



Autism Family Support Association (AFSA)

**Feedback on the Victorian Draft Disability Action Plan
2018 – 2020**

July 2018

AFSA Feedback – Draft Disability Action Plan 2018-2020

The purpose of the Autism Family Support Association (AFSA) is to assist and support individuals with an Autism Spectrum Disorder (ASD) by providing emotional and practical support for parents, carers and families. AFSA is an incorporated, state wide voluntary parent based support group. Through parent to parent support our aim is to improve the outcomes and quality of life for individuals with ASD and their families and carers. By supporting carers better we can help those with ASD live more fulfilling lives. AFSA represents the lived experience of those who love and care for those with ASD. AFSA has been in existence for more than 30 years and is a registered charity. Committee members provide their time and expertise on an honorary basis.

AFSA recognises that a Victorian Autism State Plan is in course of being developed and that hopefully some of the issues and concerns experienced by people with autism and their families will be better addressed in the future.

As the contents of the Victorian Autism Plan are unknown at the time of writing this submission, we will seek to highlight some current issues and concerns of people with autism and their families that AFSA thinks are relevant to the preparation of the Victorian Disability Action Plan.

In **summary** we would say that the draft document should be adjusted in a number of ways:

Under “culture and community”

- There should be reference to the need to improve funding and support for disability “day services”.
- There should be reference to the need to improve and support communication programs and initiatives for those with little or no functional communication.

Under “health and wellbeing”

- There should be reference to the need for those with chronic medical conditions to have regular medical reviews.
- There should be more emphasis on the need for more accommodation/housing and respite.

Under “safe and secure”

- There should be more specific reference to action to prevent abuse.
- There should be a focus on the need for advocacy services to be adequately funded, upgraded and available to all.

Under “capabilities”

- There should be reference to a workforce strategy being implemented to improve the quality and skill of staff looking after people with ASD and other disabilities
- There should be reference to the need to put in place more effective and robust complaint systems.
- There should be reference in the plan to work being undertaken to actively resolve “demarcation” issues between different systems of support and organisations over responsibilities for example between the State Education system and the NDIS. These issues can arise over support around health and mental health, support for communication needs and support where an individual has complex needs and issues.

Following is some further **elaboration and support** for our contentions above regarding additional things we believe should be included in the Plan.

Victorians are connected to culture and the community

People with ASD have the same rights to social inclusion and benefits as all other citizens, but, unfortunately, they remain some of the most vulnerable in our community. As adults, they have the right to live independent and full lives of their own choosing, with the appropriate supports. It is time to eliminate the attitude that it is the responsibility of the parents of the person with ASD to remain their carer for life. As a community, it is imperative that education is provided to change attitudes towards those on the autism spectrum, with improved understanding of their unique needs and challenges. We need to promote acceptance that all people with ASD (regardless of their level of ability) deserve and have a contribution to make to society. People with ASD should have an expectation to live a good life, the same as any person would expect.

Many adults with ASD attend generic **disability day services**, as they are unable to participate in employment or education. These services are typically under resourced and often provide little more than “childminding” for adults. Expectations of all the players in the system need to change so that meaningful programs involving social development, education and work can occur. Staff in these services need to have the resources to make better things happen! In the changed environment of the NDIS where there will no longer be “block” funding we need to ensure that the market is working and good services have the ability to operate.

Improve and support Communication Programs

There is no adequate framework within the education, adult and accommodation services to support language and other forms of assisted communication by those with ASD who have a significant deficit in this area. The education system should provide the foundation communication building blocks for all children, including the ASD population. Literacy and communication is a basic human right, and is a basic requirement for everyone to function and be included in the community.

All people with a language deficit should have a communication assessment by a speech therapist with specific knowledge of ASD and the subsequent development of an individual communication plan. Typically, many schools do not provide this vital resource to support communication programs for students with ASD. Due to a lack of functional speech or assisted communication, many of these children with ASD develop inappropriate and difficult behaviours as their means of communication. These children are then “labelled” as being difficult and/or dangerous. There should be no excuses for this, and as a society, we should be ashamed.

The present government has legislated that teachers will be required to upskill each year to remain registered to teach and this should apply to other professionals who work with people with ASD.

Without a functional method of communication, how can children learn, be a part of the community and have a good life. This is something we all expect, so our ASD loved ones should have those same expectations. It is completely unacceptable and unlawful, given a person’s human right to communicate, in whatever form this takes, to find a person’s communication is not supported by staff. It has been reported by parents of people with ASD that communication devices are left unused in bags and cupboards.

