

TIPS FOR RUNNING A SOCIAL GROUP (OR, I WAS A CRUISE DIRECTOR IN ANOTHER LIFE)

The AUsome Social Group for Teens and Young People with Autism Spectrum Challenges

by Nancy Alar, July 18, 2001

For the past 5 years, the Madison chapter of ASA has sponsored The AUsome Social Group, a monthly social group for teenagers/young people with autism spectrum challenges. Nancy Alar coordinates their activities. This social group has produced some long term friendships for the participants and their families, given the young people many unique experiences and created a lot of "just plain fun". The presentation discusses the group philosophy, how it's organized and maintained, what activities have been done, how activities are planned, their newsletter, problems encountered and other relevant information.

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Tips for Starting a Social Group:

1. **Think positive - It's not as much work as it sounds.** All you need is a computer and a sense of fun. Start by doing things you and your family enjoy. The AUsome newsletter invites others to join me and my family in an interesting adventure.
2. **Start small.** The AUsome Social Group now has 64 members, but we started with 4. Our first activities were very conventional - like bowling.
3. **You don't have to do everything at once.** This document is a series of tips that has evolved over the past 5 years. Just because AUsome has a formal newsletter and a scrapbook doesn't mean your group has to do that, especially right away. Do whatever works for you.
4. **Maintain a list of group members.** I use an Access data base for this purpose. I collect name, address, phone numbers (home, work, parents), e-mail address, birthdate, parent's names and a general comments field. I keep this list updated religiously.
5. **Mail out a newsletter for your group.** Set up the newsletter in the same format each time (folks on the spectrum like predictability) and keep all old copies on a computer. I plan monthly activities, but set up and mail information for 2 months at a time. You might want to do things differently. To facilitate mailings, I use self-stick stamps and self-sealing envelopes. Our local Autism Society Chapter pays for the mailing costs. Some of my group members prefer e-mail. But only about 50% of the members have an e-mail address. Of those that have an e-mail address, less than half seem to read their e-mail regularly. I mail one paper copy to each member and then forward an e-mail copy to all those with an e-mail address. This may change as the group grows.
6. **Take pictures of and write up a summary of what happens on each outing.** These pictures and summaries form the basis for our AUsome scrapbook.
7. **Create and maintain a group scrapbook of activities.** Include pictures, the setup information from the newsletter, a summary of what happened at the activity and other items like ticket stubs. I didn't start the scrap book until after the first year and wish I'd done it sooner. Members of AUsome love to look through our scrapbook. This scrapbook is also used as a display by the local Autism chapter for things like fund raisers and conventions.
8. **Remember that any group like this develops from the personalities involved.** Your version of a social group may be very different from Madison's AUsome Group.
9. **Locate an initial source of interested recruits.** AUsome started with 4 teens who volunteered to participate in a panel discussion. The AUsome Social Group is officially for those 12 and older, but a group for younger kids could work the same way.

10. **Affiliate with a local Autism Society chapter.** This will give you a source of funding, tax-exempt status, a source of recruits and you may be included under the chapter's liability insurance. It also gives your group "legitimacy" if you are connected with a known organization.
11. **Make use of computer technology where possible.** I keep computer files of all past activities so I can reuse maps, popular activities, etc. I keep a database of participants complete with addresses, e-mail, phone numbers, date of birth, parents names/numbers, special interests, etc. I generate mailing labels and return address labels from my database.

Tips for running a social group:

