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KENTUCKY AUTISM
TRAINING CENTER 

How to Start and Sustain a Support Group!

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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



My son had been diagnosed with Autism for over 2 years when my son's Speech Therapist, my wife and myself started up our Support Group. We still could not discuss his diagnosis with anyone, even our families. I'll never forget what it felt like to drive home that first night after our first Autism Support Group meeting. It felt so good to sit in a room full of people, that knew what our family had been going through, and share things. I've learned so much from the parents in our group, even the new ones. And it's given us such a sense of accomplishment knowing that we have been able to help others too!

Russ Baker Hazard, Ky

Things to consider when forming a support group

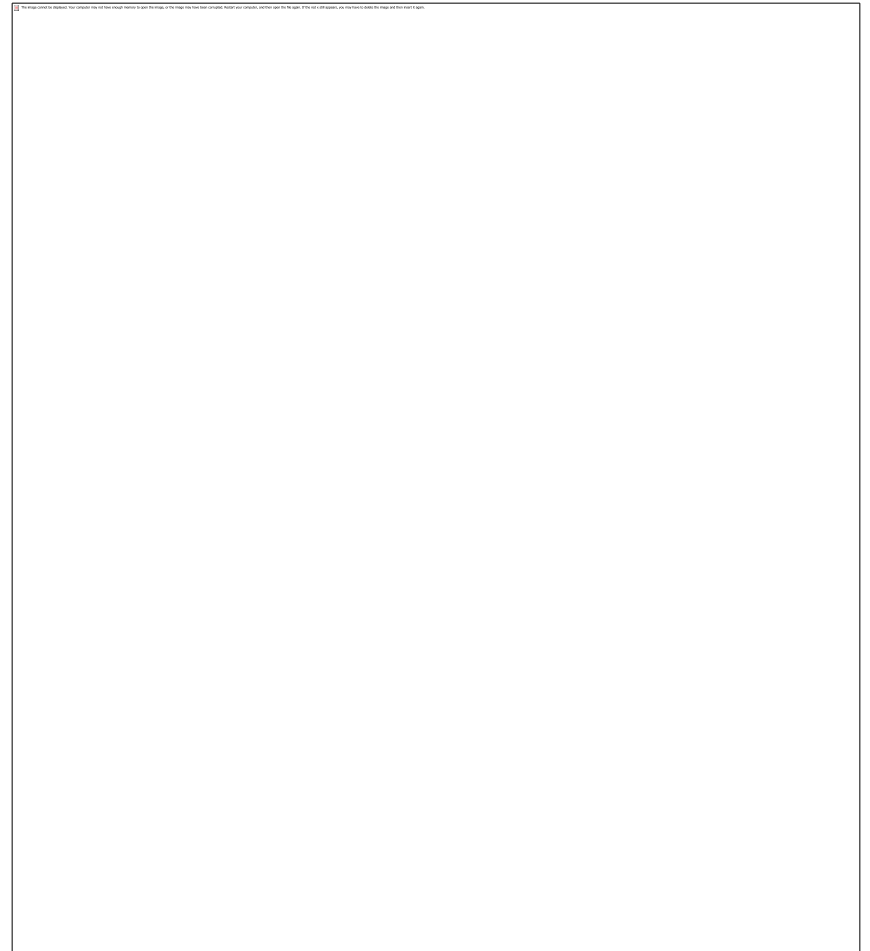


Who?

Reach out to . . .

Finding families

- Ad in the newspaper
- Flyer distributed to schools and providers
- KATC Facebook page and listserv
- Contact other groups in the area



Established groups are a resource

- Kentucky Special Parent Information Center (KY-SPIN)
- Office for Family Leadership (OFL)
- Partnership for Families and Children
- Family Resource and Youth Service Centers
- KY Seed
- First Steps

Key Professionals in Your Region

Superintendents

Community Mental Health Center

Principals

First Steps Point of Entry

District Special Education Directors

Other Parent-Related Groups

Family Resource Youth Service Centers

Media Resources

Special Education Cooperative Staff

Health Department

Educators

HealthCare Professionals

Providers

Businesses with an Interest in
Autism

Vocational Services

Think about group leadership

- Understands autism and impact on the family
- Motivates people toward the goals you have set for your group
- Knowledgeable of evidence-based practices for support individuals with autism
- Exudes energy and knows how to energize others

More thinking about leadership

- Open to new suggestions and who doesn't take things personally
- 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

Continually cultivate leadership



Burnout

Experience of long-term exhaustion and diminished interest.



