

THE FIRST TWENTY YEARS OF AFSA

Back in the mid 1980's a group of parents from the Irabina Day Training Centre decided that there was nothing out in the wider community that provided support for families after they had moved from the autism specific services to more generic options. They formed a committee that became known as the Autistic Family Support Association or AFSA. Their primary aim was to provide mutual support for themselves and other families who had a family member with autism and to share information about new treatments and strategies for the management of autism.

To begin with they organised morning and afternoon coffee meetings and evening information sessions. A newsletter, called Contact, was produced to help keep families in touch. During the years since many people have been involved with the committee and each have brought to it their own special issues and viewpoints to share. By providing the opportunity for members to have a forum the committee soon had many ideas for projects, activities and working parties.

The following outline is derived from the articles published in the AFSA newsletter, Contact.

AFSA PROJECTS 1980's & 1990's

- Incorporation in 1989
- A parent survey
- Production of an award-winning video "Autism: the Early Signs" – funded by Victorian Health Promotion Foundation
- A Parent Information Kit, brochure and parent story "I Can Still Smile" (by Deborah Johnson) to increase public awareness of autism
- Telephone and personal support to AFSA families was provided by an amazing lady, Gloria Jones who would travel Victoria, often at her own expense, to advise and guide families. In 1991 Gloria's role morphed into a professional Family Counselling Service run by the Victorian Autistic Childrens & Adults Association (VACAA) and funded by a philanthropic grant. In 1993 VACAA negotiated a recurrent grant with Community Services Victoria (CSV) to fully fund this position.
- Family Communication Camp in partnership with Dr Carl Parsons, LaTrobe University and Speech and Language students
- Seminars and Workshops with guest speakers
- Providing a parent voice and perspective to VACAA, government and other disability support services
- School Holiday Support Program – funded by a Commonwealth Government grant
- Family Day excursions – Diamond Valley Railway, Kew Traffic School, local parks
- Fostering country support groups – the number of small regionally based groups ballooned during the 1990's – some have disappeared, some have evolved into services and some have undergone several reinventions and remain as primarily family support groups
- Supporting the establishment of the Asperger Syndrome Support Group (1990)
- Contact mailing list was 400+ families by 1997

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- AFSA and the VACAA liaised with a group of parents from Tasmania at the 1992 National Conference in Melbourne resulting in the formation of Autism Tasmania

AFSA PRESIDENTS 1980's – 1990's

- Mary Jane Blackman
- Robyn Shanahan
- David O'Sullivan
- Gloria Jones – Honorary Life Member
- David Heath
- Liz Wilks
- Margaret Hortin
- Maria Pickering
- Peter Laming
- Phil Lipshut

HOW DID WE VIEW AUTISM IN THESE EARLY DAYS?

This is an extract from an item published in Contact, September 1994, and used by AFSA to promote greater public awareness and understanding of autism. It was written by Amanda Golding, long time member of AFSA.

WHAT IS IT LIKE TO BE AUTISTIC?

AUTISTIC – alone, disinterested, isolated, unsociable, obsessive, resistant, out of control, mute, aggressive

These are just some of the words people use when asked if they know “What an autistic person is like?” Each word expresses clearly what we may see when we meet a person with autism. But what is it like to be autistic? What do autistic people see when they meet us?

NON-AUTISTIC – inconsistent, loud, intrusive, unpredictable, hurtful, confusing, strange, scary.

It is all a question of perception.

The ability to be flexible and change and activity, conversation or instruction quickly can be perceived by a person with autism as being unpredictable and confusing. If everyone around you is being unpredictable all the time, what would you do? Have a tantrum, go off by yourself, ignore everything?

Understanding spoken language and body language is difficult for the autistic person. Verbal language may consist of a string of incomplete words, or the words may stand alone and not form a meaningful idea or instruction.