1. **Try to include some type of refreshments in each activity.** AUsome often ends up at fast food restaurants, but we also sometimes have picnics, go for ice cream or bring snacks to pass around. Young people really like to eat and some of the best social interaction occurs over food.
2. **Allow for the sensory issues so common for people with autism spectrum disorders.** This is a major focus of our group. I avoid activities with loud noises, cigarette smoke, intense odors, large crowds, strobe lights, etc. (Note: even autistic young people with noise sensitivity seem surprisingly immune to loud popular music or noises they make themselves.)
3. **When thinking up activities, use your imagination.** Things that are normally work (washing cars, gardening, cooking, etc.) can be fun if organized right. Also things that are normally considered transition or job investigation (visiting businesses like a green house or a bakery or touring a construction site) can be fun, especially if you have connections there. Public service activities (like adopting a stretch of highway) allow members to contribute to the community. Attached are some activity ideas I have come up with.
4. **Keep activity costs reasonable.** I try to follow a general guideline that AUsome activities shouldn't cost more than \$5 a person. Free activities are best, but not always possible. When there are costs for an activity, try to arrange for each individual to be responsible for paying their share directly. It's time consuming and difficult for a group coordinator to be the "middle-man" for fee collection. When AUsome was in it's 2nd year, I applied for and got a grant to allow AUsome to do some more expensive things. That has helped a lot.
5. **Don't do too many things like going to plays or movies.** There is limited opportunity for interaction in a setting where everyone is sitting facing forward for a long time.
6. **Don't expect young people with this type of disability to be universally thrilled with social activities.** It tends to be something very hard for them (That's why they benefit from a group that provides encouragement). Sometimes they do become very compulsive about attending the group because it is seen as part of their "routine." The longer the group has been running, the more my son seems to remember the others in the group and look forward to the activities.
7. **Take into consideration the needs of more challenged individuals.** Non-verbal and more challenged individuals need social opportunities as much or more than the higher functioning. Everyone should be treated as a valuable individual.
8. **Try to plug into the interests of individuals in your group.** Many autistic people have intense interests boarding on obsessions. If someone is interested in cars, a visit to a car show can be really exciting.
9. **Consider doing something with video games.** Video games seem to be an almost universal interest, especially for the young men in AUsome. Our annual video game night is one of the favorite activities. (Caveat: Temple Grandin considers video games addicting and an unproductive use of time, especially for autistic people - AUsome group members disagree.)
10. **Provide some physical exercise if possible.** Many young people in the AUsome Group have limited opportunities for exercise.
11. **Try to have activities (sometimes) that those with limited mobility can enjoy.** There is no one in a wheelchair in the AUsome Group at this time, but there are different levels of physical ability.
12. **Ask for special accommodations for your group.** Almost everyone has been real helpful with these things. I frequently get price reductions and other special treatment from places like bowling alleys,

miniature golf sites, etc. Our yearly trip to the juggling show has been a success because we have been able to have reserved seats (something no one else gets). This means we can sit together, have good access to exits, and understanding people in surrounding seats.

13. **Don't expect every activity to be a success.** Sometimes you do your best and things don't work out. Consider this a learning experience.
14. **Don't expect everyone to come every time.** Families are busy. People forget. My goal is to plan activities I will enjoy with my family even if no one shows up but us.
15. **Ask for an RSVP for activities, but don't expect a perfect response.** I find it is much less stressful for me to structure things so that I don't have to know exactly how many will show up. Plan to call everyone on your list if you absolutely have to have an answer.
16. **Set up support systems for reminders and transportation.** I've found I especially need to do this for some young people living on their own. I try to call certain people on my list who I know want to come, but just can't seem to get organized enough to get there by themselves.
17. **Call everyone on your list once a year.** I call everyone on my list as part of my planning for the annual juggling show in January. This also allows me to check the accuracy of my list, update addresses and phone numbers and find out if anyone wants to be removed from the list.
18. **Don't expect friendships to develop immediately.** The fact that my son now has one true friend and can remember the names of several others in the group has been a big victory.
19. **Encourage family members, friends and siblings to participate in the activities.** There is no way one person can do effective "crowd control" with a large group of autistic people. Although some AUsome group members come alone, I always mention that friends and family are welcome. Family members provide needed support and transportation and have a chance to establish their own contacts. A group of "normal" young people might resent the intrusion of family members in their activities, but that has not been a problem for AUsome. I try to set up activities so that there is a feeling of independence. For example: when we had the talent show, only actual group members could showcase their talent.
20. **Consider enlisting one or more peer models.** I have 3 such "normal" volunteers in the group now and one is earning community service credits for high school.
21. **Maintain the focus on group members.** Address all communications to the autistic spectrum individuals. I try to write my newsletters on 2 levels. Basic information is always in the same format and bolded. Enough details are provided so family members know what to expect.
22. **Provide nametags for everyone at activities.** This helps group members remember each other's names and encourages family members to chat. Right now I am using disposable, stick-on nametags. Supplies like nametags are financed by our grant.
23. **Expect to become attached to every person and family in your social group.** This was something I never anticipated, but it happened very early in the life of AUsome. I feel like I have acquired a new extended family. Autistic spectrum people are very interesting. I think it's pretty cool that I know so many of them. They've given me a truly unique and multi-faceted source of insight into my son's condition.
24. **Be very safety conscious and check into insurance coverage.** I try not to go outside the Madison area because of transportation/liability issues.
25. **Think up a "cool" name for your group.**
26. **Do what works best for you and your group and don't be afraid to change things.** I plan AUsome activities 2 months at a time because it keeps down mailing costs, and seems like less work to me.
27. **Protect each individual's and family's privacy.** Do not release names, addresses or other information about group members without getting their permission.
28. **Expect to have an unreasonable amount of FUN!!**