

## **Definition of SUPPORT GROUP**

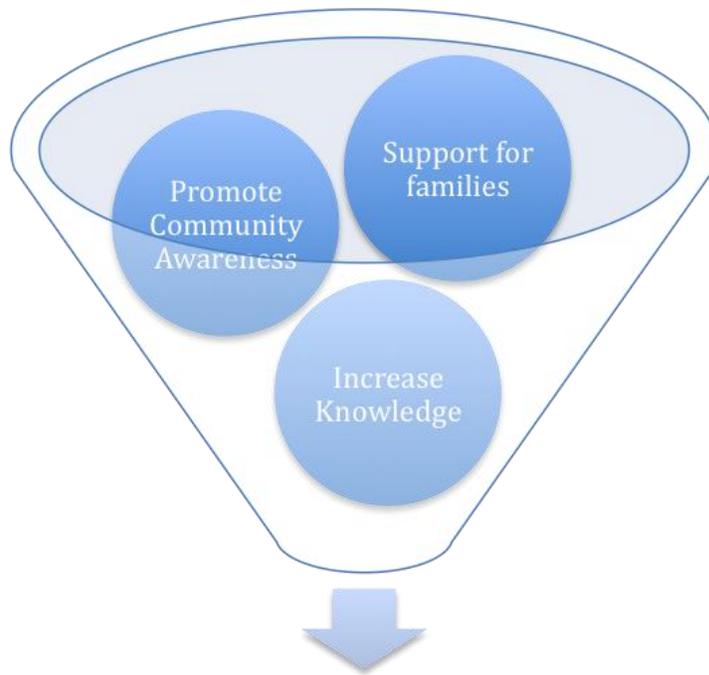
Support group *noun* : a group of people with common experiences and concerns who provide emotional and moral support for one another

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### **Why should I consider starting a support group?**

The demands and challenges of raising a child with an ASD can be overwhelming. The importance of parent-to-parent support cannot be overstated. Parents of children with disabilities can identify with feelings of loss and frustration, help find programs and funding for therapies, laugh and possibly even cry together. Many enjoy the company of another parent because there is a shared and true understanding of how hard parenting can be. Talking with another parent is a great place to find practical advice for issues that may be difficult. Parents report that they often learn as much from talking with other parents as they do from professionals and books.

There are many different kinds of support groups. Each group is unique to the need of the community it serves.



## Improve lives of families

Group activities can be a mix of monthly support meetings, family gatherings, awareness activities and invited speakers. If you want to have an active group that improves the lives of families in your area the most important thing is to make sure everyone in the group has the same expectations for the group.

### **Things to consider when forming a support group**

As you begin the initial stages of planning a parent support group, consider drafting a mission statement to define the direction of your group. This will build a shared understanding among those whom you would like to become involved in your venture, and is an important factor especially in the early stages of your group. These statements do not have to be written in stone in the initial stages of your group. They will serve to provide focus with respect to the direction you wish your group to take. As your group becomes more established over time, these statements can be revisited by the members of the group and revised as needed.

**Mission statement is useful when there is a need to . . .**

- Clarify who a group is
- Orientate new members
- Create a sense of teamwork
- Improve external communications
- Develop consistent message

**Taking the mission to the next level**

<b>We advance our mission of</b>	
<b>. . . and seek to (impact)</b>	
<b>by serving (or supporting)</b>	
<b>in (geographic area)</b>	
<b>through (programs, services or resources)</b>	
<b>and emphasizing our strengths</b>	
<b>We are sustainable about by</b>	

## Goals

Consider setting three goals for your group. These goals will help member focus efforts and build positive momentum. It is critical the members agree on the goals and focus of your group. When setting goals consider the following:

- What are the objectives of the goal?
- What are the strategies that your group will use to reach the goal?
- Who will lead activities?
- What is the time-line?
- How will your group measure results?



**It is perfectly OK if your group has one goal.**

**1) Meet for coffee once a month and share our stories.**

## Think about group leadership

The dictionary definition of a leader is someone who is the “guiding or directing head” of an organization. This simplistic definition may not fully target the qualities you would like to see in the leadership of a parent support group. Qualities you might consider include someone who...

- Has a genuine understanding of autism and its impact on the family
- Can motivate people toward the goals you have set for your group

- Is knowledgeable of evidence-based practices for support individuals with autism
- Exudes energy and knows how to energize others
- Is open to new suggestions and who doesn't take things personally
- Has a steady temperament and who has that skills to motivate the entire membership toward the group's goal
- Make sure all the "work" is NOT being done by just one person

**Burnout** - experience of long-term exhaustion and diminished interest.

### **Find a place to meet**

Parent support groups around Kentucky meet in many different places. Some of these places include schools, churches, public libraries, comprehensive care centers, or a local bank's community room. Choose a location that is geographically convenient for parents as well as one that is welcoming and inviting. From time to time, groups must change meeting locations as their group grows or as situations change. Try to keep location changes to a minimum. If you know that a change in location is on the horizon, develop a plan to notify group members and the community well in advance.

