



ASPERGERS

VICTORIA

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Submission to the Department of Health and Human Services New Youth Policy

6th November 2015

Aspergers Victoria appreciates this opportunity to comment on the needs of young people in Victoria affected by Asperger syndrome (an autism spectrum disorder) and to contribute to the development of the new youth policy.

About Aspergers Victoria

- a) Aspergers Victoria Inc. is a registered health promotion charity, largely run by a team of over 40 volunteers, providing essential information and support services to those living with Asperger Syndrome including young people, as well as to teachers, health professionals and others in the community seeking information about Aspergers. Our vision is to promote the positive aspects of Aspergers, and to make a difference to the lives of individuals and families living with Aspergers, by providing support, knowledge and skills development to enhance lives and influence community views.
- b) The services provided by Aspergers Victoria are essential for young people with Aspergers to realise their potential to fully participate in the community. Many of the problems young people with Aspergers experience with school absenteeism, VCE incompleteness and unemployment could be avoided with increased understanding of Asperger syndrome, support in the community and appropriate accommodations in schools and workplaces.
- c) Aspergers tends to be a hidden problem because the condition is often not recognised in individuals, this is partly because people with Aspergers have average or above average intelligence. Due to a life long neuronal difference in the brain people with Aspergers perceive and interpret the world differently, which can cause issues with communication and behaviour, which are made worse if Aspergers is not recognised and understood by others. Many people are affected by Aspergers, estimates of prevalence vary from 1 in 250 people to as high as 1 in 150 people but this estimate does not include those without diagnosis. Males are diagnosed at a rate of 4-6 times higher than females.
- d) Aspergers Victoria run many support groups and events which cater for all members of the Aspergers community including Teens and Young Adults, their parents/carers, siblings and partners, as well as teachers, employers and health professionals seeking information and advice about Aspergers. Last year we delivered seven seminars, attended by nearly 750 people; attracted 40,000 visits to our website; maintained Twitter and a Facebook forum which reaches up to 10,000 views, produced quarterly 20-page newsletters; engaged in face-to-face contact with nearly 3,500 people; and serviced thousands of helpline calls and emails. We provide a resource library, an information pack and fact sheets to members. We also supported four families after the suicide of their loved ones with Aspergers. This is all done by our dedicated team of volunteers with absolutely minimal external funding, however the explosion in demand for what we do with no funding means our organisation is at breaking point with volunteer overload. No other organisation in Victoria offers



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the direct support services on the scale that we do – and with almost zero government or other funding.

- e) Peer support and social groups for the Aspergers community are well known globally to be vital, but they are at times intensive and demanding to run. We provide professional training and skills development to our volunteer team, many of whom have Aspergers. Through their progress, they in turn provide hope and inspiration to many others. All of our Board and some of our volunteers either have Aspergers, or have close family members living with Aspergers.
- f) The key message is that what should be done for young people with Aspergers is increased funding for essential services and support such as provided by Aspergers Victoria. The current lack of funding requires urgent attention in order to avoid preventable severe mental health problems and issues with social isolation, school absenteeism, VCE incompleteness and unemployment.

DRAFT VISION

Q. What does Aspergers Victoria think of the draft vision?

The draft vision of the new youth policy aligns with the vision of Aspergers Victoria to promote the positive aspects of Aspergers and to make a difference to the lives of young people with Aspergers, by providing support, knowledge and skill development to enhance lives and influence community views. Aspergers Victoria welcomes the draft vision to maximise opportunities and remove barriers for young people to realise their potential, for the following reasons:

- a) With the right support, Aspergers can be more of a “diffabiity” not a disability. The lack of community understanding of Asperger syndrome and lack of funding for support services is a barrier to opportunities for young people with Aspergers to use their ability to realise their potential to fully participate in the community, in school and in the workforce.
- b) Young people with Aspergers face particular challenges due to their lack of understanding of social interactions and their anxiety, which lead to them dropping out of school, not gaining employment and experiencing preventable mental health issues. Their ability to participate can be transformed if they are given additional support such as social skills training, clear guidance and anxiety tools early enough so they can develop ways to manage their Aspergers and then fully contribute their strengths and skills to our community.
- c) Opportunities for young people with Aspergers to participate fully in the community, school and workplace can be created when others, including teachers and employers, are aware of how to communicate and understand their mindset effectively. The use of clear and concrete terms can prevent misunderstandings that can occur. A calm, patient and respectful communication style can avoid sensory overload that may be experienced by an individual with Aspergers. Recognition and focus on their strengths rather than any deficits is crucial.
- d) The key point is that young people with Aspergers are currently facing significant barriers to realising their potential for participation in school and work, but with increased understanding and appropriate support problems can be prevented and overcome. Furthermore addressing the needs of



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young people with Aspergers is becoming even more urgent because with increased awareness and research more young people are being recognised for the first time in their lives as having Aspergers.

