

UNIVERSITY OF  
**LOUISVILLE**<sup>®</sup>

KENTUCKY AUTISM  
TRAINING CENTER 



# Social Media and Online Communities for Family Support Groups

Presented by Diandre Glover Thomas

Program Coordinator

Kentucky Autism Training Center

# Learning Objectives

- Participants will learn about the benefits of creating an online network of support
- Participants will learn about roles, rules and privacy issues within online communities
- Participants will learn how to set up a Facebook group and a Yahoo group
- Participants will learn best practices to keep their online community active



# Isolation

Parents of children with autism need to connect with other parents in a supportive environment on a regular basis

# Three Benefits of Social Networks for Support Groups

- Give parents of children with autism an opportunity to meet and connect with other parents

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- Give parents of children with autism an opportunity to meet and connect with other parents
- Help support groups organize meetings, activities and events.
- Provide an opportunity for parents to share information about helpful resources and/or provide supportive words of encouragement for online community members.

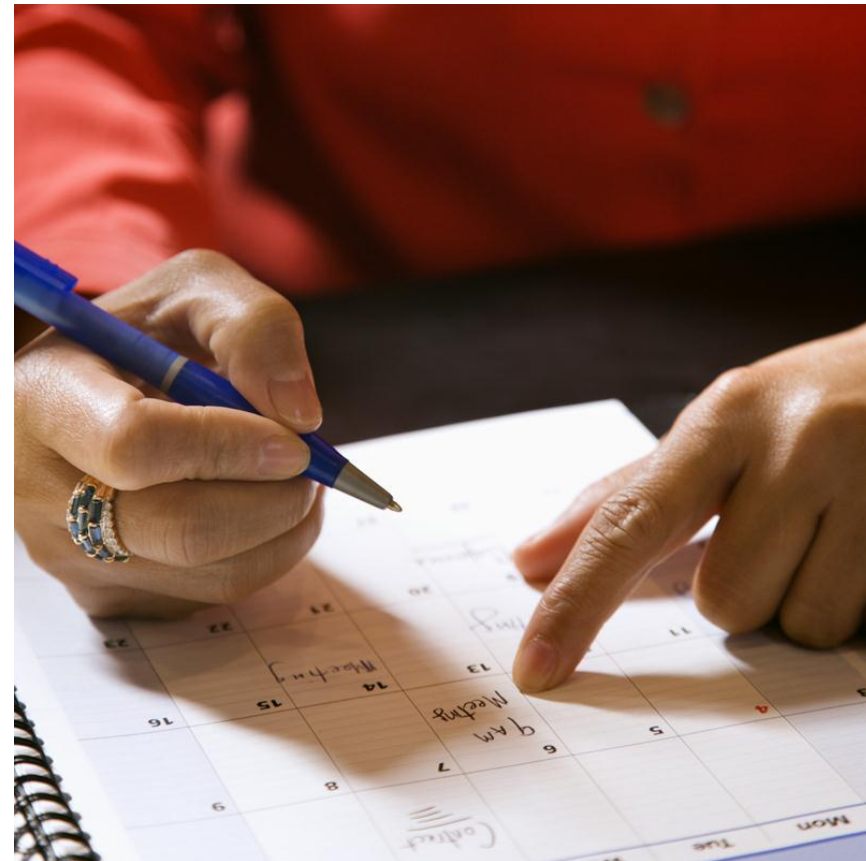
# Meet and Connect with Other Parents

Through sharing pictures, videos and stories about their families' highs and lows support group members are able to get to know each other better and form a deeper connection with one another



# Organize Meetings, Activities and Events

Support groups can post information about social activities and fundraisers such as awareness walks, bake sales, pot luck dinners and monthly meeting updates





# Parents Share Information and Give Encouragement

Parents can share if they had a tough day with their child or if their child did something they were really proud of or they can share resource information such as free training events and summer camp information





Get  
Connected!



**Join an existing  
online group**

# Two choices



**Start your own  
online group**

# Join an Existing Online Group

# Join an Existing Online Group

## PRO

Community is already in place and you only need to become a member and join in the conversation

autism-aspergers : This is a list for parents to share stories, treatments, therapies, ideas, a - Windows Internet Explorer

http://health.groups.yahoo.com/group/autism-aspergers/

File Edit View Favorites Tools Help

Convert Select

Favorites Suggested Sites Free Hotmail Web Slice Gallery

autism-aspergers : This is a list for parents to share st...

New User? Register Sign In Help Preview Mail w/ Y! Toolbar Mail My Y! Yahoo!

