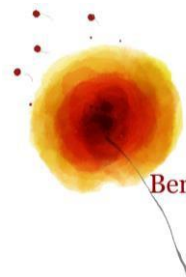
Department of Education and Training (DET), Victoria

The DET promotes implementation of School Wide Behaviour Support Programs and provides links by way of introducing the basic information for ‘beginners’ on the concept of School Wide Positive Behaviour Support Programs. The DET endorsed PBS program reports (via U. S. Department of Education, Office of Special Education Programs. Technical Assistance Center on Positive Behavioral Interventions and Supports. (2015) cited in Department of Education and Training, Victoria) the primary goals and methodologies as:

“Initially developed and used in special education to refer to a framework for improving identification and delivery of educational supports for students with significant learning disabilities, and later became a framework for supporting academic needs of all students.” and “grounded in the behavioral and prevention sciences and emphasizes within a multi-tiered support system framework” to “address the social, emotional, and behavioral needs of students with challenging behaviors in a comprehensive and deliberate manner, similar to how academic instruction is provided.”

“The underlying theme is teaching behavioral expectations in the same manner as any core curriculum subject.”

Amongst the SWPBSP examples are “re-teaching expected behaviours” and determining “What behaviors are an instant trip



to the office and what behaviors are taken care of in the classroom and specific examples around “keep feet and hands where they belong. Keep food and drink in backpack.” Other concepts within this framework are listed as rewards, token systems, positive reinforcement, praise and behaviour contracts with “...specific and contingent encouragement and recognition when social skills are used.” It also recommends “Increased precision to minimize rewards for problem behavior” and “controlled reduction of natural rewards for problem behaviour.”

It is also recommended that “...specific praise is likely the most critical component of the recognition system, many schools choose to develop a “gotcha” program. The gotchas are a system for labeling appropriate behavior, and they often serve as prompts for adults to remember to catch kids engaging in appropriate behavior (rather than catching them when they engage in inappropriate behavior).”

Education Queensland (in conjunction with AEIOU and Autism Queensland)

Prominent features of PBS according to Education Queensland (in conjunction with AEIOU and Autism Queensland) involve- “Ignore – Redirect – Reward”

“Rewarding and replacing behaviours” and incorporating the “...process for changing behaviour, including how reinforcements will be utilised or accessed” and to “Consider motivation and reinforcements; we all respond to rewards.”.

Amaze

Amaze, on PBS, states that “All government schools in Victoria are moving towards implementing a School-Wide Positive Behavioural Support model in compliance with Department of Education and Early Childhood Development requirements.” With “Best practice requires a dual approach towards students with behaviours of concern.” Amaze unfortunately states that “students with ASD may choose behaviours which are unexpected or socially inappropriate. It is likely that students with ASD will require some support to develop appropriate social skills and pro-social behaviours.”.

Raising Children Network:

The Raising Children Network reports that “Positive Behaviour Support (PBS) emerged in the 1980s, evolving from Applied Behaviour Analysis (ABA).” with the “...aims to teach children more positive and socially appropriate ways of communicating and getting what they want – for example, using words or signs to communicate.”

Here, PBS is stated to “Improve social, communication, academic and daily living skills, as well as difficult behaviour.” and is “Suitable for people with behavioural difficulties, including people with autism spectrum disorder.”

The key, according to the Raising Children Network is **“Replacing difficult behaviour.. Reduces self-stimulatory behaviour reduces tantrums and disruptive behaviour.”**

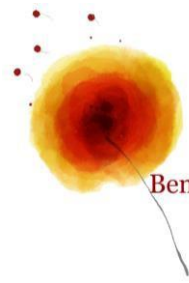
Sadly, the Raising Children Network are also of the opinion that “There are many treatments for autism spectrum disorder.”

Government of Western Australia, Disability Services Commission:

The goals for PBS per the Disability Services Commission of WA, includes to “...help the person develop new skills and re-engage in positive behaviour and interactions as quickly as possible.” The Disability Services Commission is kind enough to include that it is preferred that PBS involves a “Reduction in aversive/restrictive/punishment approaches.”.

Synapse

Synapse recommends graded exposure to triggers, positive reinforcement and behaviour agreements amongst strategies under Positive Behaviour Support.



None of the sources included within this response, clearly prohibits restrictive practices.

Once again, we have a narrative other than from the autistic person, but focusing on those external to the autistic person.

This tends to be the basis to 'interventions' - of which the term itself is negative, demeaning and ableist- inferring autistic people are 'broken', 'less than', in need of 'cure/treatment/fixing'. Amy Sequenzia, "non-speaking Autistic activist, writer and poet" on 'intervention':

"Early Intervention"

Problem: language

To intervene is to stop something from continuing its course.

Why is it necessary to intervene with the natural course of being Autistic?

"Early" implies that there is a need to "catch" things early, before it progresses.

Autism is not a disease. It is not progressive. It just IS.

It is disrespectful because it ignores our own timing.

Autism is a developmental disability and respecting that is important, instead of applying a neurotypical timeline of neurotypical milestones to neurodivergent children.

And while some aspects of occupational therapy and life skills can be beneficial, if there is no respect for each child's timing, and if it is done in a manner that is compliance based/reward based, and if this is called "Early Intervention", then it is just another name for ABA"

Sequenzia (2017) further states :

"Early Intervention is ableist.

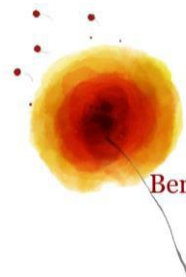
It implies that Autistic children (or disabled children in general) need to have interventions to prevent them from being who they really are, acting and reacting to the world in the way their brain naturally does.

Early Intervention is saying: intervene as soon as possible before they show their autism. Train them from very early to be what is more acceptable to (an inflexible) society.

Why not start supporting kids from an early age? Why not Early Supports according to the actual needs of each child?

A form of 'early intervention' is 'Positive Behaviour Support' (PBS). Aspect defines PBS as "based in the science of learning and there is strong evidence for PBS as an effective approach for challenging behaviour."

Negative connotations aside, this introduces the concept of the seemingly all omnipotent 'evidence based' 'interventions'.