DRAFT OBJECTIVES

Q. What does Aspergers Victoria think of the draft objectives?

Aspergers Victoria welcomes the draft objectives of the new youth policy for young people and would like to make the following comments in relation to achievement of the objectives for young people with Aspergers:

- a) To participate fully in education, training and employment, key issues need to be addressed in relation to misunderstandings, bullying and inflexible approaches by schools and tertiary institutions, as well as increased understanding and making suitable accommodations in the work place.
- b) To be supported and to prevent and address issues early, barriers need to be addressed in relation to school and workplace lack of awareness on the part of students, teachers, work colleagues and employers and even better, skills need to be developed by people in these groups for effective communication with young people with Aspergers and for effective management styles when working in supervision roles with young people with Aspergers.
- c) To feel a sense of belonging, acceptance, value, safety and connection with their families, culture, local communities and civic society, we need to address the lack of awareness, support and skills to ensure effective communication for individuals affected by Aspergers as well as for all community members.
- d) To be given a fair go young people with Aspergers need respect, understanding and calm, clear communication with others with whom they interact. To be given a fair go young people with Aspergers also need access to skills development programs and support groups which provide specific information and peer friendships with other young people with Aspergers, which reduce their social isolation, and have been proven to improve their contribution to society and prevent mental health problems.

WHAT'S IMPORTANT TO YOUNG PEOPLE?

Aspergers Victoria thinks the following actions should be taken to improve educational opportunities for young people:

- a) Increased awareness, acceptance and understanding of the needs of young people with Aspergers is needed, in particular in relation to school attendance, participation in class, homework overload, exam and VCE allowances, and social interaction with teachers and peers.
- e) Due to lack of awareness and understanding, Aspergers is often not recognised in individuals, even when a student is experiencing significant problems at school and even when teachers are observing significant problems with communication, behavior and learning. Aspergers and High Functioning Autism are at one end of the Autism Spectrum and involve specific diagnostic criteria, but rates of diagnosis may not accurately reflect the number of young people living with the effects of Aspergers. More young women may be living with Aspergers which is unrecognised, the higher rate



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of diagnosis in males is attributed to under diagnosis in females and also their tendency to learn social skills through observation.

- b) This lack of recognition is partly due to the hidden nature of Aspergers but also due to lack of teacher training. People with Aspergers usually have average or above average intelligence but process information differently. Concrete thinking and honesty are characteristic traits, but can lead to misunderstanding and misinterpretation of intent. There is a huge variation in attributes experienced by individuals, for example, for some people sensory overload is more of an issue than for others and there are known behavioural differences between males and females.
- c) Even when an Aspergers diagnosis is obtained, lack of understanding, lack of funding, and lack of attention to the particular needs of the individual is often a concern. This is the case despite availability of a wealth of information, training and strategies that can assist young people affected by Aspergers in educational and community settings. Aspergers Victoria has most of this information available.
- d) The effects of Aspergers are made worse when misunderstanding occurs or inappropriate approaches are implemented, causing increased anxiety and sensory overload. This then results in that individual being unable to concentrate, learn and contribute. Appropriate accommodations include flexibility with some school rules or provision of additional visual information. When misunderstandings continue to occur between a young person with Aspergers, their peers, teachers and parents, this can manifest in school refusal, bullying, and inability to achieve their true academic or creative potential.
- e) Increased awareness, knowledge and training are required for students and especially teachers in all educational settings from primary right through to tertiary.

Aspergers Victoria thinks the following actions should be taken to improve the mental health of young people:

- a) There is a general lack of public awareness of Aspergers resulting in misunderstanding and exacerbation of mental health problems for young people. Aspergers is often not recognised in individuals even by parents, teachers nor health professionals. This can be the case despite significant problems with behaviour and social interaction. Symptoms such as sensory overload and the need to learn social skills in defined steps, for example, are misunderstood by others including peers.
- b) Even when an Aspergers diagnosis is obtained, misunderstanding and lack of appropriate responses to the particular needs of the individual from families, teachers and health professionals is of great concern. Everyone who interacts with young people - peers, teachers, parents and health professionals – needs awareness, knowledge and training for understanding and communicating effectively with young people with Aspergers.
- c) Mental health problems caused by Aspergers such as anxiety and depression can be significant, but the complications such as severe depression, school refusal, unemployment and suicide are all preventable. Strategies for promoting effective communication, appropriate support with understanding and respectful relationships with young people affected by Aspergers, are



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recognised as essential by the Aspergers community, but this information is not well known in the general community, nor even amongst health professionals.