Not only is understanding someone's speech difficult, but so is interpreting what they mean. Words and phrases have many meanings. Again and again people with autism interpret words and

comments literally. A simple comment like “we might run into Jack in the supermarket” can cause horror because ‘run into’ means to hurt or run over, it doesn’t mean ‘meet’.

The autistic person is largely unaware of other people’s thoughts and feelings – their mental states. Disinterest, rudeness, antisocial responses and muteness are ways of coping with the confusion of not knowing how to handle the conversation of another person who is not saying exactly what they think.

If you were living in a world of such confusion, what would you do to bring some order into your life, to reduce the confusion and stress – to develop some control over your environment? Autistic people seem to us to be rigid, obsessive and resistant to change. But what they are really doing is trying to reduce the disorder, unpredictability, stress and pain they constantly experience.

Non-autistic people can assist with the development of alternative ‘controls’ or behaviours that are more acceptable and allow the autistic person to participate and learn. There will be resistance and old obsessions will be replaced with newer versions, but over time and with persistence, patience and skill, we become less intrusive and unpredictable and the autistic person becomes less resistant, obsessive and alone.

AUTISM: THE EARLY SIGNS – HOW A SMALL IDEA BECAME AN AWARD-WINNING VIDEO

Taken from an item written by David Heath, President of AFSA, who was the driver of this project.

Early in 1988 David was searching for recent appropriate audio-visual material to complement the speaking engagements of Gloria Jones who was President of AFSA that year. Gloria found it very difficult to convey the behaviours of autistic children without something visual to illustrate her words. This was in a time when there was little community awareness of autism which was considered a rare condition affecting about 2 to 10 per 10,000 children. Diagnosis before the age of four or five was rare.

Through contacts David was referred to the Victorian Health Promotion Foundation for funding to enable production of a high quality, professionally produced 30-minute video focussing on the education of professionals about autism and the importance of correct and early diagnosis and early intervention. In addition, the video would help educate the families of autistic children to help reduce their stress and the wider community leading to a greater acceptance of autistic people.

An enthusiastic team was gathered including AFSA committee members, Hardy Stow (Leki Films), Nell Jones (Principal, Irabina), Wendy Hoffman (Psychologist) and Dr Bruce Tonge (Child Psychiatrist).

Three wonderful families agreed to be filmed and a final edit was presented to a national conference in 1990 and very well received. The screening rights were taken up by the ABC, the VHPF funded the production of the video in four community languages and the VACAA distributed the video on AFSA’s behalf. A second project was funded to research and evaluate the impact of the video. This work was undertaken by Vicki Bitsika and VACAA.

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Several years later two of the original families participated in the production of a follow up video, Autism: The Teen Years, produced by Mark Poole who had been involved with the earlier video.

SCHOOL HOLIDAY SUPPORT PROGRAM

One of the first grants obtained by AFSA was from the Commonwealth Government to fund provision of 1:1 support to enable autistic children to participate in community school holiday programs. Robyn Shanahan was appointed coordinator and she worked tirelessly to recruit support workers and match them to families and activities. A coordinator in Geelong was also appointed. When Robyn retired from this role in 1991 it was taken over by Kerry Strapp. The program operated for over ten years and finished when the funding was no longer available.

SPEECH AND COMMUNICATION CAMPS

Another long-time project managed for AFSA by Liz Wilks was the annual Speech and Communication Camp. Each camp was run over a weekend at a variety of venues out of Melbourne for five or six families. Recreation activities were arranged for the siblings, parents were able to meet with each other to share concerns and experiences and each autistic child was assessed by student speech and language therapists under the supervision of Dr Carl Parsons and lecturers from the LaTrobe University Speech and Language Department. Families received very detailed assessment reports which included recommendations and suggestions. Not only did Liz liaise with families and LaTrobe she also sourced funding and donations to help defray the cost to families.