YAHOO! GROUPS Search Search Web

Internet Explorer cannot display the webpage

autism-aspergers · This is a list for parents to share stories, treatments, therapies, ideas, advice and support. Search for other groups... Search

Home

Members Only Messages Post Attachments Files Photos Links Database Polls Members Calendar Promote

Home

Join This Group!

Activity within 7 days: 4 New Members - 39 New Messages

Description

This list is for parents and caregivers of kids with autism and aspergers, and any other disability. Professionals are welcome as well. I am the mother of 4 special needs boys, and I created this list to share stories, ideas, treatments, therapies, advice and support. It's a list where we can all make friends and have fun. There will be no flaming tolerated.

Message History

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
2012	534	300	418	515	415	211	262	241	131	183	101	
2011	444	525	454	339	356	1234	217	162	255	206	294	312
2010	1	6	7	12	338	398	271	267	341	219	282	218

Group Email Addresses

Post message: autism-aspergers@yahoogroups.com  
Subscribe: autism-aspergers-subscribe@yahoogroups.com  
Unsubscribe: autism-aspergers-unsubscribe@yahoogroups.com  
List owner: autism-aspergers-owner@yahoogroups.com

SPONSOR RESULTS

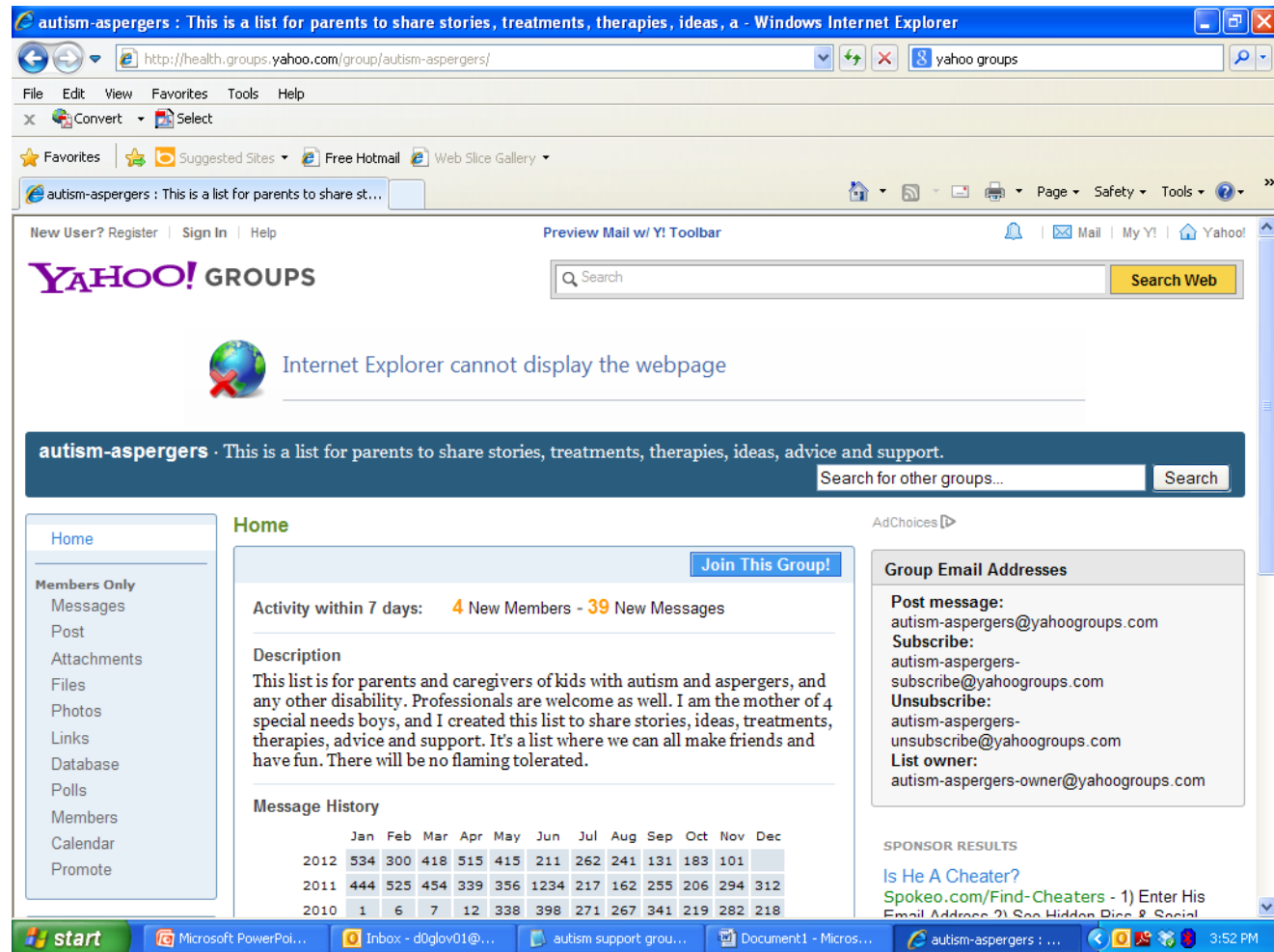
Is He A Cheater?  
Spokeo.com/Find-Cheaters - 1) Enter His Email Address 2) See Hidden Disc & Social