School environments and therapies are often far from inclusive; strategies are based on 'positive behaviour support', 'behaviour management' and thinly veiled ABA inspired techniques; often strategies enforcing compliance rather than meaningful, respectful support. Often these 'positive behaviour' and compliance based methodologies involve strategies such as:

- group, public display 'behaviour charts', effectively 'naming and shaming'
- negative consequences, punitive authoritarian and arbitrary restrictions
 - inappropriate negative consequences such as withholding recess (this is significantly detrimental for children with sensory integration differences and needs and movement needs)
 - enforced yard duty with teachers, wearing 'hi-vis'- effectively communicating a lack of compliance with the entire school
 - removal of earned points/rewards for 'behaviour'
 - 'time out' (or exclusion/isolation)
 - Excluded from school
 - berated/spoken 'down to' in front of the class
- Rewarding compliance/expected behaviours or non-autistic based preferences; then perceived as 'effective' and 'positive outcomes' despite the cost to the autistic person and these outcomes not being meaningful but superficial using interests as a form of coercion
- Autistic people are pressured, shamed or guilted into compliance overtly or by way of expectations- this is disrespectful of genuine needs and reduces autonomy
 - Expectations irrelevant and often harmful for autistic people such as pressuring/enforcing eyecontact, 'The 5 'L's of listening etc
- Reducing or refusing any autistic person's need because it is different, such as the need to stim, fidget, avoid eye contact, move etc

A 'reward' based approach is also a commonly used methodology in 'compliance' training/behaviour management, 'positive behaviour support'. Many autistic adults, autistic professionals and others have repetitively explained these methods as not only ineffective, particularly in a meaningful way- but can be harmful, especially for autistic people.

Flanagan (2017) provides further explanation around this, citing: "Rewards can be seductive, according to Marvin Berkowitz, a professor of education at University of Missouri-St. Louis and author of *You Can't Teach Through a Rat*. They're easy, they seem to work—particularly with the hard-to-reach kids—and many teachers are taught according to the behaviorist model, which posits that people repeat conduct that's reinforced and avoid what's punished." Further to this Flanagan (2017) notes, via Principal Valleroy, that special education relies heavily on extrinsic rewards with its students. "The use of extrinsics is a common practice in special education.". Of course, this is no surprise to us.

Flanagan (2017) further reports that a "...substantial body of social science research going back decades has concluded that giving rewards for certain types of behavior is not only futile but harmful." Extrinsic rewards: they cripple intrinsic motivation, limit performance, squash creativity, stifle good conduct, promote cheating, can become habit-forming, and spur a short-term mindset. Daniel Pink, author of *Drive: The Surprising Truth About What Motivates Us*, is quoted by Flanagan (2017) - Giving prizes for routine and mindless tasks can be moderately effective. But offering rewards for those tasks that are "inherently interesting, creative, or noble...is a very dangerous game." When it comes to promoting good behavior, extrinsic rewards are "the *worst* ineffective character education practice used by educators," (Berkowitz

cited in Flanagan 2017).

Yes, to the non-autistic therapist or observer, the 'intervention' and 'PBS' may look successful in that an autistic child may stop stimming. But this is based on expectations that are not relevant to autistic people, which dismiss our real and valid needs. Stimming is often an incredibly beneficial 'behaviour', integral to our being - our wellbeing, focus, self-regulation, expression and so on. This is not meaningful outcomes, but coercion and at a potentially profound cost to the autistic person. 'Evidence based' in these circumstances are not a meaningful or ethical foundation on which to deliver education, therapy, services; nor foster inclusion or community acceptance.

These methods provoke shame, undermine self-confidence and motivation and are at best damaging, disrespectful and misguided. The education delivery system and some therapies are largely based on a model perceiving 'behaviour' not as the form of communication that we know it to be, but as challenging, unwanted, and distracting. Education and therapy delivery based on these misguided models serve to degrade self-esteem, confidence, motivation, mood and mental health, wellbeing, ability/function and are highly anxiety provoking. This perpetuates the cycle of negative consequences being imposed and resulting in more distress, overwhelm and overload exhibited or communicated by behaviours'.

In most cases, behaviours are a form of communication for all people. The education system and many therapies use methods primarily based on presumption that perceived challenging or unwanted behaviours are intentional, whereas we know that children instinctively want to learn, conform and be accepted. Using negative stigmatising language inferring behaviour is voluntary or needs are simply preferences or choices, perpetuates the perceived need for 'intervention' and 'PBS'. Language such as 'tantrum', 'doesn't like', 'picky', 'bad' all dismiss what are valid needs and differences.

Often PBS based approaches and education is delivered in an authoritative method in which learning is 'done' to the child, not in partner with or inclusion of. Often entrenched views and culture within education and therapies results in attitudinal barriers - an unwillingness to embrace authentic information from the autistic community but instead clinging to willful ignorance and arrogance.

Success in education and therapy is often measured by what is observed or according to standardised tests and expectations, which is superficial and inaccurate at best. This does not take into account, the extraordinary pressure and effort that many autistic people are subject to, in environments and circumstances that involve significant sensory and social challenges. Observing desirable behaviour and absence of obvious distress is not an indication that a person is not suffering and experiencing significant difficulties. This highlights how essential it is to work with and truly *hear* what autistic people have to say.

BAASS would recommend positive support strategies as opposed to persisting focus on 'behaviours' and the above methodologies. We absolutely welcome the opportunity to work collaboratively with any organisation/service welcoming of experience and insight into development and delivery of programs more inclusive and meaningful for autistic people. We feel the more authentic, autistic led organisations, mentors and autistic community members consulted and actively participating, the better practices and outcomes.

'Evidence based' intervention and autistic people

We question and challenge much of the 'evidence based' 'intervention' commonly recommended for autistic children and the autistic community. There is certainly value in seeking respectful therapies and supports if genuinely required.

At the point of diagnosis for a child, the emphasis is oft a scrambling rush to ‘implement’ copious amounts of ‘interventions’ in the hopes of ‘curing/treating’ and ‘improving outcomes’- thinly veiled attempts to ‘normalise’ autistic persons, make them ‘indistinguishable from their peers’ and to meet mainstream timeframes and expectations.

For example, the Raising Children Network describes ‘early intervention’ as “..doing things as early as possible to work on your child’s autism spectrum disorder (ASD) characteristics.”. This premise implies that autistic people- particularly children- are in dire need of ‘intervention’ to rid them of their differences.

This is not respectful of the fact that autistic people are neurodivergent, we do not develop in the same ways in the same areas as those around us and this does not focus on what is meaningful for the person.