It is very unfortunate that these “labelled” children grow up, leave school, and become a member of the adult community, still “labelled.” The longer their communication needs are not adequately addressed, their negative behaviours will escalate. Again, adults with ASD are disproportionately represented with “behaviours of concern”, requiring high levels of support and very large funding packages. The Victorian tax payer bears the financial brunt.

Evidence suggests that intensive and consistent communication resources and behaviour management strategies for each and every ASD child with language deficits must be provided in the school system. There should be greater coordination of expertise from all allied health experts in the field to provide advice, training and assistance to both families and all providers of services.

Parents and families are an integral element in the life of the ASD person, so there must be greater choice and voice given to them in the use of communication programs. This is vital given the increase in the availability of cost effective and emerging technologies to enhance

the life of those with ASD. It needs to be easier for communication aids and devices to be purchased.

Adults with ASD who have not had the opportunity of effective and quality services and support should not be forgotten. It is widely recognised that the earlier interventions are implemented, the better the result for the child. But intervention services can be implemented at any time in a person's life, and, although it may require more intensive intervention due to age and ingrained habits, adults with ASD deserve the same consideration to provide them with the opportunities for a good life. Most people with ASD will require intervention therapy at different times throughout their life, and in particular, during times of transition and periods of great change or challenge.

Individuals with ASD vary in their communication skills. Some may never develop language. Others might acquire simple language, whilst others will develop fluent and effective language. Some have sophisticated vocabulary and/or the ability to speak with great technical complexity on certain topics, but may still have difficulty understanding or expressing complex or abstract concepts. Sometimes their conversations may be very one-sided, and struggle with the back-and-forth nature of conversations. Some individuals with ASD have comprehension problems, often more so than suggested by their expressive language. Even the most able individuals with ASD report auditory comprehension difficulties at times at some level. Many rely heavily on visual skills to compensate for auditory comprehension problems. Some individuals with ASD may not develop speech but will be able to communicate through alternative assisted communication methods such as signing, picture exchange systems, printed word or communication devices. Some people require intensive assistance to communicate.

Victorians are healthy and well

Many people with ASD have chronic medical conditions (eg epilepsy; food allergies; skin conditions; diabetes; hearing problems; mental health issues – anxiety, depression, mood disorders, substance abuse, OCD). It has been estimated in earlier years that up to one third of people with ASD have epilepsy. All people with ASD who also have chronic medical conditions should be offered annual medical reviews to support the management of these conditions. Federal and State Health Departments should consider developing a voluntary database to measure the extent of treatment provided. There is anecdotal evidence from parents/carers that a number of adolescents and adults with an ASD self-medicate to help cope with their anxieties leading to significant substance abuse. This observation needs to be researched to establish the extent to which this occurs. Regular medical reviews (which occur for residents of government supported accommodation) would also assist in the detection and management of substance abuse.

It is extremely common for people with ASD to present with a range of co morbidities which further impact on their functioning, management and progress. Some examples of co morbid conditions include intellectual disability or cognitive impairment, mood disorders, sleep disorders, depression, anxiety, epilepsy, attention deficit disorder, obsessive compulsive disorder. Despite many years of conversation and review, Disability and Health still manage to pass individuals from one system to the other and not acknowledge that support is required from both service areas working in partnership.

More Accommodation/Housing and Respite

Anecdotal evidence suggests long waiting lists for people with ASD to access appropriate accommodation. There are long waiting lists or inability to even qualify to get on the “list” or Register for government housing. Victoria is one of the States that has supported residential services and which provides accommodation for those with a disability.

There should be a priority for better models of housing suitable for people with ASD. The present models may not suit the unique challenges experienced by this group of people. Many struggle in the group home setting. More work needs to be done either by government or through government support for groups looking for clever and creative living styles to suit this group of people. Greater transparency is required on demand and supply of accommodation. While there appears to be some willingness on behalf of government and the NDIA to recognise the problem in housing AFSA urges this be a priority as the population with ASD continues to age.

There is a lack of suitable “respite” services to support families with an ASD family member, particularly for parents and families of adult children. A break for these families is vital for their wellbeing, so they can continue their caring role.

There must be better assessment services put in place to prioritise needs for housing and respite.

