

Report of the findings of the 2006 Autism Victoria Member Survey

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Overview

The survey was distributed with the Winter 2006 issue of the member magazine, *The Spectrum*, could be downloaded from our website or from Issue 8 of *eSpectrum*. 168 surveys were returned, of which 84% were current subscriber members of Autism Victoria. The responses generally reported a high level of satisfaction with current Autism Victoria services. A number of suggestions for improvements were made. In some instances they were requests for services already available, indicating that Autism Victoria needs to review its communication strategy. In other cases they were for services beyond the scope of the association to provide, or are better provided by other agencies. There were also several suggestions for improvements which will be acted upon.

The committee and staff of Autism Victoria would like to thank all members who participated in the survey. Comment and suggestions about our services are always welcome, and can be lodged in person, by mail, phone or email, or via the Have a Say form on our website.

Demographic Profile of Correspondents

Questions 1 to 5:

Respondents to the survey were mostly family members, such as parents, primary caregivers and grandparents (74%). Professionals made up 22% of respondents, and individuals with an autism spectrum disorder made up 4% of survey respondents. Of these groups, 86% were members of Autism Victoria, and the remaining 14% were receiving 'e-Spectrum', but not necessarily members.

Regional distribution of respondents:

Eastern	26%	Barwon SW	7%
Southern	30%	Hume	4%
Northern	13%	Gippsland	2%
Western	11%	Grampians	4%
		Loddon Mallee	3%

Of those who responded to the survey, 24% were caring for toddlers or preschool aged children, 29% were caring for primary school aged children, 19% were caring for secondary school aged children, and 28% were caring for adults. This indicates that the survey responses fairly equally represent the demands of caring for a person with autism spectrum disorder across the life span.

Autism Victoria Information and Support Service Usage

Question 6 – percentage of respondents using specific Autism Victoria services:

Family Counsellor	Information	Peak Body Role
a. Received at least one phone consultation = 17%	e. Contacted the Autism Victoria office for information materials or advice = 54%	j. Obtained posters, brochures or other awareness promotion materials = 24%

Family Counsellor	Information	Peak Body Role
b. Received at least one face to face consultation = 6%	f. Borrowed from the Autism Victoria Library = 45%	k. Participated in the Research Reference Group or attended the 2005 Research Forum = 5%
c. Received email support = 6%	g. Used the Autism Victoria Web Site = 58%	l. Attended the 2005 State Conference = 10%
d. Attended a group presentation = 7%	h. Received <i>The Spectrum</i> magazine = 98%	
	i. Received the <i>eSpectrum</i> electronic bulletin = 24%	

Questions 7 – 9 - Ease of access, value of information and quality of staff response:

Service Component	Service was easy to access	Information was valuable	Staff were helpful
Phone consultation	95%	94%	99%
Personal consultation	65%	91%	91%
Email support	91%	92%	91%
Group presentation	66%	88%	87%
Information or advice	93%	95%	99%
Library	91%	99%	97%
Website	98%	97%	97%
The Spectrum	99%	100%	99%
eSpectrum	88%	93%	93%
Awareness materials	84%	93%	92%
Research Forum 2005	59%	87%	85%
State Conference 2005	63%	88%	90%

Whilst most services at Autism Victoria were rated as '**easy to access**' (ranging from very easy to somewhat easy), improvement could be made in the areas of accessibility of personal consultations, group presentations, the research forum and state conference.

The majority of respondents felt **valuable** information was given through Autism Victoria's various services. Improvement could be made in the areas of information provided in group presentations, State Conferences and the Research Forum.

Whilst most respondents rated Autism Victoria staff as being **helpful**, improvement could be made in the areas of accessing the research forum, and helpfulness during group presentations.

Summary of satisfaction with existing services

168 respondents returned surveys, representing carers and individuals with Autism Spectrum Disorder from toddlers to adults. The majority of respondents had accessed a variety of information and support services provided directly by Autism Victoria staff, and had been satisfied with this information and support. Some areas for improvement in existing services were greater access to individual consultations, group presentations, the Research Forum and State Conferences, and more staff assistance and value of information provided in the latter three events.

Specific comments and suggestions for improvements were invited from survey respondents, resulting in input on a wide range of topics. Here is an overview of some of the most common, and some suggestions from Autism Victoria, including some items that have already been, or will be implemented. See the box at the end of the discussion for full details on how to contact the relevant Autism Victoria staff member and/or services referred to.