Take for example, this research based statement from Aspect, in relation to childhood autism diagnosis and early intervention- “All research evidence supports that early intervention makes a significant difference for children with autism. Getting the news that your child has autism can be confronting, and families need help to be able to support their child, explains Aspect Senior Manager Early Intervention, Rachel Kerslake. “If parents aren’t in a good position to actually support learning and working with their child, they’re not going to get the outcomes that they want.”

The significant difference in autism is measured by who? This statement also places heavy emphasis on the parents - getting the outcomes *they* want.

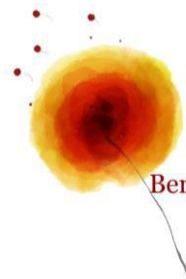
We are interested in the outcomes that autistic people want for themselves - what is meaningful for them, what supports are respectful and accept different neurology.

Devita-Raeburn (2016) comments on ‘evidence based research’ behind supporting ABA and behavioural ‘therapeutic’ ‘interventions’ “..whenever experts are asked whether ABA works, many experts respond: “It depends on the individual child.”. It is also recognised that “There is a large body of research on ABA, but few studies meet the gold standard of the randomized trial” and that “of 58 studies on Lovaas’ ABA model, only 1 met its standards.”.

This leads to considerations around the quality and meaning behind ‘evidence based’ therapies based on research around efficacy of ABA and similar theories.

Michelle Dawson (2014), autistic and an autism and cognitive science researcher, describes some of the origins of ‘research’ ‘evidence based’ outcomes; the ethical and deficit based implications for ‘intervention’ as indicative in a 1970’s UCLA authored peer-reviewed research perceiving intervention as successful based on “transforming the inadequate and inappropriate behaviours of young children.” These were deemed so and “this behaviour intervention was considered essential for many reasons: the children’s disordered behaviours caused emotional distress in their parents; the behaviours were disruptive and judged unacceptable by society and the children’s peers; the behaviours also displaced the proper functioning of these children, who were said to be suffering; and intervention at the earliest possible sign of deviant behaviours was necessary since the prognosis for adolescence and adulthood was notoriously poor and treatment later in life was known to be futile.”.

It is clear that these misconceptions still motivate much of the way autism is approached even now. Successful and desired outcomes in changing behaviours and assimilating autistic children arose from intensive interventions around “the principles of operant conditioning to displace maladaptive behaviours” using punishments for ‘bad behaviour’, rewarding ‘good behaviour’. The premise and result was all too familiar; “The authors concluded that it is more realistic to change those hurt by intolerance than to change the intolerant behaviours of society.”.



Dawson (2014) raises further excellent discussion:

The second question is whether autistics are human beings with human rights. There are all kinds of rights, but *human* rights are those claimable by and essential to all humans. At first glance this question is impossible to argue on the facts. I'm an untreated diagnosed autistic. How do I prove I'm human? And should I have to?

A second look bases the answer on what happens to human beings whose human rights are denied. Historically, it has been arduous, expensive, and ultimately futile to study and develop treatments for persons who have no human rights. Science also has a bad history of conjuring experiments, evidence, and data to prove that prevailing prejudices are justified. We did not find out a lot about women until women became human beings with human rights.

Instead, we found out about the researchers and the societies they served. Past attempts to treat the many defects of womanhood now look grotesque and contemptible.

So do the research and treatments directed at different races, abilities, and orientations before these differences were recognized as being intrinsic to human beings with human rights.

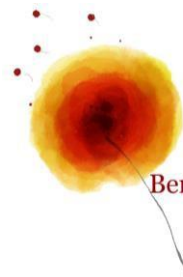
After elbowing aside all the conspicuously non-empirical behaviourist false equations, false oppositions, and articles of faith, the real evidence predicts that regardless of how diligent scientists are *in every other respect*, if the human beings who they study and treat are denied human rights then this study and treatment can be considered neither ethical nor scientific. Further, evaluating the scientific validity or "success" of the results of this kind of science is impossible.

When 'evidence based' is not measured according to the experiences and values of the community they relate to, and is primarily based on such horrendous archaic beliefs around disability, it ceases to be worthwhile or relevant. Real and meaningful research based on autistic ways of being, priorities and as is meaningful for them directly, must be an utmost and urgent priority. Until then, many therapies and autism related 'interventions' will continue to be based on irrelevant data and will harm our community. Yes, 'intervention' may result in a positive result as perceived by a non-autistic person - but this is not meaningful or reasonable for the autistic person. This is placating a community that views harmful therapies and indistinguishability as priority over wellbeing.

One such resource of comprehensive and excellent content around ABA, 'interventions' and autistic learning is an article by Dawson (et al, 2008); in which states "Autistics are no longer routinely institutionalized and are entitled to public education, but there continues to be a dearth of data linking early autism interventions to adult outcomes. Instead, there are data indicating that currently popular interventions may be unrelated to child outcomes." (Eaves and Ho, 2004; Gernsbacher, 2003; Lord et al., 2006 cited in Dawson et al, 2008).

In fact, "The educational and psychosocial intervention literature in autism, despite undeniable quantity and prominence, has failed to produce "a clear direct relationship between any particular intervention and children's progress" (NRC, 2001 cited in Dawson et al, 2008)."

Dawson (2016) further supports our position around efficacy of 'interventions' such as PBS/ABA and the erroneous and



inauthentic preface in stating “The effectiveness of comprehensive early intervention programs is judged against autism’s presumed poor prognosis, and according to the extent to which typical skills have successfully been acquired and atypical autistic behaviors have successfully been extinguished (Handleman and Harris, 2001; Smith, 1999). While as yet providing no empirical foundation for the popular contention that intensive early interventions result in successful, independent typical adults.”

Dawson (2004) raises that “No researcher knows or has cared to study the differences between treated (with ABA) autistics who “recover”, and untreated (with ABA or anything else) diagnosed autistics who do not “recover”—and regardless of being thoroughly indistinguishable, have lives encompassing learning, achievement, intelligence, and autonomy...{some} Behaviourists insist that there is no such thing as this second kind of autistic.”

Dawson (2004) discusses “scientifically proven” and “medically necessary” in relation to ABA and ‘evidence based’ as terms that “encompass the assumption that scientific and medical ethics have been accounted for. In autism, these terms are applied to a treatment whose ethics remain unexamined and unchallenged.”

Dawson (2004) further outlines that challenging the autism-ABA industry’s ethics “...requires that autistics be seen as human beings with human rights. We do not live in a society that acknowledges this. We are in a society in which autistics have rights only if and when we resemble non-autistics.”