### **Choose a date/time to meet**

Scheduling the support group meetings is an area in which consistency is a key consideration. Parents of children with autism have schedules that are packed. Try to decide on a regular day and time each month, for example "the second Tuesday of each month from 6-8:00pm." This consistency allows parents to get the meetings on their calendars well ahead of time.

### **Designate a contact person**

You will want to identify a contact person on all of the information sent out about your group. Potential members may have questions about the group before they first attend. This document was developed by the Debbie Lorence and Rebecca Grau with Kentucky Autism Training Center. July 2009, May 2010

Most groups provide a name, phone number, and email for the contact. You may not be comfortable in providing a home or cell phone number. In that case, you might consider creating a special email account dedicated to the support group business. Just remember to check that email account frequently.

## **Home base**

Another option might be to create a Facebook page. This page can be the bulletin board for your group. Therefore, one person is not responsible for all group communications.

## **Create a “marketing” plan**

You will want to get the information about your new group to as many people as possible. Suggestions to accomplish this:

- Consult with an online service provider database on the Kentucky Autism Training Center (KATC) website. Share the information about your group with those providers listed in your area
- Contact the local hospitals, area therapists (mental health, occupational, and speech therapists), comp care centers, and your Special Education Cooperative. These folks may be a great source of support in getting the information about your group to parents they think will benefit from the support.
- Consider sending an email to everyone in your address book. Ask those contacts to forward your information to others they think might be interested. You just never know who might be familiar with someone that has a family member with autism. Your contacts' contacts can benefit from the information that you send.
- If you have a local newspaper, submit an article or a letter to the Editor (these are actually at no cost, as opposed to buying ad space) and put flyers around town (in physicians' offices, in the windows of local businesses, in the public library, in local churches, in local hospitals and comp care centers).

- If your community has a community college or university, you might consider contacting various schools of education within the institution (such as education, social work, psychology, speech pathology, and occupational therapy) to share information about your group.
- Notify the individual schools within your target area as well as the Special Education Department in the district's Central Office. You can often place flyers in the local schools, at the Central Office, or send a stack to go home in students' backpacks.
- Some support groups have gotten air time on local a radio station to raise awareness of autism in general, as well as to talk about their group and their groups' events.
- Utilize existing listservs to publicize your group. As your group grows, consider forming your own listserv to target those individuals you know would benefit from the information. You can also consider sending me an email at [rebecca.grau@louisville.edu](mailto:rebecca.grau@louisville.edu) with all your information and I can put the information out on the statewide KATC listserv.

### **Decide if you will offer childcare**

It is often difficult for parents to find someone to watch their child. In many cases, one parent attends the support group meeting while the other parent stays home with the children...even though both parents could benefit from the information (as well as from the shared time together). Some support groups are able to offer childcare to remove this barrier for parents. If you can, great! If this is not a possibility in the beginning, revisit this option for the future.

### **Decide if you will offer snacks**

Since many on the current support groups around the state meet in the late afternoon or early evening, some have light refreshments for the members. In some newer groups

with limited financial resources, members take turns bringing low-cost, no-fuss snacks and drinks.

### **Consider whether you will need “seed” money**

If you can secure a location at no cost and you do not plan to offer refreshments in the beginning, then you can start a support group with little or no financial commitment. Always keep in the back of your mind the idea of how you might encourage and utilize potential donations from the community as your group grows some groups have started these efforts by using suggestions found in the book “Fundraising for Dummies.”

### **Decide if your group will meet year-round**

Some support groups around the state meet during the school year only. Many of these groups meet in a local school, making it difficult to schedule meetings when school is not in session. Other groups have recognized that their attendance goes down as families get busier in the summer months and take a break during those times. Other groups continue to meet each month year around.

### **Consider a Kick-Off event**

Sometimes, small groups of parents who recognize the need for a parent support groups have organized a small community awareness event, such as a walk, to get out the word about their newly-forming group. The initial events are generally small but have grown in numbers in subsequent years.

### **Consider the creation on your own website**

Many of the support groups around the state have their own website to showcase their group, announce upcoming events, and raise awareness of autism-related issues. You might try to find someone who has expertise in creating web pages at little or no cost.

Make sure, however, that the site is updated on a regular basis. Old, outdated information is not helpful.