Information Services

Information for families waiting for early intervention services:

Autism Victoria can assist families waiting for early intervention services in the following ways:

Consultation with the Family Counsellor.

Members of Autism Victoria can access the Family Counsellor Service for advice about activities they can be doing with their child to encourage their development. Members living within a one hour drive of our office in Glen Iris can access two home visits, or families are welcome to visit our office for these consultations. Rural members can be supported by telephone and email contact. Discussions with the Family Counsellor may include suggestions of appropriate books to borrow from Autism Victoria's library.

Provision of information about alternative services:

Specialist Children's Services, through the Victorian Department of Human Services, employs allied health professionals such as speech pathologists, psychologists, occupational therapists, education advisers and physiotherapists to work with preschool aged children. In most regions of Victoria, these therapists provide a service to families who are on the waiting list for centre-based early intervention programs. The statewide contact number for SCS is 1800 783 783.

Autism Victoria has a database of private professionals experienced in the area of Autism Spectrum Disorders. We can suggest which type of professional can assist with the skills your child needs to learn. We can also discuss different funding sources to help pay for private services, such as the Carer Allowance, Flexible Funding Packages, and Medicare initiatives.

Information Services re School aged Children:

In a forthcoming issue of *The Spectrum* magazine, there will be an article written by the Family Counsellor about different schooling options and supports available to children with Autism Spectrum Disorder, including base rooms.

The issue of information for teachers was discussed in the article 'Sharing the Diagnosis' in the Summer 05/06 issue of *The Spectrum*. A reprint of this article can be obtained from Autism Victoria. If the information is not specific enough to your situation, the Family Counsellor should be consulted.

The Autism Victoria Information Support Officer is currently developing more specific information packs and awareness posters for distinct audiences, such as schools. This will also involve collating existing information sheets, and developing new sheets as gaps are identified. News about these will be distributed via **The Spectrum** and **e-Spectrum**.

Information for teenagers

Services for teenagers with autism are usually provided through the general disability system (eg. Disability Client Services through Department of Human Services). We can also recommend other general disability services accommodating teenagers with autism, such as respite, recreation, or therapy groups.

Autism Victoria is aware of the following specific supports for teenagers with Asperger Syndrome:

- **South-Eastern** - MOIRA teen Asperger Group- contact (03) 8552 2222; more information in the latest edition of 'e-Spectrum'.
- **Eastern** - ASSN teen Asperger Group- contact (03) 9845 2766
- **Northern** - TAPS- Parent Support group for teens, meeting in Coburg - contact Autism Victoria on (03) 9885 0533 for contact details
- **Western** - 'Saturday Club' via Western Autistic School- contact (03) 9337 9175
- **Country Victoria** - Bendigo Youth Adult Social Group for ages 16-25 www.freeweb.com/byaaq, contact Tristan on 0412 233 884; and Warrnambool 'High Flyers' Social group for 16-25 yrs. Contact (03) 5561 2301

We have a teen/adolescent section in our library, with books related to puberty, schooling and other adolescent issues. An article about puberty appeared in the Spring 2006 volume of *The Spectrum*.

Information & Services – Adults

Services for adults with autism are usually through the general disability system (eg. Disability Client Services through Department of Human Services). We can also recommend other general disability services supporting adults with autism, such as respite or recreation programs.

Specialist Services for adults with autism:

- Alpha Autism, including autism specific day programs, recreation and employment programs.
- Statewide Autistic Services, including autism specific respite and recreation programs.
- Mansfield Adult Autistic Services (MACCRO).
- Autism Adult Social group. For more information contact Amanda Golding at Autism Victoria.

Services for adults with Asperger Syndrome:

- Alpha Autism, including employment program, and social groups, including 'women only group'.
- Autism Victoria Asperger's social group. For more information contact the Autism Victoria Family Counsellor.
- Asperger Syndrome Support Network adult social group.

If you are an adult who has recently been diagnosed, or a family member of an adult who has recently been diagnosed, you can contact the Autism Victoria Family Counsellor for information and support. We have several personal accounts, written by individuals

diagnosed with ASD as adults, available to borrow from Autism Victoria's library. The family counsellor can also recommend a range of useful books.

There are several excellent books on partners/relationships and Autism Spectrum Disorder available to borrow from Autism Victoria library.

General Information Services - All Ages

Several suggestions were made for improvements to our existing Information Packages. These included a 'welcome kit for new members', packages for specific diagnoses /ages/ needs, flow charts for pre and post diagnosis families, and information in other languages.