“The poverty of autistic social outcomes, regardless of our abilities, is consistent with persons who have no rights and merit no ethical consideration... Only when people with differences have legal and human rights can they be ethically researched and ethically helped.”

Until this happens in autism, behaviourists can’t evaluate what recovery from autism means and how it might be manifested. They have no way of knowing whether recovery from autism is a good or terrible result.” (Dawson 2004)

Dawson, (2016) provides further researched critique into the ‘evidence base’ of behavioural interventions:

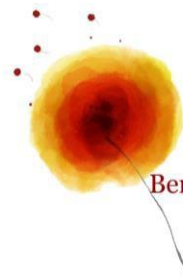
data from an uncontrolled trial show that neither intensity nor quality of early ABA programs is related to short-term outcomes (Sallows and Graupner, 2005).

Although physical punishment within behavioral interventions became illegal in many jurisdictions and was replaced by other methods (but see Foxx, 2005), a nonrandomized controlled trial that depended on contingent aversives (Lovaas, 1987; McEachin et al., 1993, cited in Dawson 2016) continues to be cited as the primary evidence that ABA-based interventions are effective. The only randomized controlled trial of an early comprehensive ABA program reported poor short-term results (Smith et al., 2000, 2001).

Until further research is conducted into the effects of these therapies from an autistic perspective, the ‘evidence base’ is not authentic, meaningful or relevant.

It is more respectful and meaningful to:

- Include a more positive and mandated requirement for real and meaningful inclusion and supports
- Fund autistic based research around meaningful outcomes, respectful and meaningful methodologies of support to develop authentic ‘evidence’ on which to base support



- Develop and deliver programs educating teachers and all staff supporting inclusive practices and supports for students as opposed to the band-aid effect of 'managing' behaviours which are resultant of unmet needs and inadequate support.
- Accept the diversity of humanity and accept each person's differences. Recognising that our needs are different, real and valid. Not pressuring autistic people to meet expectations other than what is meaningful for the person. Respect each person's needs and embrace them, accept them and promote inclusion. Don't stifle, crush or pressure an autistic person's natural way of being.

Any training and services provided in schools and within undergraduate studies should be developed and delivered with majority input from the autistic led organisations, autistic professionals and autistic community. Services and education regarding autism will be meaningless and at times further harmful, if this is not the case.

Report Recommendations 4.13, 4.14

Autism Teaching Institute (ATI) teacher training and PD

BAASS Response and Recommendations 4.13 & 4.14

BAASS absolutely oppose the involvement of the Autism Teaching Institute and formally requests the complete removal of any reference to, let alone use of, the ATI within the Report Recommendations, or as per requested addendum.

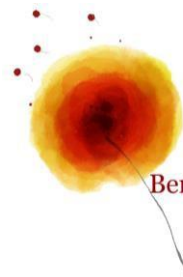
Western Autistic School (WAS), established the Autism Teaching Institute (ATI) which is a Registered Training Organisation delivering training to mainstream teachers throughout Victoria.

There has been a strong reliance by WAS on seclusion rooms and restraint.

None of the WAS policies, procedures and guidelines reflect the overwhelming international research that makes it very clear that inclusion gives the best social and academic outcomes to students with disabilities.

WAS is itself, a 'special school', provides "respite" information for parents and uses restrictive and abusive practices (as cited by United Voices for People with Disabilities (Peter Cross Convenor/Chair - United Voices for People with Disabilities (UVPD)), Julie Phillips; Disability Advocate, Submissions to the Senate Inquiry Into The Education Of Students With A Disability, submissions to the Parliamentary Inquiry into Services for Autistic People and reported in The Age) and the Western Autistic School's own "School Policy on the use of aversive stimuli as a strategy for altering the serious behaviour or a student."

In fact, the WAS "School Policy on the use of aversive stimuli as a strategy for altering the serious behaviour of a student", condones the use of aversive techniques. This policy states "The program must work quickly from actual administration of the aversive to become a prompt to the student." "The student may, in the presence or reminder of the aversive, will either inhibit a serious behaviour or respond positively to the adult." Some such techniques directly stated in the school aversive technique policy include seclusion, removal of privileges that relate to human rights (eg. "lunch time outside with friends"), suspension and exclusion.



Using terminology such as “enact loss” and promoting techniques around “Negotiation (with us winning) is usually the best method of approach.”.

Report Recommendation 7

Gender

Focus on recognition of gender specific considerations in autism diagnosis, presentation, needs. Specific support for organisations targeting autistic girls and women and awareness campaigns around specifics of autistic girls and women.

BAASS Response and Recommendations 7

We would like to further include and recommend that gender be removed from the equation as relates to autism assessment and diagnosis.

Historically, autism was misperceived as something only relating to males and we still see higher ratios of male diagnosis. As the Report, Chapter 7 introduction (p.259) recognises; autism relates to “.. all genders and all genders experience issues with diagnosis...and accessing services.”. However, this is not intended as a more diverse and inclusive statement, but relates to extending understanding and diagnosis around differences of females and autism.

This chapter of the Report highlights the myriad of significant issues around female differences compared to historical presumptions and perceptions and the profound impact this can have on girls and women in regards to gender biases in diagnosis - being dismissed or overlooked, missed diagnoses or misdiagnoses, severe lack of funding, supports and services for autistic females.

Our experience and knowledge and as reinforced in this chapter, highlights the lack of understanding, knowledge and experience around autism diagnosis and genders different to ‘male’. The issues faced by autistic females in seeking recognition, understanding, diagnosis and supports are very real and significant concerns.

The heavy reliance on strict ‘classic’ diagnostic criteria and the absence of experience in the subtlety and how to ‘tease out’ the differences in autistic people presenting differently has a profound impact on many. We have experienced, both personally and through our advocacy work, people being immediately dismissed when seeking information and diagnosis around autism, based on immediate and incredibly inaccurate ‘snap’ judgements such as because the person “interacts”, or “can make eye contact”. As ludicrous as this sounds, it is still very much a common experience within services specifically for diagnosing autism. This highlights the extreme need for insight, training and policy/guidelines development and delivery with majority involvement of autistic people.

However, these considerations and issues are amplified for gender diverse people.

The recent focus on awareness of autism as relates to girls and women has been a crucial step towards recognising that autistic people, just like the rest of humanity, all present and experience things differently. This extends to gender, which is not a binary concept and as particularly recognised within the autistic community, there is a particularly high percentage of LGBTIQ+ and gender diversity within our autistic community.