REPRESENTATION AND AFFILIATIONS

Autism Services Coordinating Committee – Chaired by Dr Allan Mawdsley. This committee comprised professionals and services working with autistic children and adults. An AFSA representative was able to provide the parent perspective, or what is now referred to as the 'lived experience'. By the mid 1990's this committee negotiated a new category in the Department of School Education Educational Needs Questionnaire – Severe Developmental Disability. This meant that autistic students no longer needed to satisfy the Intellectual Disability or Severe Communication Disorder categories to receive additional support funding. This committee also prepared the first Australian Autism Assessment Guidelines to be used by multi disciplinary teams.

Victorian Parents Advocacy Collective (VPAC) – a proactive group of volunteers supporting families facing schooling issues. The main issue they addressed was the conduct by the Department of School Education of disciplinary inquiries and ongoing suspensions of autistic students due to disruptive behaviour. They also supported parents to negotiate mainstream school enrolment.

Victorian Autistic Children's & Adults Association (VACAA), from 1996 known as Autism Victoria – affiliation, Autism Week participation, family counselling service, information resources, representation on government inquiries (1989 Autism Review, 1994 Health & Community Services Autism Services Reference Group) .

Asperger Syndrome Support Network – established in the late 1980’s, AFSA provided practical and emotional support to this group of parents whose family members were diagnosed with Asperger Syndrome, a newly described variant of the classic Kanner like autism condition.

TRENDS IN AUTISM TREATMENTS

During the late 1980’s and into the 1990’s AFSA provided information and support to families on the following trends, programs and alternative treatments that were circulating around the autism community worldwide – some useful, some not so useful.

- Metabolic or Chemical Therapies for Autism – DMG or Dimethylglycine, Secretin, Vitamin B6, Clomipramine, Fenfluramine and others – now largely disappeared.
- Genetics of Autism – establishment of a ‘gene bank’ and associated research projects – a genetic factor is now an accepted link in the causation of autism.
- Measles Mumps Rubella (MMR) Vaccination link to onset of autism – research subsequently refuted.
- Auditory Integration Training, Facilitated Communication and Irlen Lenses – taken up by some families and are still available although not widely utilised due to mixed outcomes.
- Lovaas’ Discreet Trial Training and Applied Behaviour Analysis – ABA is now a widely practiced therapy approach especially in the early years after diagnosis.
- Giant Steps, Apple Intellitools and Intellipics, SonRise Program, Compic, TEACCH, Early Start Denver Program – have all contributed ideas, strategies and tools to the autism landscape in ensuing years.

AFSA has always tried to be neutral in relation to therapies or “treatments” focussing instead on supporting families and carers in a “practical” way.

AFSA IN THE 21ST CENTURY

AFSA PRESIDENTS 2000 - 2023

- Phil Lipshut
- Michelle Graffeo
- Meredith Ward
- Richard Joseph
- Tracy Ann Pettigrew
- Jan De Witte
- Catrina Mulderry
- Michael Tucker

WHY DID AFSA EXIST AND KEEP GOING?

Reflections of the AFSA President Michael Tucker (2016-2023) and Secretary Amanda Golding (2010-2023).

The focus of AFSA operations has generally reflected the interests, experience and abilities of the current committee membership (and often the President). In the 1980s and early 1990s, AFSA focussed on “connecting” families to one another as they often were in the early stages of coping with a diagnosis of ASD in their families and the implications of that diagnosis.

AFSA seems to be unique in Australia as a “standalone” family support group for families supporting a family member or members with ASD. Why might this be? In other Australian States, as far as we are aware, the main organisations that existed and operated in the ASD “space” were service providers. In other States the centres that delivered the services to children with autism were often providing “support” to families. AFSA has always been comprised of volunteers.

From the mid 1960’s autism services in NSW, Queensland, South Australia and Western Australia were established using a centralised format. In Victoria a number of different autism specific service providers evolved, spread over various parts of Melbourne and country Victoria. This “decentralised” model of service provision contrasted with the set up in the other states where the “centralisation” of service provision presumably provided more opportunity for parents to support each other.