Victorians are safe and secure

Evidence would suggest that people with ASD are over-represented within the system as being relinquished due to lack of support and families being overwhelmed and unable to continue to cope in their caring role. Parents/carers must be appropriately consulted with and allowed input into policy development and the implementation of programs.

While it might seem unnecessarily emotive, it needs to be remembered that there are regular and often tragic reports of individuals with ASD, dying through misadventure such as drownings after “absconding”, and subject to restraint and violence. This is often despite

heroic efforts and struggles by parents/carers to keep their children safe. Sadly, there remain many reports of abuse of the disabled, including those with ASD, in supported accommodation, schools and varied other areas of the system and the community. AFSA wants to see some of these bad stories turned around, by comprehensive action that involves all the stakeholders working together across all parts of the system, for the benefit of those with ASD.

Advocacy services to be adequately funded, upgraded and available to all

As we move into the full implementation of the NDIS it is even more critical that the right advocacy services are there to support individuals with ASD when negotiating their care and support plans. The advocacy industry remains unregulated and it appears anyone can call themselves an advocate. This preys on the vulnerability of families, who at times are overwhelmed and desperate, due to the stresses of their caring roles.

There needs to be adequately funded advocacy services which are readily accessible with clear guidelines and adherence to a mandatory code of conduct for provision of advocacy services.

Government funding rests with a limited number of recognised advocacy services. However, most of these are mandated to be involved with systemic advocacy, which is a vitally important element for systemic changes to occur. However, many families at some point will require the services of an independent advocate to support them through their individual negotiations. There remain many obstacles within the disability service sector, including education, that seem insurmountable to many families with an ASD loved one. AFSA believes that government funded advocacy services are limited in the advocacy services they can provide. The peak ASD body in Victoria is not funded to provide individual advocacy. In the absence of individualised support, many families feel abandoned and alone, leading to carer stress, depression and PTSD. A list of service options or a brochure with website links is not an adequate advocacy support service.

Regulated advocacy and support services need to be available for parents/families from diverse backgrounds and in ALL regions of Victoria.

There are many residents with ASD in supported accommodation facilities who no longer have active family involvement to ensure the continued quality of their care, support and wellbeing. Unfortunately, not all support staff working in these facilities have the desire, or at times, the correct expertise to ensure their client's complete care. These residents with ASD are extremely vulnerable to abuse and neglect, and it is imperative that well-resourced advocacy services are provided as an independent safeguard for this group of individuals to ensure their wellbeing and proper care.

As the population of those with ASD and their families gets older, individual advocacy and related support services will be critical to the system.

More Responsive and Accessible Complaints Systems Needed

We need robust complaints systems that allow for timely and thorough investigations concerning the wellbeing of people with ASD. These systems need to be comprehensive, with the right powers and resources, and the ability to investigate in both public and privately controlled services. Any recommended outcomes from such processes must be able to be implemented quickly. DHHS has an incident reporting system but this does not cover poor service delivery. There is anecdotal evidence that families are unwilling to complain about problems with services for fear of their family member with ASD being disadvantaged. And it takes a strong, well supported family to pursue avenues of complaint, including the legal system, in the face of crowds of bureaucrats, interminable meetings and hearings and pages of regulation, policy and procedures.

Victorians have the capabilities to participate

Improve quality and skill of staff working with people with ASD

Work in the disability sector needs to be valued. We need to attract and retain skilled and motivated staff. The ASD population, in particular, due to their complex needs and challenges are at a greater risk of receiving inappropriate support. This can lead to abuse and neglect. High levels of staff turnover results in inconsistent levels of care and support. Consistency is so vitally necessary for ASD people who struggle with change, anxiety and difficulties communicating or conveying their needs or frustrations. The never ending requirement to explain the particular needs of the person with ASD due to constantly changing staff creates issues for all stakeholders - remaining staff, parent/carers and the ASD person themselves. This increases the stress and workload of all concerned. We need a “production line” that educates and continues to build a workforce that can adequately support people with ASD.

For the families of those with severe and complex presentations of ASD*, finding and retaining well qualified and caring support workers remains a major worry. How can our loved ones have a good and productive life without this vital element? We have high expectations of the skills necessary, as we well should have. Most jobs and professions require appropriate skills, qualifications and training, and a level of financial remuneration commensurate with those qualifications.

* estimated by Amaze to be approximately 25% of the total ASD population cohort

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