It is becoming more widely known, that girls and women - and gender diverse people, present differently and this can be in subtle ways.

Removing the focus and misconceptions around male autism theories is just the initial steps in what needs to be a broadly expanded understanding of autism and diagnoses as the genetic neurological difference it is, removing gender entirely from the process and understanding of what autism is.

There is an urgent need for funded research into diagnostic criteria across a diverse population and to widely promote an understanding, experience and training in autism overall, outside of the gender misconceptions.

The push for recognition of girls and women, whilst is a positive step in the right direction, continues to exclude various communities who will continue to be dismissed, misunderstood and misdiagnosed with the long-lasting impact that can have. Expanding diagnosis to provide autism and assessment diagnosis based on the person - simply human beings, without focus on any gender, will be more inclusive and appropriate.

The intersection of gender diversity amongst autistic people is little researched as yet but the writing that does exist, highlights a range of significant difficulties unique to gender diverse autistic people.

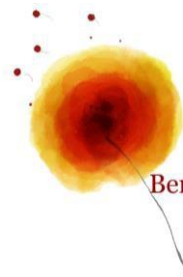
From gender clinic statistics, approximately 20% of gender diverse persons presenting, are autistic or meet several of the criteria of autism diagnosis (Rudacille 2016). What's more, is that this is equal across sex presentations of birth assigned male and female.

"Significantly greater proportions of participants with ASD (5.4%) or ADHD (4.8%) had parent reported gender variance" (Strang 2014) and "the incidence of autism among the children was 7.8 percent, 10 times higher than the rate in the general population. Among the adolescents in the sample, the incidence was even higher, at 9.4 percent." (Rudacille 2016).

Approaching prevalence from another angle, gender variance in autistic children was assessed and found rates that were "7.5 times higher than expected," (Strang 2014).

Aside from the considerations around missed diagnosis, this population experiences harmful stigma and misperceptions around autonomy and presumptions resulting in further dismissal for example, White (2016) for The Atlantic, reports in relation to transition-related care "hormone therapy and other medical assistance is often deemed redundant, or dismissed as an obsessive trait or part of a "strictly autistic profile". Gender diverse autistic people are often subject to twice the judgement, dismissal and stereotyping than the cisgender autistic community, including girls and women.

White (2016) **"While this shift has ensured many cisgender women are now finding diagnoses, approaching autism in strictly male/female terms has still largely excluded gender-diverse people from the conversation."**



Brooks (2015) also provides invaluable perspective and insight and expresses:

"Queer environments don't often account for our sensory processing issues or social differences, whereas autism services don't often recognize that we may identify beyond the gender binary or have queer relationships. Shifting the focus from the tired narratives of delayed diagnosis and sex differences can help the autism community take responsibility for improving our day-to-day quality of life, whatever our age at diagnosis or gender identity."

"It's also past time for mainstream discussions of 'women with autism' to recognize that a significant portion of the autistic community identifies as gender-queer or non-binary. ...As a non-binary queer person, I'm sad that both the LGBTQ and the autism communities don't offer more inclusive programming."

"Gender norms should not be imposed on people with autism to make the rest of the world more comfortable. Why teach girls with autism how to apply makeup, dress in a feminine manner and shop? Therapists, educators and parents only consider these to be important goals because our society imposes strict gender norms."

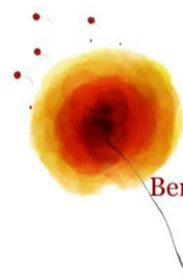
"As a member of the LGBTQ community who is also autistic, I encounter inequality based on my gender identity, my sexual orientation and my disability. Societal barriers in housing, employment, transportation, healthcare and education systematically exclude queer, gender-queer, transgender and disabled people; outdated and negative attitudes about gender, sexuality and autism affect our social relationships."

Autism diagnosis will not be all-inclusive until gender is irrelevant as relates to diagnosis. Clear priority lies in moving past the focus on the complexities and differences in female diagnosis, to the removal of gender as a consideration. A focus on the wide variation and intricacies of autism in itself should be the primary focus with all resources directed towards more inclusive diagnostic processes and the push for education, experience and policy around gender diverse approaches.

Report Recommendation 7.2 makes mention of autistic girls and women benefiting greatly from "the work of community groups, such as the Yellow Ladybugs, that are focused specifically on their needs."

BAASS Response and Recommendation 7.2

We find it problematic that specific mention has been made around Yellow Ladybugs and would like it noted and included within an addendum, that this recommendation focus on wider range of needs, not excluding many autistics based on gender or level of "function". To remove the focus from 'girls and women's' specific needs, a focus could be more broadly on understanding that all autistic people present differently and widening the scope to include that. As



discussed, gender diverse autistic people have more considerations around differences in presentation and missed or misdiagnosis and this must be recognised and included.

We would suggest instead, that there be funding and resources made available to a variety of groups able to justify and demonstrate meaningful inclusion and acceptance of all audiences within their target group. Whilst specifically purposed groups can be great and much needed, the autistic community urgently needs further than this - initiatives that include gender diversity and an understanding of the many diverse autistic communities.

We acknowledge the great initiatives the Yellow Ladybugs has been successful in and credit the contribution to highlighting the expansion of understanding around autism as not just 'male based' and the intricacies that need to be considered in understanding autism more broadly.

We would also like to acknowledge our concerns around Yellow Ladybugs in that this organisation excludes a significant part of the 'female' autistic community in focusing on "aspergers" and excluding autistic girls based on 'function' level. Yellow Ladybugs limits the group specifically to "...autistic girls who would typically attend mainstream school, or girls who miss out on funding to attend specific Autistic Schools".

The Yellow Ladybugs age criteria also excludes a range of autistic girls and limits socialisation and relationships amongst a broader age range. Groups involving wider age ranges are often more beneficial for all children and often the preferences and of particular relevance for autistic people; known to be more beneficial also in workplaces (Firth, 2016). Gray (2011) shares insight into this, saying "...age-mixed play offers opportunities for learning and development not present in play among those close in age, permitting younger children to learn more from older playmates than they could from playing with only their peers."

The Department of Human Services (2004) recognises the benefits of wider age groupings and recommend not emphasising ages of children and considering interests as a group rather than individual expectations, and specifically avoiding generalisations about children based on their age.

We feel the above again further highlights the need for including a Report addendum, incorporating further considerations around the requirements of groups recommended or funded and what that can involve.