All of these suggestions will be considered by Autism Victoria staff in the context of a full review of our current information packages and collection of information sheets on specific topics. This is a primary objective of the newly funded Autism Victoria Information Service. We will seek to achieve a balance between generic and specific information and guides, and utilise available technology options to present the materials in a variety of formats – printed, electronic, web based.

One of the challenges is the sheer breadth of circumstances making it difficult to meet individual needs with a generalised package, information sheet or reading list. At all times, Autism Victoria emphasises the need to be able to provide families and individuals with one to one support from staff who understand Autism Spectrum Disorder, the service system and have a good knowledge of available resources. Our service is funded by the Department of Human Services and requires that we provide the support necessary to enable clients to best utilise information resources.

Information in other languages:

Autism Victoria has a small number of resource materials in languages other than English, including many in Vietnamese, and some in Turkish, Italian, Greek, Arabic, Cambodian, Chinese and Spanish. We have a Japanese translation of one of Donna Williams' books. Autism Victoria also has information about parent support groups for families who speak Chinese or Vietnamese. The former group has a range of books translated into Chinese to borrow.

Translated materials can also be found at:

- www.mhcs.health.nsw.gov.au
- Association for Children with a Disability, for some disability general translated materials in Arabic, Chinese and Vietnamese www.acd.org.au
- Action on Disability in Ethnic Communities, contact Phone: 03 9480 1666 or 1800626078. info@adec.org.au. Web: www.adec.org.au/resources.html
- ACT-NOW program were looking at translating some written materials about Autism, www.med.monash.edu.au/spppm/research/devpsych/actnow/

Specialist Professionals:

Autism Victoria has a database of professionals specialising in Autism. We can provide contact details of speech pathologists, occupational therapists, psychologists, counsellors, psychiatrists, natural therapists, paediatricians, dieticians, etc. These professionals are either known to us via the informal Autism Victoria professional network, or have been recommended by families. We do not publish this database for general circulation, and require those interested in names of professionals to contact us to discuss their specific needs.

Information about autism treatments:

For a recent Australian review of the effectiveness of various treatments for autism, visit <http://www.dadhc.nsw.gov.au/DADHC.htm>. Click on 'Policies & Publications' then click [A review of the research to identify the most effective models of best practice in the management of children with Autism Spectrum Disorders](#). This 159 page research document was commissioned to provide a current and well-researched evidence base to inform policy decisions and capacity building in relation to services for individuals with Autism Spectrum Disorders and their families. This document was reviewed in late 2006, and it is anticipated that the federal Family and Community Services department will produce a parent booklet based on this report in 2007.

Autism Victoria has various articles related to treatments - many are reprints from **The Spectrum**. These are available on request. Various treatments can be discussed with our Information Support Officer.

As with all treatments, biomedical interventions have not proven to make a significant difference to all people with Autism Spectrum Disorder who try them. With this in mind, Autism Victoria still provides information about such treatments in the interests of enabling families to be better informed, so they can better make their own decision about which interventions to try. There are several books in Autism Victoria's library in relation to biomedical treatments.

Sibling support:

The Autism Victoria Library has a variety of books for siblings, and for parents about supporting siblings. Useful siblings websites:

- www.yourshout.org.au (for adolescents)
- www.acd.org.au for the publication 'Supporting Siblings', and for directory of siblings groups

Parent input:

Letters, comments and advice are always welcome for publication in the Reader's Forum section of the **The Spectrum**. We have published a number of suggestions in recent newsletters from parents, ranging from 'a lunchbox idea' to 'natural treatments' and 'supplements'.

Dietary approaches:

Information about the Gluten Free, Casein Free (GF/CF) dietary approach can be found in a number of books in Autism Victoria's library, which all include a recipe collection.

Items for the Library:

The Family Counsellor is responsible for selecting books and purchasing materials within the budget set for the Autism Victoria Library. Suggestions of specific books to add to the library are always welcome. New additions to the library depend on the funds available, and whether a suggested book's content is not already over-represented with the current holdings. Several titles were suggested via the member survey, and have been purchased for the library. Donations of books to the library are always welcome, and we appreciate the past donations from companies such as Footprint books, Book in Hand and Coordinates, and also individuals who have made donations.

Books about the non-verbal child:

There are several personal accounts by parents in the library about raising children with autism who are (or were) non-verbal. New items to the library depend on what is being published by distributors in the autism field, and the multitude of new titles do not include information of this nature. The Family Counsellor will continue to look for books about this topic.