What?

mission and goals of our group

Strategic Planning – just consider it

- Simple or complex
- Seek outside guidance and facilitation
- Process and progress – not perfection
- All opinions are equal and valid
- Gives a group focus

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

Example Mission Statement

Advocates for Autism Awareness is a group of families providing hope and support to one another; striving to build partnerships between families & professionals; and promoting community awareness through education, information & advocacy.

**Identity Statement:
Taking the mission to the next level
(La Piana, 2008)**

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

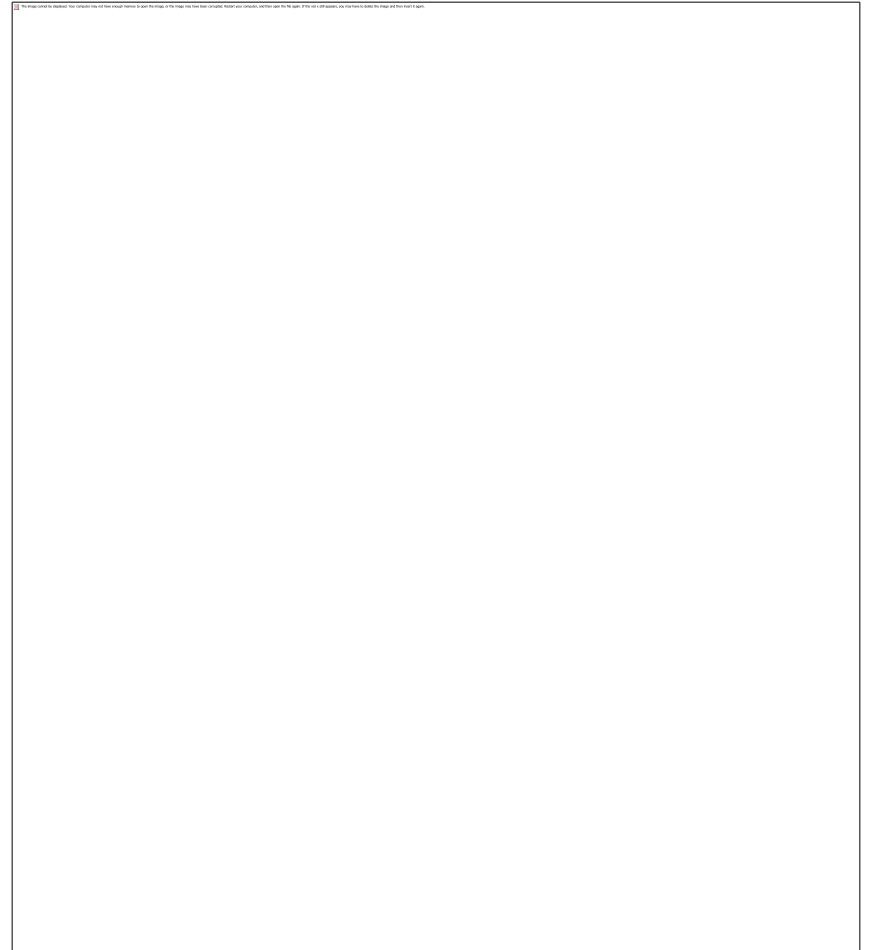
Example Identity Statement

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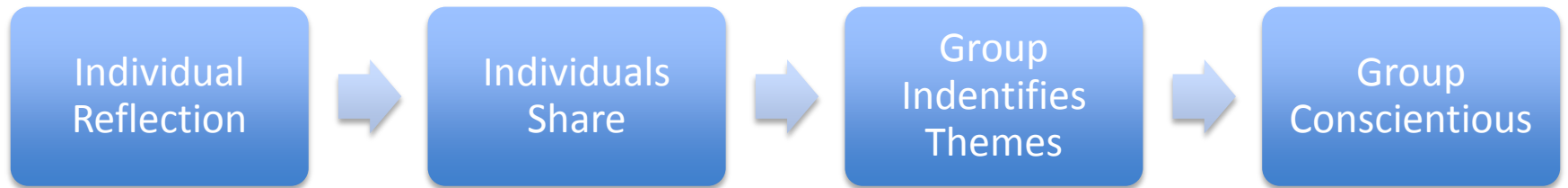
We seek to impact individuals with Autism Spectrum Disorders in future by serving families and professionals in Central Kentucky.

Goals

- 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?



Building conscious around goals: Sample Activity



Example Goals

1. Develop a social and support network
2. Provide opportunities for family education
3. Promote Autism Awareness and Advocate

Goal: X

Objectives	Strategies	Activities	Leadership	Timeline	Results

Where?