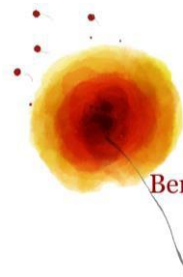
Report Recommendation 8.2

Public health and mental health services accommodating the needs of autistic people and autism specialists within these systems.

"That people with ASD are identified on presentation to health services and that this information is recorded."

BAASS Response and Recommendations 8.2

We applaud many recommendations and ensuring authentic and genuine autism specialists are available and placed widely amongst general and mental health services is crucial, this recommendation requires clarity in that as it stands,



Bendigo Autistic Advocacy
and Support Service

Co-Convenors
Beck Kelly - Tony Langdon - Susanna Flanagan

interpretation indicates it serves to strip autistic people of their rights in disclosure and in protecting their autonomy and preferences around this.

Any implementation around persons having to identify and have this recorded is potentially a violation and autistic people have the right around when and to whom they disclose their diagnosis, discrimination and vilification is a very real threat and experienced by many. These very recommendations include numerous significantly detrimental suggestions and yet the Inquiry was specifically relating to the autistic community. It is not difficult to consider how this recommendation could impact on autistic people.

Report Recommendation 9.8 and 9.9

Funding an expansion of the Mansfield Autism Statewide Services and 'travelling teacher' program.

BAASS Response and Recommendation 9.8 and 9.9

BAASS opposes the recommendation 9.8 in relation to the expansion of the Mansfield Autism Statewide Services Model (MASS) across regional Victoria.

It is recommended that this be removed fully from the State Inquiry report.

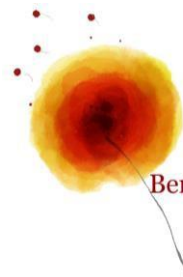
A number of issues that have been reported to us include the alleged use of restraint on children that attend the 9 week term at the Mansfield campus. Disability Advocate Julie Phillips wrote to us regarding concerns she had regarding restrictive practices being used at the MASS campus. BAASS wrote to Mansfield on 2 separate occasions requesting amongst other things, information around if Mansfield uses restraint and if so do they have a restraint policy that we could view and asked for qualifications regarding their behavior therapists. We received no response even though we received notification that our email had been read.

In one of the case studies presented to us by Julie Phillips it was noted "Primary school age boy with severe behaviours of concern sent to MASS for two terms 2017. The boy was subjected to restraint and seclusion frequently. Incident reports were not provided to the parent and refused upon request. Upon leaving, severe behaviours of concern remain. No recommendation was made to obtain the services of a credentialed practitioner, nor was a recommendation made to use the only established evidence based intervention for Autism Spectrum Disorder."

The use of restraint and seclusion has been documented frequently in our response to this Inquiry as causation for ongoing trauma especially when directed towards children.

It has also been reported to us by a client that attended a camp that Mansfield condone the use of forced eye contact and therapies to reduce self-stimulatory behavior (stimming).
Eye contact for many autistics is hard and can cause sensory overload and in some cases causes actual physical pain.

In the Blog *Faith, Hope and Love with Autism*; a child by the name of Phillip writes "My eyes see very well. Most people seem to need to have to look long and hard to make sense of a picture. I can take in a whole picture at a glance. Each day I see too many little petty details. I look away to not get overwhelmed by a lot of little bits of information. I



watch things a teacher or person I listen to, tell me to watch. This helps me concentrate on what I should be focusing on.”

Judy Endow writing for Ollibean states “When I was a youngster I received too much bright, bold, painful sensory information from making eye contact. To guard against the intense physical pain I did not engage in eye contact. If my teacher demanded eye contact I obediently did so, but at a price. I would float out of my body, hover up near the ceiling and look down, watching the little girl of me”.

Eye contact or lack thereof is a societal issue. Eye contact for some autistic people is extremely hard and to force this upon a person knowing that it causes harm and anxiety is dangerous and not accepting of the natural diversity of the individual.

In relation to self-stimulatory behaviour and reports to us that therapies are being used by Mansfield staff to reduce these behaviours, BAASS vehemently opposes the use of any type of therapy to reduce stimming. Stimming is a natural part of the autistic person that assists us to self-regulate and calm ourselves. It is also a part of who we are as people. To remove or reduce this is harmful and detrimental and can cause the autistic person harm.

Briannon Lee writing for Respectfully Connected states “Stimming (self-stimulatory behaviour) is like breathing for autistic children and adults. It feels good, helps us feel connected and focused. It is harmful to interfere with children developing and enjoying their own stims. Unless children are hurting themselves or others, respect their need to stim; never shame them or stop them. Stimming is beautiful!”

Also stimming is for differing variants in autistic people as stated by Real Social Skills, “Stimming is not just necessary. It is also natural, and good. Flapping in response to a nice texture is not fundamentally different from smiling in response to the smell of a flower. Rocking in response to someone saying something offensive is not fundamentally different from frowning in response to a slur. It is ok for autistic people to have autistic body language”.

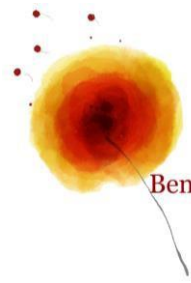
Mansfield has adopted the Positive Behaviour Support (PBS) model for their travelling teacher service and for their Dookie campus. BAASS has already taken issue with PBS in recommendation 4.12 but will reiterate that BAASS opposes the current structure of the PBS due to the behavioural based “management” and ‘interventions’, as they are detrimental to autistic people.

Please refer to BAASS recommendation 4.12 in regards to this as our opposition toward PBS and the inclusion of this in the recommendations of the Parliamentary Inquiry and the Mansfield teaching structure.

We would like to draw attention to the MASS *Therapeutic Residential Placement Guide 2017*, which outlines the Mansfield Services for placements in any of their programs. This guide is an overview of all services and requirements that MASS adhere to including the \$15,000 per term fee structure, which is completely over priced and out of reach for a majority of families.

The guide outlines developing person centred goals, outcomes and strategies, positive behaviour supports, measuring outcomes, intervention focus, the programs aim and history.

It was reported to BAASS by disability advocate Julie Phillips in a second case study that a “Secondary school-aged boy without any formal diagnosis of Autism Spectrum Disorder received a one day a week day service from MASS. After six months in 2017, when the school that organised the one-day service was requested to provide the goals, strategies and measurable outcomes for the claimed ‘program’, it could not do so, rather a list of activities was provided from MASS.” In conclusion in her letter to BAASS Ms Phillips wrote



"I infer the following from the above:

1. MASS do not have staff that is sufficiently qualified to address severe behaviours of concern.
2. MASS staff does not act professionally or collaboratively with parents, in terms of withholding important information from them in relation to incidents.
3. MASS do not seem to understand the basics of any program, that is goals, strategies and measurable outcomes.
4. MASS do not use restraint and seclusion as a last resort, as they are content to use restraint and seclusion frequently without engaging or making a recommendation for family to engage qualified specialists.