In Victoria the ‘peak body’ for autism, the Victorian Autistic Children’s and Adults Association (VACAA), was not a service provider. It had been formed in 1967 as an umbrella body that brought together the various support services for people with autism primarily for mutual support, fund raising and public awareness purposes. These services formed the governing body of the VACAA and in the mid 1990’s AFSA was admitted as an affiliate.

In the early 1990’s, after the Victorian Green Report of 1986 led to the requirement that all school age children had to be in schools conducted by or auspiced by the state Education Department, there was some reorganising and expansion of several of the original Victorian autism services and the establishment of several Special Developmental Schools - Autism. In response an AFSA Parent

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Information Pack was developed and distributed. A statewide network of parents and families was being established and built upon with AFSA at the helm. AFSA was able to use the then premises of Autism Victoria (VACAA) in Glen Iris to hold its monthly meetings and utilise some office support.

During the 1990's, as more children were being diagnosed with ASD there was an even greater need for parents of children who were not in autism specific services to be able to support each other and share information. The population of children (and adults) with ASD in Melbourne (and Victoria) was being educated or supported in an ever-increasing number of special and mainstream schools and generic services.

In the late 1990s Autism Victoria (VACAA) received a large bequest which was dispersed to its affiliates. AFSA received \$50,000 which has allowed our association of volunteers to continue as an organisation (even in lean times) because of the "buffer" these funds have provided along with prudent management of resources.

AFTER THE TURN OF THE CENTURY

An article in the Autism Victoria Autism News magazine in 2001 noted that AFSA activities and membership had waned considerably. Liz Wilks continued to produce the Contact newsletter in print until about 2006 when it became an irregular email-based publication. The School Holiday Support Program remained but was now managed by two service providers – Gateways in Geelong and Statewide Autistic Services in Seaford. A member of AFSA, Meredith Ward, spearheaded a new AFSA initiative, the Advocacy Council. This initiative grew from the Irabina Parent Action Group (IPAG) which had been lobbying government hard for an improved funding deal for autistic early childhood intervention services.



As part of the rejuvenation of AFSA the committee prepared a strategic plan and developed a new style and logo. An AFSA web page was developed in 2008 and electronic communications and document management systems were established.

www.afsaconnect.org.au

With tireless enthusiasm Meredith advanced the advocacy role of AFSA. In 2004 as the new AFSA President, she wrote "AFSA is changing and evolving. We have a new logo, new mission and we are moving in a new direction, steadily, with purpose underpinned by a strategic plan. We believe the words Connecting Families best describe AFSA's purpose. 'The autism community seems so disconnected and difficult to navigate' is a frequent comment that we hear." She concluded that

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“AFSA is an organisation, which, through active participation at many levels, can be a catalyst for change.” (Autism News, September 2004, page 5)

During Meredith’s term as President the voice of parents, representing the lived experience of autism, was constant and achieved significant impact. In the period from 2006 to 2009 Meredith played a critical role in working with other stakeholders to develop an Autism State Plan that was launched by the Victorian Government in 2009. Unfortunately, politics intervened and the plan was not actioned.

AFSA FROM 2011

AFSA is managed by a volunteer committee of management with a four-person executive - President, Vice President, Secretary and Treasurer. Communication with members and the general community has been by the usual communication methods of the time. In the 1980s, 1990s and early 2000s it was by paper newsletter “Contact”. It then moved to mainly to email and in recent years via a website www.afsaconnect.org.au as well as Facebook from 2016. A quarterly eNews, *eContact*, was reestablished in 2022.

In 2014 the committee revised the AFSA Constitution in line with the requirements and Model Rules of the **Associations Incorporation Reform Act (Vic) 2012**. AFSA has been appropriately registered with relevant Government agencies including the ATO (Income Tax Exempt), the Australian Charities and Not For Profit Commission (ACNC) and relevant State Government agencies. Our name was altered to Autism Family Support Association in line with preference at the time. The changes required AFSA to reestablish its membership list. The number of registered AFSA members in 2023 is 290.