- Schools
- Churches
- Libraries
- Comp Care Center
- Banks
- Community Centers
- YMCA

When?

Consistency is key

How?

Format of meetings

- Informal chat
- Social events
- Invited speaker
- Watch video together
- Use facilitation tools provided by the KATC
- Consider needs of other family members (ie dads, siblings, grandparents)

Consider group guidelines

- <http://www.deafkids.org/Forming%20parent%20group.pdf>
- [http://autismharrisburg.org/docs/Chapter Bylaws 2010.pdf](http://autismharrisburg.org/docs/Chapter%20Bylaws%202010.pdf)

Childcare

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Snacks



Seed money

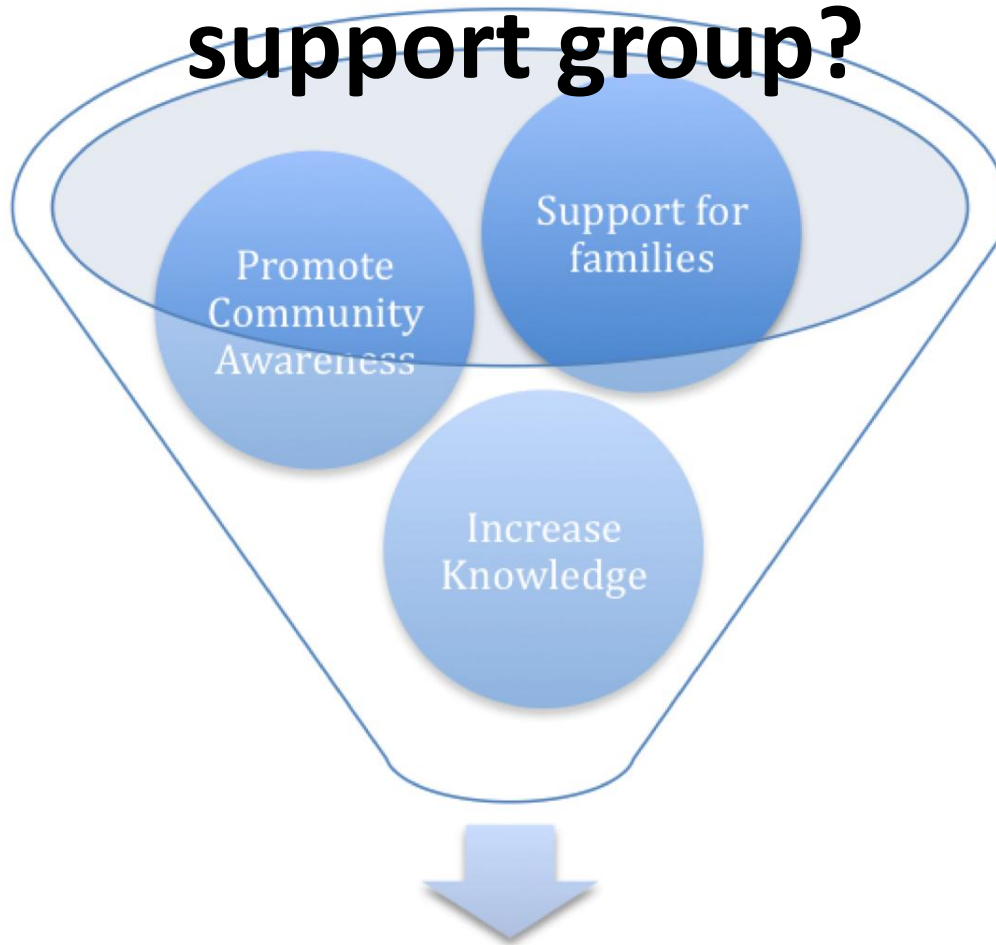


To 501 or not to 501



Why?

Why should I consider starting a support group?



Improve lives of families

QUALITY

IS

more IMPORTANT

THAN

QUANTITY



When I found the Powell Co Parents and Professionals group, I found a place to turn toward the small shining light that is the hope found in the vast darkness of our son Patrick's new and frightening diagnosis. People there knew the language that I was having to learn. They had been where we were going and could help us find our way back to feeling normal.

-Marilyn Barnett

Many in my group say that the support group "is sooo much cheaper than therapy!"

Terri Srinivasan

Maysville

Have fun



How the KATC can help your group

- Act Early materials
- KYPLANS
- Family Guide
- To Do List for new families
- Webinars
- Local presentations
- Reach local professionals and families