We strongly recommend The Mansfield Statewide Services Model including the travelling teacher program **not** be rolled out across Regional Victoria. All evidence suggests that this program is not inclusive and is ultimately harmful and traumatic to autistic people.

Report Recommendation 10.5 and 10.6

Education and training for frontline public transport officers and Victoria Police Accessibility Action Plan including understanding of autism including the diversity of presentation of autistic people.

BAASS Response and Recommendations 10.5 and 10.6

This recommendation is desperately needed as a statewide action plan, developed and delivered predominantly with autistic advocates, mentors and community- for **ALL** first responders.

For example, see our recent Public Statement below in relation to a recent event involving an autistic child and first responders- in this case Police.

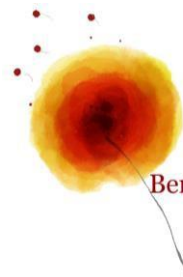
BAASS Public Statement 8th October 2017

BAASS responds to the recent events in Bendigo in which a child was restrained by several police.

We are not fully aware of the situation or privy to all details. It would be remiss of us or others, to make judgement on what we don't know.

What we do know is that this highlights the desperate need for more support and training for all first responders. It is imperative that autistic mentors be involved in development and delivery of ongoing training and support.

This is not about autism -the child being autistic is irrelevant.



Bendigo Autistic Advocacy
and Support Service

Co-Convenors
Beck Kelly - Tony Langdon - Susanna Flanagan

This is about a society that also needs support and understanding around human diversity and in acceptance of differences.

BAASS recommends further support and funding be provided in training for first responders and particularly welcomes the opportunity to provide autistic mentoring and resources. As in any area of disability, disabled voices are the priority in providing authentic insight and lived experience based training and support.

And our second statement:



Co-Convenors
Beck Kelly - Tony Langdon - Susanna Flanagan

Bendigo Autistic Advocacy and Support Service

Public Statement

Sunday 8th October 2017

Bendigo Autistic Advocacy and Support Service (BAASS) responds to the recent events in Bendigo in which a child was restrained by several police.

We are not fully aware of the situation or privy to all details. It would be remiss of us or others, to make judgement or comment on what we don't know.

What we do know is that this highlights the desperate need for more support and training for all first responders. It is imperative that autistic mentors be involved in development and delivery of ongoing training and support.

This is not about autism -the child being autistic is irrelevant.

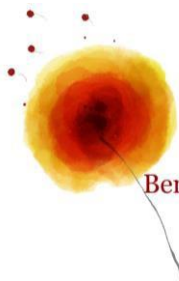
This is about a society that also needs support and understanding around human diversity and in acceptance of differences.

BAASS recommends further support and funding be provided in training for first responders and particularly welcomes the opportunity to provide autistic mentoring and resources. As in any area of disability, disabled voices are the priority in providing authentic insight and lived experience based training and support.

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[@AdvocacyBAASS](https://www.tumblr.com/advocacybaass)

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It is crucial that all first responders receive authentic training in inclusive practices - including autism specific considerations.

Report Recommendation 10.10

Funding coordinator positions of the I CAN Network across the state to ensure roll out of support and mentoring programs in primary and secondary schools, camps and training opportunities for mentors.

BAASS Response and Recommendations 10.10

BAASS recognises and appreciates the many brilliant successes of the I CAN Network and the many wonderful contributions made to the autistic and broader community.

We recommend this be expanded within an addendum to incorporate inclusion and prioritisation of local area self-advocates, disability led organisations and groups and mentors. A collaborative approach, allowing local groups the lead in their own communities is a much more productive and appropriate recommendation. Local level services/organisations with meaningful autistic representation are community members with ground level experience and in-depth knowledge of local dynamics and needs and in provision of advocacy, mentorship and support within those communities.

Priority should be collaboration between statewide and local efforts, with deference to the local organisations in any given area. Expanding this recommendation to be more inclusive could positively influence any potential or existing vested interests or biases.

As opposed to singling any one organisation in a broad statewide fashion, focus could be well prioritised also on breaking down attitudinal barriers as one of the most significant barriers to meaningful support and inclusion within schools and communities.

Recommendations around any specific organisations must include specific inclusion of expected commitment to supporting the majority voice heard, being that of autistic led programs and services over non-autistic programs and disability services committing to minimum ratios of disabled to non-disabled members.

A concern we raise is around the financial aspect of not only supporting local and statewide authentic organisations - but that it be recommended that all disability orgs/services commit to prioritising paid positions/wages, particularly autistic staff positions as paid positions (mentors and trainers etc).

It should be noted that cost viability be a consideration for services and viability for families, particularly given autistic people and their families are already disadvantaged with limited access to expensive program, yet need it the most. Transparency and accountability around these considerations are paramount to delivery of authentic, genuine and relevant programs/services for the autistic community.

All Report Recommendations

BAASS Recommendations

The Recommendations acknowledge, in places, the importance of autistic input in relation to the development of programs/policy/resources etc. relating to autistic people.

For absolute and meaningful inclusion, there would ideally be specific mention of autistic involvement, and a clearly defined expectation around level of involvement and input, included within every recommendation relating to the autistic community.

All Report Recommendations as such, must include specified majority input from autistic people as **the** most relevant and valuable perspectives and insights into their needs.

The general consensus amongst business board membership and diversity tends to most widely cite the figure 30%, to ensure meaningful and relevant perspective and input into any working group/committee/organization etc. The figures vary depending on the particular dynamics of the relevant community and reflect a similar percentage to the identified target group.

Compounding the issue of poor disability representation amongst leadership in general and of particular importance, within disability organisations, is a persisting “...wider lack of awareness about disability equality issues, even within charities: race, gender and sexuality tend to be higher up the agenda. Plummer (2017) with Lazard (2017) concurring with “We tend to be the last on the list. Disability equality is the last thing talked about”.

Although diversity amongst leadership is also widely acknowledged as best practice and ethical, “diversity on most boards” is sadly lacking, “disturbingly so” (Dexter, 2017).