At various times over its life AFSA has been in receipt of State Government Grants that support disability organisations. AFSA has been continuously in receipt of the Disability Self Help Group grants since 2009 which cover basic running costs such as insurances, meeting room hire and communication operating costs. This grant has enabled AFSA membership to remain free of charge and in recent years we have not had to charge families to attend information and social gatherings.

The rate of diagnosis and the prevalence of ASD in the Victorian community (and everywhere) has increased substantially since those early days when the quoted incidence was 2 to 5 per 10,000 children. The push for recognition and better services continues to grow. The parent voice is increasingly being heard. In 2007 the Olga Tennison Autism Research Centre (OTARC) was established at Latrobe University. In Victoria the 2006 Disability Act was legislated to provide greater support, recognition and protection for those with disabilities including those with ASD. There was a greater debate/discussion about the autism “spectrum”, the recognition of Aspergers syndrome and DSM5. In 2007 the Commonwealth Government provided significant funding for early intervention services for those with ASD – Helping Children with Autism.

The introduction of the National Disability Insurance Scheme (2012) has provided yet another challenge for families. Ten years on the scheme has delivered both positive and negative impacts

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and the importance of the voice of participant families and carers is as critical as ever. AFSA has contributed to several reviews of elements of the NDIS.

It has been interesting for those of us who are 'old timers' and have lived through so many iterations of autism – autistic person, person with autism, autistics, Aspergers Syndrome and now the universal Autism Spectrum Disorder, on the Spectrum or Spectrum Disorder along with the readily identifiable acronym ASD. To AFSA members they are simply our much-loved family members.

4/10/2015

AFSA CELEBRATES ITS 30TH BIRTHDAY

Our cake is cut by two founding members,
Robin and Bernie Shanahan,
sadly no longer with us.



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However, it has become increasingly apparent that as the spectrum of autism broadens, the needs of autistic children, teenagers and adults presenting with severe or more challenging autistic behaviours were not being adequately considered by services, the government and the wider community. In the past decade the focus of the AFSA committee has been to represent this group presenting with severe or profound autism.

AFSA's response to the ever-changing disability landscape both at state and national levels has been to develop a series of Agendas and Statements. With many opportunities to raise our concerns presenting themselves via reviews and face to face meetings, AFSA needed to ensure our demands were consistent, relevant and effective.

The AFSA website has evolved into the repository of our key documents – Agendas for Action, Statements and Submissions. All of our statements and submissions that are prepared to address specific situations or terms of reference are derived from our three key Agendas – Agenda of Issues, Agenda of Education Issues and Agenda of NDIS Issues - <https://www.afsaconnect.org.au/afsa-agendas-of-issues/>

In 2016 the Victorian Parliament's Family and Community Development Committee undertook an inquiry into services for people with autism. AFSA wrote a submission and appeared before the Committee. In 2017 the Committee handed down its Report making some good recommendations for improved services (101 in all). The AFSA President Michael Tucker was part of an Advisory Committee to the Minister on the Government's final response to the Parliamentary Report. An interim response by the Government in December 2017 committed to a Victorian Autism Plan and it was launched in the second half of 2018. Unfortunately, there has been minimal evidence of government action and AFSA is now part of an Autism Plan Advisory Group to 'refresh' the plan. The challenge continues.

In 2016 the committee arranged a new design style for AFSA as well as a completely redesigned website. Also in 2017 the AFSA committee commenced organising an annual information session to complement the Annual General Meeting guest speaker and occasional programs for parents run in partnership with other organisations. Following from their success an application for a Supporting Carers Locally grant was made and great plans were laid – then COVID hit. The committee rose to the challenge and with significant funds from this grant AFSA families were supported through these tough times with Cinema vouchers, lunches and dinners and grazing boxes as restrictions allowed.

In 2023 several long time AFSA committee members retired, handing over to a new committee who will take AFSA forward with fresh eyes and new skills.

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