An Autism Victoria Toy Library?:

For children of preschool age, there are around 150 toy libraries across Victoria, and it is not necessary for Autism Victoria to also provide this type of service. For more information, contact (03) 9555 4055 or visit www.toylibraries.org.au. As some children with autism enjoy playing with toys intended for children younger than their chronological age, a toy library can still be useful for a school-aged child.

There are several specialist toy libraries for children with disabilities, such as autism. These include Noah's Ark Toy Libraries, located in Bendigo, Endeavour Hills, Geelong, Heidelberg, Horsham, Ringwood, Windsor, Sunshine, Swan Hill, Traralgon and Wangaratta. For more information, phone the statewide manager, (03) 9500 2521, or visit www.noahsarkvic.org.au/services_fam.asp. The Autism Behavioural Intervention Association has an excellent library of games and flashcards that can be utilised to teach children with autism. Contact (03) 9830 0677 to join.

Library Access, Loan Period and Reservation System

The current loan period for the Autism Victoria library is 3 weeks, and there are no plans to change this to 5 weeks. For highly sought after items, we have multiple copies to try to keep the waiting time to a minimum, however there are some resources which have a several month waiting time. A five week loan period would significantly increase this waiting time. If borrowers have not finished using their library items by the due date, staff at Autism Victoria are always happy to extend the loan for a further 3 weeks, provided no-one else has reserved the item.

Our computerised library database was generously designed and implemented for us on a volunteer basis by a member. Occasionally computer glitches happen and despite best efforts, some data is lost. Members can always check the progress of their reservation by contacting the office.

As we do not have the resources to operate branches, and to assist those living outside an accessible radius of our Glen Iris office, we post library materials to members all over Victoria, and ask borrowers to reimburse postage costs.

Raising Public Awareness*Medical and Allied Health Professionals:*

There are several items in our library suitable for GP's, and there is also an excellent new website for medical and allied health professionals – www.nes.scot.nhs.uk/asd/. New materials being developed by our Information Support Officer will specifically target this sector.

Raise Community Awareness of Autism:

Autism Victoria aims to do this by distributing free information packs, brochures and poster kits all year round to individuals, families, students, and organisations. We have events in May each year for Autism Awareness week, including an increased focus on media opportunities. Autism Victoria also offers presentations to groups to increase autism awareness. The Autism Victoria Executive Committee has an active Government Liaison and Public Relations sub committee, convened by Meredith Ward who has been contracted by Autism Victoria to further develop this aspect of our Peak Body role.

The Executive Officer represents Autism Victoria on several committees, reference groups and task forces convened by government, both state and federal. Autism Victoria is a

corporate member of the Australian Advisory Board on Autism Spectrum Disorder (previously the Autism Council of Australia).

Autism Awareness Week:

Each year the Autism Victoria State Council and Executive Committee consider a range of options for activities during this week. Various factors determine the overall plan – such as resources, opportunities, what others are organising. The amount of media coverage depends on the news of the day and what ‘stories’ are of interest to the media. It is a very fickle area!

Lobbying for more and improved services:

Following strong lobbying from Autism Victoria, the State Labour government promised, in their recent pre-election campaign, to develop an ‘Autism State Plan’. Now they have been re-elected, we will ensure that they begin working on this as soon as possible. The comments for improved services given by our members on the survey will provide invaluable input to this process.

Family Counsellor Service

Regional Services:

Regional visits are offered twice a year. This year Wodonga and Ballarat have both received visits. The availability of regional visits is advertised regularly in **The Spectrum**, however only three regional groups/agencies have made contact with the Family Counsellor.

There is no professional fee payable to Autism Victoria, however the host is responsible for all expenses incurred ie. travel costs (air ticket or mileage), transit arrangements, accommodation, meals, handout materials etc. The host is responsible for arranging venue(s), contacting families in the area and arranging appointment times. The visit normally comprises of several days of counselling and a day or evening group presentation. Typically 10 families can have individual consultations and an agency can cover the visit costs by charging an entry fee to the group presentation.

Case Management:

Autism Victoria is not able to offer case management, which is provided by a range of agencies with the funding and expertise in this area. However, Autism Victoria is able to provide consultancy support to case managers on issues specific to the client’s autism.

Increased counselling services:

Currently the Family Counsellor Service is only funded at 0.6 of the cost of employing the counsellor. Autism Victoria raises the additional funds required to employ one full time counsellor.