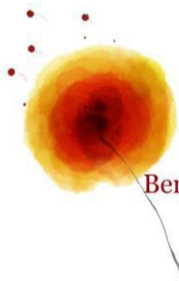
Neil Barnfather (2016), “a blind person, a senior executive who sits on boards and as a start-up champion..” notes that “When it comes to diversity on boards, I would confidently say that disability comes in a poor fourth behind gender, age and ethnicity”.

Ratios of disabled people amongst boards/leadership/policy makers etc of organisations/companies/charities etc. specifically disability related - is an even more specialized consideration and of even more crucial importance.

That there is very little writing, research or consensus available on ratios of disabled leaders and positions within such organisations is also disturbing and undoubtedly reflective of the heavily entrenched ableism and dismissal of disabled people and disability within the community. Barnfather (2016) laments that “...we must ask ourselves if there is a lack of concern about this issue”.

It is an essential consideration in this conversation, that it be abundantly clear and enshrined in policy; that representation of disabled people on boards/leadership within disability organisations is not enough. It is imperative that ratios are significant and meaningful- disabled people must make up a significant component of active, decision-making and policy development and delivery positions.

Barnfather (2016) substantiates this in stating “However – and this is a big however – disabled people must be on boards not purely to oversee disability issues, but to offer their talents, skills and experience”.



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The World Health Organisation (2011) considers disabled people invaluable and essential in being actively consulted and involved “...in formulating and implementing policies, laws and services.”

A consideration around this very subject and in the interests of genuine and transparent motives and intent would be to initiate research into establishing meaningful standards around expected - preferably mandated - disability representation within all things disability.

It is the recommendation of BAASS, that meaningful representation of disabled people within disability related companies/groups/organisations (and so on) aim for a minimum of 50% of leadership to be people identifying as disabled or with disability.

As relates to these particular Report Recommendations, BAASS asserts that is *essential and crucial* that development and delivery of all resources, education, programs etc involve minimum 50:50 autistic & neurodivergent people to non-neurodivergent people on any committee/panel etc. relating to autistic and neurodivergent people, to be meaningful and not simply tokenistic.

Christina Ryan, Founder of the Disability Leadership Institute and is a “management consultant (organisational development specialist) who embeds inclusion and ethical frameworks across organisational structures & culture. She has held CEO, senior management & team leading positions across both government & non-government sectors for 20 years, is a high level strategic thinker & noted innovator, using design thinking & collaboration to build new approaches.”

Ryan (2017) concurs that in relation to disability organisations and related content, “the international benchmark is more than half managed and owned. So, more than half the board, more than half the staff, etc.”. (Ryan, C. 2017).

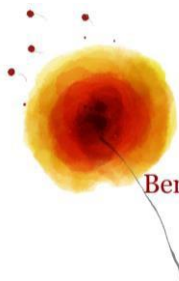
Some Report Recommendations are of particular magnitude in relation to the vital requirement of significant and meaningful input from autistic people. As such, we recommend that this be clearly outlined in relation to these recommendations, including specific minimum requirements of autistic input and range of sources of autistic input.

BAASS Recommendation re. Report Recommendations 3.1, 3.2, 3.3 and 3.4

These recommendations are of particular importance as they will impact on the entire autistic community in relating to development of programs/policy/resources in training for all General Practitioners; infant and early childhood diagnosis and training of Maternal & Child Health Nurses and therefore require specific mention of autistic involvement, and a clearly defined expectation around level of involvement and input.

Recommendation 3.4 relates to development of diagnosis consistency relating to autism and therefore requires specific mention of autistic involvement, and a clearly defined expectation around level of involvement and input.

The diagnostic process and developing consistency is something that autistic people must absolutely have heavy input into. Many of the autistic community have had extensive and significantly negative experiences around diagnosis and there is an overwhelming lack of knowledge and experience – and in some cases- attitudinal barriers around wilful ignorance and dismissal of persons and families.



BAASS Recommendation re. Report Recommendations 5.2, 5.3, 5.4, 5.10, 5.17, 5.18

These recommendations particularly relate to development of diagnosis and resources relating to autistic adults and autistic parents.

These recommendations require addendum with specific mention of the need for autistic involvement in developing and implementing these recommendations and a clearly defined expectation around level of involvement and input. Autistic people diagnosed in adulthood have unique experiences and considerations around assessment and diagnosis, with the most valuable insight and perspective crucial in considering adult diagnostic assessment, diagnosis, resources, education and programs.

Recommendations involving needs of autistic parents must include majority input from autistic parents as **the** most relevant and valuable perspectives and insights into their needs.

BAASS Recommendation re. Report Recommendation 5.7

Establishment of an education program for Victorian employers.

Once again, it is crucial that this recommendation incorporate specifically robust and meaningful autistic input, in particular as relates to local areas and a range of perspective and experiences within an addendum to the Report.

BAASS Recommendation re. Report Recommendations 6.1, 6.2

Ensuring the NDIS establishes clear communication strategy - “to provide accurate, timely and clear information in an appropriate manner” and training including ongoing PD for all NDIS planners around autism and Early Childhood Early Intervention.

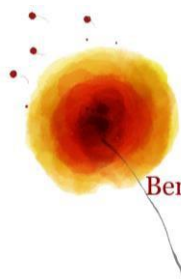
It is *essential and crucial* that development and delivery of all resources, education, programs etc involve minimum 50:50 autistic & neurodivergent people to neurotypical people on any committee/panel etc. relating to autistic and neurodivergent people, to be meaningful and not simply tokenistic.

We thank you for taking the time to consider our response and recommendations. It is our passion and mission to work collaboratively on all levels from personal, family and community to systemic advocacy and support. We welcome the opportunity to discuss any raised recommendations further and to consult on the development of an addendum to the current Report Recommendations and in implementing the many recommendations that stand to promote a significant positive impact for the autistic community.

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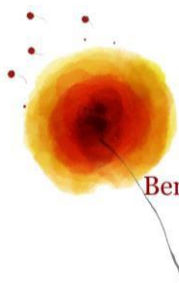
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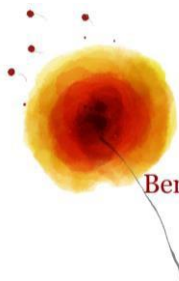
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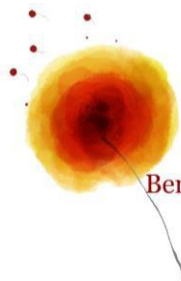
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