### **Format of your support group meetings**

Many support groups vary the content of the meetings each month. If you would like to have training workshops for your meetings, consider who you might be able to contact to provide these, preferably free of charge. KATC has a list of workshops that can be provided for family support groups. Consider any local contacts, such as physicians, school personnel, comp care staff, First Steps staff, the Kentucky Special Parent Information Center (KY-SPIN), the Office for Family Leadership (OFL), your Special Education Cooperative, or your local health department. Approach individuals in these organizations about providing workshops based on the needs and interests of your group members. Many groups schedule informal, open topic meetings from time to time. Still other groups will plan family events, such as picnics at the local park in the summer, or family Holiday celebrations in November or December.

### **Thinking about workshop topics...**

Chances are great that your group's membership will include parents who have children ranging from a very young age through young adulthood. You will need to consider this fact as you plan workshops and programs for your monthly support group meetings. Try to create a balance between programs geared to parents of children in various age groups. This helps everyone feel that their needs and concerns are being respected. Consider this...at first thought you might not feel that the parents of a 6 year-old would be interested in my workshop "Puberty and Autism." This has not proven to be the case. Parents of younger children recognize that they will utilize in the years to come. Conversely, if you are having a workshop geared mainly to those members with younger children, contact members with older children and encourage them to serve as

“been there, done that” experts on the topic. The importance of the voice of experience within the membership of your group cannot be overstated.

### **Create a sign-in sheet for your meetings**

In the early stages, this will help you to obtain the names and contact information for the individuals that attend your group. Create an email list using this information and update it as new parents attend. This will help you maintain contact with those parents who find it difficult to attend meetings each month. During the first few months, you might want to consider using this information to send monthly reminders several days in advance of your scheduled meetings.

### **To 501 or not to 501**

The decision to become a 501 (c)3 is a consideration that is frequently mentioned. You can get information about making the decision at the Internal Revenue Service’s website.

### **Bridges not Barriers**



### **Don't be afraid to ask for help if you need it**

This document was developed by the Debbie Lorence and Rebecca Grau with Kentucky Autism Training Center. July 2009, May 2010

Scheduling and organizing meetings, finding speakers, planning events, and maintaining your electronic media can be time consuming. Ask for help of other members before you burn yourself out. Many individuals might find it difficult to ask how they can help...but would love the opportunity to help you when asked directly.

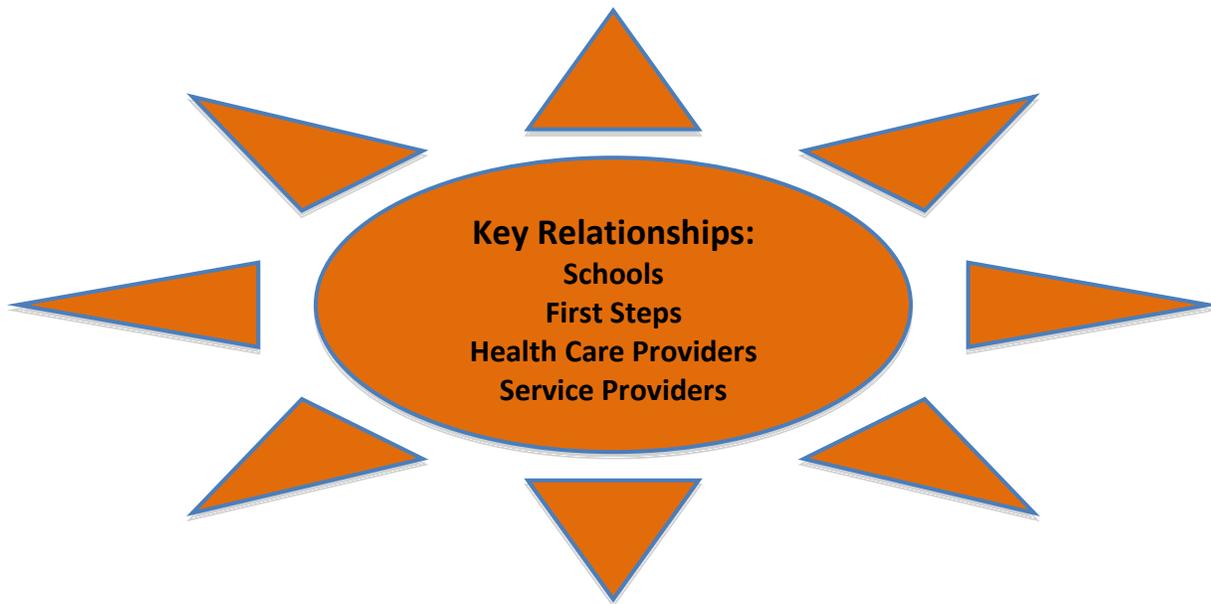
### **Continually cultivate leadership**

Many a support group ceased to exist when the sole leader of the group decided to step down. Families move, children transition, and changing life situations can impact the ability of one individual to lead a group. Try to make sure that you have shared leadership within the group. This will greatly increase the opportunity for your group's longevity. Recruit parents of young children for leadership roles on an ongoing basis. This will boost the chances that the group will continue even if long-term leaders move on.

