

## Suggestions for Establishing Support Groups or Self-Help Networks

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Support groups can be an invaluable resource for parents, partners and 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, support groups can provide important information on local services and supports, such as personal experience of local schools, knowledge of local therapists or services, and can sometimes act as an advocate in liaising with local government on issues that affect you as a collective of individuals with similar concerns.

This Information Sheet has 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 possible.



### The purpose

We recommend that you 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 and that you are all in agreement.

**For example:** The group's purpose is to provide mutual support, information and activities to families supporting a person with Autism Spectrum Disorder in <insert your region>.

### 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 created.

All new people in contact with the group could receive a copy of the guidelines.

For example:

- ◀ List of group/network members and contact details
- ◀ Names and roles of key people
- ◀ Meetings – where, when, frequency and format
- ◀ Costs – how much per annum, how and when fees are paid, and how is the money used
- ◀ Newsletters and notices – when are they issued and how are they circulated?
- ◀ Types of activities to be held

## Key roles

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

Role	Person Responsible
Meeting Convener	Chairperson
Notes, Letters & Communication	Secretary
Contact point	Information Officer
Financial recorders	Treasurer

The following tasks might also be important to the group:

- ◀ Liaison with a key parent support network or family support agency
- ◀ Liaison with Amaze
- ◀ Publicity or PR
- ◀ Projects convener

## Funding

It may be possible to access some funding for your support group through your local

government council. The title of the person you 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 Amaze and other key 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.

### Amaze

Amaze is a not-for-profit organisation and the peak organisation representing individuals with Autism Spectrum Disorder in Victoria.

The organisation is governed by a board of Governance consisting of nine elected members, each serving a three-year term on a rotational basis.

Amaze and other state organisations are members of the national Australian Advisory Board on Autism Spectrum Disorders (AABASD).

**Membership:** people with ASD, families, and professionals can become a member of Amaze for an annual fee. We encourage interested members of the community to show their support by becoming members: the more people we represent, the stronger our lobbying capacity.

**Publications:** we produce a member magazine called 'The Spectrum' and a fortnightly electronic newsletter called eSpectrum: we welcome information about Support Group activities for both these publications.

**Website:** [www.amaze.org.au](http://www.amaze.org.au) – our website provides an online calendar – it is free to post free events so upload your local events to let your neighbourhood know about them.

## The Autistic Family Support Organisation

The Autistic Family Support Association is a parent run association providing mutual support and a voice for families.

Contact can be made with AFSA by leaving a message on 0400 226 408 or via the website [www.afsconnect.org.au](http://www.afsconnect.org.au)

## Asperger's Victoria

Asperger's Victoria (previously the Asperger Syndrome Support Network or ASSN) is a member organisation based in Box Hill and providing a range of services to individuals with a diagnosis of Asperger's Syndrome and their family members. Contact can be made by leaving a message on 03 9845 2766 or completing their website contact form: [www.aspergersvic.org.au/contact-us-directory](http://www.aspergersvic.org.au/contact-us-directory)

## Membership of Amaze

All support groups may become 'Support Group Members' of Amaze. Support Group Membership is free of charge and gives your group a limited range of benefits. Please note that for discounted attendance at events and to attend the family information sessions, an individual or family membership will be required.

Visit [www.amaze.org.au/membership](http://www.amaze.org.au/membership) to see the various member types.

For a free Support Group Membership, contact the membership team on 03 9657 1601 or email [membership@amaze.org.au](mailto:membership@amaze.org.au).

## InfoLine – 1300 308 699

The InfoLine is available on 1300 308 699 and is often the first point of contact for parents of individuals with an ASD diagnosis.

When people are looking for support, our Information Team can give information about support groups in their area.

We keep a list of Victorian support groups on our website and we encourage you to keep us up to date on changes to your group, such as contact names and numbers or meeting times/dates/locations. Please send updates to [info@amaze.org.au](mailto:info@amaze.org.au).

## Resources

We can provide you with a range of resources: please do not hesitate to contact us for assistance on 1300 308 699.

## And finally...

Remember a support group is really what you make it. Some support groups are very active in setting up social skills groups, guest speakers etc, whilst other have more modest goals.

Remember that it may take time to build up these sorts of activities and you have to start somewhere!



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