- d) We have been advised that people with Aspergers are unlikely to receive NDIS funding. Symptoms experienced by people with Aspergers such as sensory overload, anxiety, depression, school refusal, unemployment and suicide can be hard to package into the severe and permanent category required for ongoing support under this scheme.
- e) The majority of information and support services for those with Aspergers are provided by Aspergers Victoria, which is the only organisation catering specifically for the specific needs of the Aspergers community. Demand for the services provided by Aspergers Victoria is growing exponentially, yet the organisation receives minimal government funding and is operated entirely by unpaid volunteers. It is of great concern to the Aspergers community that due to lack of funds Aspergers Victoria is under threat of closure.
- f) Government funding is urgently needed to improve access to information, support groups, training and services for the young people affected by Aspergers, their families, teachers, employers and community members. Many people are affected by Aspergers, estimates of prevalence are around 1 in 250 people, actual prevalence is likely to be significantly greater as this estimate does not include people who do not have a diagnosis, due to lack of knowledge, lack of services, or lack of acceptance of Aspergers in the community.

Aspergers Victoria suggests the following actions should be taken to improve the lives of young people in Victoria:

- a) The most important point is that separate and adequate funding should be provided for support services and training for young people affected by Aspergers, as distinct from Autism, as their needs are significantly different despite the DSM-5 determination of autism. This approach is consistent with the Victorian government strategy to fund “better support for people with autism spectrum disorder” through providing “better targeted and integrated services” (Outcome 11 Victorian state disability plan). More funding for research is also needed to better understand the needs of young people with Aspergers. The need for better understanding of the “incredibly diverse spectrum” of autism related disorders and the need for further study of Aspergers is acknowledged in the field of specialist ASD research.
- b) Many people with Aspergers are proud to call themselves “aspies”, participate in the workforce and raise their own children with their spouse. Also, an increasing number of adults are being recognised as having Aspergers, which can be a welcome realisation which helps to resolve long standing difficulties sustaining employment, spousal relationships and parenting their own children, so newly diagnosed adults need similar information, understanding and support services.
- c) There is an urgent need for more funding to support services to improve mental health and to keep young people affected by Aspergers in education and employment. The needs of young people with Aspergers are not being met by services which currently receive funding to meet the needs of the broader community of people with Autism. Instead Aspergers Victoria regularly receives referrals and requests from specialist organisations to assist individuals with Aspergers



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and their families, as well as to provide information and advice to parents, teachers and health professionals.

- d) The key point is Aspergers Victoria provides unique services to young people in the form of peer support groups – no other organisation provides these services - which are highly-regarded by the Aspergers community and supported by research evidence, and yet we are under threat of closure due to insufficient funding. Aspergers Victoria is grateful for the DHHS grant of \$ 2272 grant received in 2014 and is awaiting results of an application for a \$10,000 self help grant for 2015-16. If this application is successful these funds will help support the work of Aspergers Victoria but more funding is also needed to support existing work.
- e) The key message is that understanding and communicating effectively with people affected by Aspergers should be common knowledge in the community, especially in schools and workplaces. Everyone will benefit from increased funding for services for young people with Aspergers, especially the broader community of students, teachers and employers, as there will be less misunderstanding and better communication in families, classrooms and workplaces.

Thankyou for the opportunity to make a submission to the new youth policy and comment on the needs of young people affected by Aspergers. Being a volunteer organisation with minimal funding, unfortunately we have had limited time to prepare this submission. Aspergers Victoria would also like to thank the Victorian Branch of the Public Health Association of Australia for acknowledging in their submission to the new youth policy, the need for increased funding for services and support for young people affected by Aspergers. We acknowledge also the assistance provided by Amaze in sourcing reference material for this submission. We hope the information we have provided will help our members and our community. Please let us know if you need further information.

Kind Regards,

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For more information:

Aspergers Victoria. (2015). <http://www.Aspergersvic.org.au>

Attwood, T. (2006). *The Complete Guide to Asperger's Syndrome*: Jessica Kingsley Publishers.

Australian Advisory Board on Autism Spectrum Disorders. (2012). *The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward-Discussion Paper*.

Autism spectrum Australia ASPECT. (2013). *We Belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism.h*

Brock, J. (2015) Chief Investigator ARC Centre for Excellence in Cognition and its Disorders
<http://crackingtheenigma.blogspot.com.au>



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Kennedy, L. (2014). *The Hidden Diffability: Aspergers at School: Strategies for Secondary School* Paper presented at the Victorian Autism Conference 2014. Retrieved from <http://www.amaze.org.au/uploads/2014/10/Aspergers-at-school-strategies-for-secondary-school.pdf>

Royal Melbourne Institute Technology RMIT. (2015). Aspirations A collection of tertiary transition experiences from people with Aspergers Syndrome. <http://www1.rmit.edu.au/browse;ID=p25qsta9g719>

Said, H. (2014). Victorian State Election - What's at stake for people on the spectrum.

Valentine, K., Rajkovic, M., Thompson, D., & Dinning, B. (2010). *Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers*: Social Policy Research Centre, University Of New South Wales.

Vermont, G. (2015). *Intimacy, Sex and Aspergers*. Retrieved from <http://www.amaze.org.au/uploads/2014/10/Intimacy-and-sex-in-Aspie-relationship.pdf>

Victorian state disability plan
http://www.dhs.vic.gov.au/__data/assets/pdf_file/0009/749862/Victorian-state-disability-plan-2013-2016-180113.pdf