AUTISM ACTION GROUPS

A “How To” Manual

Reimagining Human Service Systems
Autism Action Groups

A “How To” Manual

What is the mission of the Autism Action Groups?
The mission of the Autism Action Groups is to provide leadership in the implementation of a regional system of services and resources to maximize the potential and quality of life of each individual with an autism spectrum disorder, and their families, across the lifespan.

What are Autism Action Groups (AAGs)?
Autism Action Groups are developed to help maximize value-added autism services by bringing together various organizations, schools, parents, local providers and others. The Autism Action Groups in Virginia consist of members from local communities who want to actively and collaboratively work toward developing quality services and resources for individuals with Autism Spectrum Disorder in their communities.

The Lifespan Connections Initiative (LCI) is implemented in the Autism Action Groups to provide the framework to guide planning and action in response to community needs. It is recognized that gaps in the service system occur throughout the lifespan for individuals with autism. It is common for communities to focus on a certain age range (e.g., early intervention) based on the growing ASD population in their regions. Autism is a lifelong diagnosis. Young children with ASD will one day be adults with ASD. The LCI provides a framework to guide AAG planning, coordination and program initiatives toward the attainment of the AAG mission and regional goals.

Autism Action Groups usually meet monthly to identify and address these needs. Once the work has been initiated, the groups take the necessary steps forward to complete the task and take action for autism.

If a group becomes aware of a gap in a service area, they are urged to take action to collaborate effectively in successfully closing that gap. Throughout the manual you will read about a few examples of what’s been done.
How is CA involved with the Autism Action Groups?

CA initiated and supported the first Autism Action Group (Central VA Autism Action Group) in 2002. We are still committed to providing support to those communities interested in developing and maintaining an Autism Action Group.

If a group of representatives from a certain area shows an interest in starting an Autism Action Group, CA will provide the framework and will assist the leadership throughout the process.

Throughout this manual, you will read several action steps needed in order to establish a successful Autism Action Group. To begin this process, you will need to contact interested community members, review the Memorandum of Understanding and hold an initial meeting with a CA staff member in attendance. After three initial meetings, you may fill out the application form provided in this manual including the support documentation (agendas, minutes, signed MOU, contact information, and proposed action goals). Once your application is reviewed, we will be in touch with you regarding your proposal to start taking Action for Autism in your community!

Once an Autism Action Group is established, CA Human Services will maintain contact with your leadership team. CA will review meeting minutes and assist with literature and documents that have been developed. CA will be responsible for updating your AAG’s information and events on the CA website, Events Calendar and will assist the leadership team with postings on Facebook.
Who should attend Autism Action Group meetings?

State Agencies
- Department of Aging and Rehabilitative Services
- Department of Social Services
- Department of Behavioral Health and Developmental Services

Members of the Community
- Self-Advocates
- Family members
- Friends
- Businesses

Service Providers
- Therapists, Job Coaches, Day Treatment Providers, Residential Providers
- Case Managers, Waiver Services Facilitators

School Personnel
- Administrators, Special Education Directors, Autism Specialists
- Private School Providers

How does the group “Take Action” for Autism?

We support AAGs to continually assess needs, plan and take action for autism based on the understanding that gaps in the service system occur throughout the lifespan (birth – adulthood).
Because each community has different needs, the work of each AAG may vary. Some possibilities are:

- Family - Friendly Events
- Family Support Groups
- Informational Resource Fairs
- Content-specific Workshops & Trainings
- Autism Awareness Conferences

Maintain an AAG Webpage:

CA will provide a webpage for each AAG on the CA website. Each AAG is responsible for notifying the CA of updates for their webpage and events calendar. Suggested topics to include on each webpage may include:

- Meeting Information
- Resource Directories & Other helpful links
- Family Support/Group Information
- AAG Events
- Contact Information

AAG Brochures:
Most AAGs prefer to create a flyer to disseminate to parents and professionals in the community. CA has created a brochure that AAGs may disseminate throughout the community as well.

Resource Directories:
A Resource Directory is a compiled list of resources available in a local AAG community consisting of medical professionals, support groups, public and private school personnel, recreational activities, employment opportunities and several more categories. Each AAG has developed and maintains a Resource Directory of organizations and service providers in their areas. Each Resource Directory can be viewed on the CA website: http://bit.ly/2TTYFfO
Interested in starting an AAG in your region? What’s next?

Assess the interest of the people in your community.

Remember that you want the players at the table to be diverse in their professions and community connections. Make sure that you have leaders who can take charge, as well as volunteers who can take action!

Review the Memorandum of Understanding (MOU) as a group.

The MOU delimitates the roles and responsibilities of an Autism Action Group and CA, as well as what’s needed from the leadership team and other volunteers within the group. The MOU is located at the end of this manual.

Did you know?
It can be relatively easy to find a convenient meeting location that’s free of charge. Just be creative and consider who will be attending!

For example, a local CSB representative could assist in reserving a conference room at their office location. Other examples of possible locations include: libraries, colleges, private and public school meeting rooms, as well as offices of service providers. This meeting location may be temporary. Just don’t change the location frequently, as this can affect participation!

The time of the meeting can be morning, day, or evening – whatever works best for the participants involved.
Still interested?

Hold an initial Meeting!