### **Keep the faith**

I have been contacted by many support group leader expressing discouragement associated with the relatively small membership within their group. Given the stressful schedules faced by parents of children with autism, this issue is understandable. I encourage leaders to focus more on the quality of their group rather than the quantity of the group's membership. You will have the opportunity to have a tremendous impact on the parents who regularly attend your group. Keep extending the invitation – be optimistic in the potential for your group to grow!

## **Collaboration is Key!**



Respect, trust, open communication, and shared goals are all indicators of collaborative partnerships. Parents and professionals have a common g

### **Become a part of the KATC Support Group Leader Listserv**

I have created a listserv exclusively for the leaders of the parent support groups around the state. Much of the information shared on this listserv is meant to be spread by the support group leader to the members of their groups. This has proven to be successful in allowing me to share information to parents on a broad scale. In addition, newly forming groups are encouraged to post questions on the listserv to the leaders of long-established groups. It is often helpful to learn about how to run a successful group from those who have “been there” and are doing a great job.

### **Bottom line...Have Fun!!**

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Your group can serve as a vehicle to provide some very important aspects of support for parents of children with autism: education, socialization, normalization, and communication. Through an environment of support and shared understanding, stress levels can be decreased and perceived confidence in the ability to raise a child on the autism spectrum can be increased. Try to maintain a culture of positivity within your group meetings. An atmosphere of constant negativity and “agency bashing” at your meetings is not helpful. Humor can go a long way in relieving stress. Make laughter a regular component of your group meetings.

### Identify and Engage the Key Community Stakeholders

School District Superintendents	
Individual Schools and each School's Principal	
School District Special Education Directors	
Family Resource Youth Service Centers	
Special Education Cooperative Staff	
Clinical Supervisor Community Mental Health Center	
Manager – First Steps Point of Entry	
Existing Parent-Related Groups	
Potential Media Resources	
Director – Local County Health Department	
Local Physicians	
Local Businesses with an Interest in Autism	

## Sample Letter for Key Stakeholders

**DEAR TITLE AND LAST NAME OF YOUR PUBLIC OR SCHOOL OFFICIAL:**

The demands and challenges of raising a child with autism can be overwhelming. The importance of parent-to-parent support cannot be overstated. Talking with another parent is a great place to find practical everyday help for issues that may be difficult. To help meet the needs of local parents, we have formed **THE NAME OF YOUR SUPPORT GROUP**.

I would like to personally invite you to become involved with our group. We meet at **PLACE, ADDRESS, and DATE**. The goal of our group is to provide education, training, and support to parents with children on the autism spectrum.

I will contact you by phone within the next two weeks to follow-up on this invitation. Again, I hope you can join us on **DATE**.

Thank you for your support of children and their families within our community.

Sincerely,

Your Name

Name of Support Group

Support Group Mailing Address

Your Phone Number

Your Email Address

## Example of a Press Release

According to the Centers for Disease Control, 1 in 110 children are diagnosed with Autism Spectrum Disorder (ASD). Autism is a complex developmental disability that typically appears during the first three years of life, and impacts an individual's ability to communicate and interact with others. According to the April 2008 issue of *Archives of Pediatrics and Adolescent Medicine*, each individual with autism accrues about \$3.2 million in costs to society over his or her lifetime, with lost productivity and adult care being the most expensive components.

Parent-to-parent support is very important in raising a child diagnosed with autism. A support group for families affected by autism spectrum disorders (ASD) is forming in **CITY and/or COUNTY**. This group is open for attendance by parents and caregivers of children and adults with ASD. The purpose of this group is to help parents cope with the issues faced in raising children diagnosed with ASD. Our meetings are held each month and will feature speakers and discussion to provide information and support to assist parent as they care for their child with special needs. Those interested in joining our group can contact **NAME** at **PHONE and/or EMAIL** for more information.

Supports for individuals with autism are available on a statewide level through the Kentucky Autism Training Center (KATC). The center's mission is to enhance supports for persons with autism by providing information and technical assistance to families and service providers across Kentucky. For more information about autism, including resources available in Kentucky, visit the KATC website as <https://louisville.edu/education/kyautismtraining/>.