



INFORMATION SHEET

SUGGESTIONS FOR ESTABLISHING SUPPORT GROUPS/ SELF HELP NETWORKS

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Support groups can be an invaluable resource for parents, partners, professionals or other individuals. First and foremost they can provide a friendly space or understanding ear. Support groups can also work on other levels such as helping to create a sense of community and lessen feelings of isolation from the wider community that people who are affected by Autism Spectrum Disorder may feel. In a practical sense they can provide important information on local services and supports (such as an informed opinion on local schools) and can sometimes act as something of a 'middle man', in terms of liaising with local government on issues that affect you as a collective of individuals with similar concerns.

These notes have been prepared to assist families and individuals wishing to start up a local support group or network. They are suggestions only, based on the experiences of existing groups.

The name

Keep your name as short as possible, and consider an abbreviation or a catchy acronym if it is possible to use.

The purpose

Perhaps write out two or three brief statements describing your purpose. You can discuss and decide on your purpose as a group in order to ensure that everyone is involved. For example:

- *The group's purpose is to provide mutual support, information and activities to families supporting a person with an Autism Spectrum Disorder in the inner north area of Melbourne.*

How will it operate?

It is a good idea to work out some basic guidelines, so that all participants have a clear understanding of who does what and there are no unrealistic expectations or false hopes are created. All new families in contact with the group could receive these.

For example:

- *List of group/network members – their address, phone number & DOB of their children*
- *Names and roles of key people*
- *Meetings - where, when, frequency, format*
- *Cost - how much per annum, how and when paid, what is it for*
- *Newsletters, notices etc - when issued, how they are to be circulated*
- *Types of activities being held and proposed*

Key Roles

Whilst you may not wish to have the formality of titles etc it is important that key roles are defined and the various tasks are shared around. The following tasks are seen as necessary to a well functioning and active group.

Task	Person Responsible
Meeting Convenor	Chairperson
Meeting notes, letters, communication with members	Secretary
Member contact point	Information Officer
Keeper of all money records	Treasurer

The following tasks could also be important to the group:

Task	Person Responsible
Liaison with a key parent support network or family support agency	This could be formal – office support, a convenor, some financial or in kind support; or informal – using meeting space, contributing to a newsletter
Liaison with Autism Victoria	Usually contact with the Autism Victoria Information Officer
Publicity	Media stories, posters, fliers etc
Projects Convenor	If you wish to undertake a specific project or activity

Funding

It may be possible to access some funding for your support group through your local government council. The title of the person that you will need to speak to may change from council to council but is usually the community/ inclusion development officer.

Who are the key stakeholders in Autism Support?

It is important that members of the group/network understand the role of Autism Victoria and other key support groups. They should have knowledge about the kind of assistance they offer and to which target groups, and how they are related. The following will assist with this explanation.

Autism Victoria Inc is the peak body for Autism Spectrum Disorders in the state of Victoria. The organisation is governed by a Board of Governance consisting of nine members. The board meets monthly. This governance structure replaced the historic State Council which comprised 22 members including a five member executive committee which oversaw the day to day operational needs of the organisation. Autism Victoria is in turn a member of the Australian Advisory Board on Autism Spectrum Disorder, as well as being a member of the National Autistic Society (UK) and the Autism Society of America. Individuals and services can become subscriber members for an annual fee. Autism Victoria represents families and individuals with an Autism Spectrum Disorder, as well as Autism aware services. Autism Victoria also encourages interested members of the community to show their support by becoming members of this non-for-profit organisation. Autism Victoria produces a quarterly magazine called *The Spectrum* and an electronic newsletter, the *eSpectrum*, which has a section specifically for Support Groups to contribute their news and comments. The Autism Victoria website can also be used by members and groups to post

comment, event details and participate in research. Autism Victoria also has a Family Counselling Support Service and an Infoline: 1300 308 699 or info@autismvictoria.org.au

The Autistic Family Support Association *is a parent run association providing mutual support and a voice for families. It is an Organisational Member of Autism Victoria and is entitled to a delegate to the Autism Victoria State Council. Contact can be made with AFSA by leaving a message on 9885 8777 or emailing afsa_aust@bigpond.com*

The Asperger Syndrome Support Network (Victoria) Inc. *Members are families with a member with a diagnosis of Asperger Syndrome. Contact can be made with ASSN by leaving a message on 9845 2766 or emailing assnvic@mssociety.com.au*
Their website is at www.vicnet.net.au/~asperger/

A new family support group can be a subscriber member of Autism Victoria but cannot be an Organisational Member unless they become an incorporated body (or part of an incorporated body) and then apply for Organisational Membership. Please contact Autism Victoria's Chief Executive Officer, Murray Dawson-Smith for more information about this on 9657 1602 or email: ceo@autismvictoria.org.au Groups are also encouraged to communicate with the Autism Victoria Board with suggestions, complaints, proposals etc. through Murray Dawson-Smith.

The Autism Victoria Infoline (1300 308 699) is often the first point of contact for parents or individuals with an ASD diagnosis and it is important for us to be able to link these people with support groups in their area. The Autism Victoria website also Autism Victoria aims to keep an up-to-date record of Victorian support groups. Therefore all support groups are encouraged to keep Autism Victoria updated on changes relating to the group; such as contact names and numbers or meeting locations.

Please do not hesitate to contact Autism Victoria with any questions. We are able to provide groups with brochures, posters and fridge magnets for the Infoline service, sample information packs (which include a

suggested reading list and other useful information). Autism Victoria also has a Service Directory that is full of Autism specific or aware services. These services range from psychologists to hairdressers, so remember to not only utilise the Service Directory, but to add to it with any services you have found useful.

Remember that a support group is really what you make it. Some support groups are very active in setting up social skills groups, guest speakers, on-line forums and dinner nights, etc, but remember that it may take time to build up these sorts of activities and you have to start somewhere!

Original document written and compiled in 2007 by Amanda Golding

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