Waiting time for Family Counsellor:

Families currently have to wait between 2-7 days to speak with a counsellor. The counsellors sharing this role care deeply about families, and their wellbeing, and try to respond as soon as possible. In most cases, this cannot be immediate due to the high level of demand on the service. Therefore Autism Victoria cannot provide emergency or crisis counselling, and directs families requiring this to:

- **Parentline** 1300 30 1300. Available 8am to 10pm, seven days a week
- **Careline** for telephone information, support and emergency respite. Available 24 hours a day. Call 1800 059 059.

Other services suggestions

Special events- seminars, forums, conferences:

The specific suggestions will be considered in planning for 2007 seminars. Members are advised that information about seminars and training in the autism area is posted on our website www.autismvictoria.org.au. Click on 'Events Calendar', then 'Victoria' to see Victorian entries. A range of organisations run seminars in metropolitan Melbourne and country Victoria during the day, evenings or weekends. Events are regularly added to the site. To add an entry, fill in the online form.

Support groups:

We are aware of over 50 support groups for families and individuals operating around Victoria. They vary greatly in size, structure and activities, depending on the resources available. Autism Victoria has a listing of these groups, and we update this periodically as groups come and go. Contact Autism Victoria for details of the group/s that could suit your needs.

One central location for all info:

Autism Victoria staff believes that this is a service that we already provide. With the newly acquired recurrent funding unit from Department of Human Services, our information services will be greatly improved, and more widely publicised.

Quality of information:

Individuals contacting Autism Victoria are invited to give feedback about the quality of our service. If you feel the information provided to you does not give you a clear enough idea of what to do next, please say so at the time, so we can rectify the situation at that point.

Membership fees:

Membership fees provide an important source of income to enable Autism Victoria to provide the services that it does. Unfortunately as costs go up, so must our fees! The association introduced a concession membership fee in 2006. Families eligible for this concession receive their annual membership for \$22.00, which is half the normal cost. Other families finding membership too difficult to maintain can discuss their situation with the Executive Officer, Amanda Golding. Some families have their membership paid by their support package, which can also apply to seminar and conference fees.

Schools should join Autism Victoria:

This is up to individual schools to make this choice. Perhaps the 'gift' of a membership by a family may encourage interest, or families could share **The Spectrum** with their child's teacher, so they can see the benefits. Schools are always welcome to contact Autism Victoria for advice, information materials or recommendations of books from the library.

More research:

Autism Victoria auspices a very proactive Research Reference Group which has a section on our web page. Researchers are able to detail their research and recruit subjects, and families are able to express an interest in research participation via the Get Involved register. Autism Victoria organises an annual Research Forum, has supported many applications by researchers for funding and has provided administrative support to the Apex Foundation Trust for Autism research grant for the past fifteen years.

AUTISM VICTORIA SERVICES & CONTACT DETAILS

To contact Autism Victoria by phone: **[03] 9885 0533** or **1300 308 699**

We have an automated telephone system, where you select the extension of the staff member who can best help you. If they are unavailable, please leave a brief message on their voicemail. Every effort is made to return calls promptly.

The Autism Victoria website is very comprehensive and easy to navigate. Features on the website relevant to items in this report include:

- A guide to services
- Reading Lists
- Research details & 'Get Involved' form
- 'Have a Say' form
- Online Shop for membership & product purchases
- Events Calendar

www.autismvictoria.org.au

Autism Victoria services and the relevant staff member to contact:

Information Services

- *Information Packages & tip sheets* #1
- *Library* #2
- *Magazine – The Spectrum* #4
- *Conferences and Seminars* #1
- *Electronic Bulletin – eSpectrum* #4

Family Support Services

- *Professional Family Support* #3
- *Assistance in accessing services* #3
- *Parent Support Groups* #1
- *New Parent Information Sessions* #3
- *Regional Visits* #3

Peak Body Services

- *Government Liaison* **
- *Representation* #4
- *Professional Panel* #4
- *Public Awareness* #1 & **
- *Policy Development* #4
- *Membership* #2
- *Administrative Support* #2

CONTACT DETAILS

#1 – Information Support Officer

Fleur Dwyer – phone option 1 or email info@autismvictoria.org.au

#2 – Administration Officer

Carol Barclay – phone option 2 or email office@autismvictoria.org.au or library@autismvictoria.org.au

#3 – Family Counsellor

Kirsty Kerr – phone option 3 or email counsellor@autismvictoria.org.au

#4 – Executive Officer

Amanda Golding – phone option 4 or email admin@autismvictoria.org.au

** – **Government Liaison & Public Relations** – Meredith Ward – phone 0400 226 408 or email liaison@autismvictoria.org.au