The agenda for your initial meeting will be most likely an introduction to the AAG – how it works, what AAGs do, etc. -- essentially a review of this manual! Depending on your participation and the interest of those who attend, you could discuss who would like to be a part of the Leadership Team. *Note: Choose your Leadership Team wisely.* The success of your group relies heavily on leadership. These individuals will create agendas, facilitate the meetings and ultimately help to ensure that the group meets their goals. CA Human Services will work with your participants to determine the composition of the leadership team.

Use a variety of ways to recruit participants to join your AAG. You can send out flyers and emails, or even post an ad in your local newspaper.

Schedule monthly meetings! After three months of meetings, CA Human Services will contact you to review your meeting participation, agendas, minutes and action steps. Participation is a key element to a successful AAG. CA recommends a minimum of eight participants at each meeting to keep the group running smoothly. As mentioned earlier, you also want a variety of individuals at the table, as well as those who are willing to take *ACTION* for autism! If your group is ready, it’s time to begin the application process to become an official Autism Action Group.
Application Process

- Copies of your meeting agendas & minutes
- Names of participants for each meeting along with contact information for your leadership team
- Signed MOU
- Proposed Action Steps for your group

A sample application is located at the end of this manual.
Congratulations!
You’re now an AAG!

Possible Next Steps

- Needs Assessment Survey
- Develop a Strategic Plan
- Determine Three Main Goals
These beginning steps give you a general guide of where to start and may not necessarily be needed for your AAG. However, they will assist your group in determining the best starting point. Your AAG may come together with a main goal or purpose already in mind and that’s okay – just as long as your group starts taking the steps necessary to remedy a service area gap identified in your community.

Usually, by the time one agenda item is completed, another idea or goal has been developed. For example, a need in your community may revolve around social activities for individuals with autism.

Therefore, your AAG could create an activity or event to offer to families, such as a movie night or arts and crafts activity. At this event, families may discuss the need for networking and discussion among parents, which would then lead your AAG to start planning a Family Support Group. By planning speakers for the Family Support Group meetings, a popular topic may be discussed as an opportunity to offer training, draw in a larger crowd and hopefully gain more participation in your AAG. Individual participants in your AAG may be involved in organizational activities or events that would be open to all members of the AAG.
Ready to take Action for Autism?
APPLICATION

Completed by (Name): Date:

Organization/Affiliation:

Phone Number: Email Address:

Which localities (include counties, cities, and towns) would your proposed AAG include?

Briefly describe the greatest service-need(s) gaps identified for the localities listed above:

Briefly describe the vision for an AAG in your area:

List the names, affiliation, and contact information of those who have agreed to be on your Leadership Team.

1.

2.

3.

4.

5.

6.

7.

8.
Briefly describe the skill sets reflected in your leadership team.

Briefly describe potential challenges/barriers to establishing a successful AAG in your area.

Please provide your AAG meeting location, frequency and times below:

Please share thoughts of your AAGs proposed “name”:

**AAG Application Checklist**

Please include copies of these documents from your first three meetings:

- ☐ Sign-in Sheets (names, affiliation, contact information) of those who attended
- ☐ Meeting Agendas
- ☐ Meeting Minutes
- ☐ Signed Memorandum of Understanding
- ☐ Any Literature/Document that has been created
- ☐ Any other work that you’d like to share with us

After you have completed filling out this form, please fax it to CA, 804-355-0932, and we will contact you.
Memorandum of Understanding (MOU)

Because the work for individuals with autism and their families is ongoing and the possibilities are endless, CA continues to support Autism Action Groups (AAGs) in local communities across the Commonwealth of VA. With commitment and dedication to the mission “to provide leadership in the implementation of a regional system of services and resources to maximize the potential and quality of life of each individual with an autism spectrum disorder, and their families, across the lifespan,” AAGs seek to bring local community leaders and interested parties together to create practical outcomes for individuals with autism in the way of services and supports.

1. CA supports the leadership team for the purpose of meeting its mission. The Director of Community Engagement:
   ✓ Maintains quarterly contact with AAG leadership by email.
   ✓ Reviews monthly meeting agendas and minutes.
   ✓ Receives notification on upcoming events (to be posted on the CA website).
   ✓ Provides oversight of web/FB pages, speakers, AAG Literature.
2. The local AAG leadership team supports their members to facilitate local community collaboration to maximize resources on behalf of individuals with autism, their families, and care givers. Oversight of the AAG is the responsibility of the leadership team. The leadership team:
✓ Maintains their own mailing list and resource directory.
✓ Creates new AAG Literature/Updates AAG Literature already in place.
✓ Disseminates information on their schedule of events, including sending out notices of upcoming meetings.
✓ Creates meeting agendas.
✓ Facilitates meetings.
✓ Maintains meeting minutes.
✓ Provides their own copies of materials for the meetings.
✓ Maintains their own files of past minutes, event documents, etc.
✓ Coordinates local community events, including finding speakers for their Family Support Group meetings.
✓ Maintains communication via AAG’s Facebook Page, if they chose to have one.
✓ Updates Autism Action Group webpage and Events Calendar as needed, if they choose to have one.

For CA: 

For: The AAG

Name ____________________________  Name ____________________________

Date ____________________________  Date ____________________________
Please remember that the AAG “How To” Manual is intended as a guidance document for those localities interested in starting up an Autism Action Group. The steps in this document are not concrete and may occur at different times than what is represented in this document.

If you have any questions regarding this document or need assistance in filling out the application, please contact Liz Smith, at Liz.Smith@cahumanservices.org or 804-355-0300.

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