start Microsoft PowerPoi... Inbox - d0glov01@... autism support grou... Document1 - Micros... autism-aspergers : ... 3:52 PM

# Join an Existing Online Group

## CON

The community is already in place and you have to get to know the people in the network



The screenshot shows a Windows Internet Explorer browser window displaying the Yahoo! Groups page for the 'autism-aspergers' group. The browser's address bar shows the URL 'http://health.groups.yahoo.com/group/autism-aspergers/'. The page content includes a navigation menu on the left, a main content area with a 'Join This Group!' button, and a right sidebar with group email addresses and sponsor results.

**autism-aspergers** · This is a list for parents to share stories, treatments, therapies, ideas, advice and support.

Search for other groups... Search

**Home**

**Members Only**

- Messages
- Post
- Attachments
- Files
- Photos
- Links
- Database
- Polls
- Members
- Calendar
- Promote

**Home**

[Join This Group!](#)

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**Group Email Addresses**

**Post message:**  
autism-aspergers@yahoogroups.com

**Subscribe:**  
autism-aspergers-subscribe@yahoogroups.com

**Unsubscribe:**  
autism-aspergers-unsubscribe@yahoogroups.com

**List owner:**  
autism-aspergers-owner@yahoogroups.com

**SPONSOR RESULTS**

[Is He A Cheater?](#)  
[Spokeo.com/Find-Cheaters](#) - 1) Enter His Email Address 2) See Hidden Disc & Social

start | Microsoft PowerPoi... | Inbox - d0glov01@... | autism support grou... | Document1 - Micros... | autism-aspergers : ... | 3:52 PM

Existing Groups can be found on:

Yahoo Groups

Facebook Groups

SupportGroups.com

MyAutismTeam.com

MyAutismTeam | MyAutismTeam welcomes all parents of children with autism (children newly diagno - Windows Internet Explorer

http://www.myautismteam.com/

File Edit View Favorites Tools Help

Convert Select

Favorites Suggested Sites Free Hotmail Web Slice Gallery

MyAutismTeam | MyAutismTeam welcomes all parents ...

beta myautismteam The social network for parents of children with autism

join / sign in >>

Sign in with Facebook

MyAutismTeam is the social network for parents of children with autism.

Find parents like you.

start now (it's free)

Ember Mother of a 7 year old boy diagnosed with ASD

In The News

TIME CBS NEWS REUTERS

Microsoft PowerPoi... Inbox - d0glov01@... autism support grou... Document1 - Micros... MyAutismTeam | My...

4:00 PM

Feedback

Joining an existing online group is a good option if you do not currently belong to a support group or if you think your support group does not want to participate in an online community

## Find Parents

151 parents near Dallas, TX

Parent's Username

City and State (or Province)

Search Filters:

Sort by:

- Featured Parents
- Newest Parents
- Most Team Members
- Most Reviews
- Most Updates

My Child's Age:

- Baby/Toddler
- Pre-school/Kindergarten
- Young School Age
- Teenage
- Adult

My Child's Diagnosis:

- Asperger's
- ASD
- CDD
- HFA
- PDD\_NOS
- Rett Syndrome
- Neurotypical

1 2 3 ... 17 [ next ]



say hi

on team

**Kelly2405**

Lewisville, TX

Mom of 2-year-old boy diagnosed with ASD

24 team members

I'm a 34 year old mom. I'm a web designer and I work full-time. My husba...



say hi

add to team

**leannlanders**

Greenville, TX

Mom of 9-year-old boy diagnosed with Asperger's

19 team members

A single mom of three, my son (who is 9) has aspergers, adhd, mood disor...



say hi

add to team

**JosephWillerth**

Dallas, TX

Dad of 5-year-old boy diagnosed with PDD\_NOS

12 team members

Dad of a 5 year old with PDD-NOS. I'm getting my masters in special ed...

MyAutismTeam.com

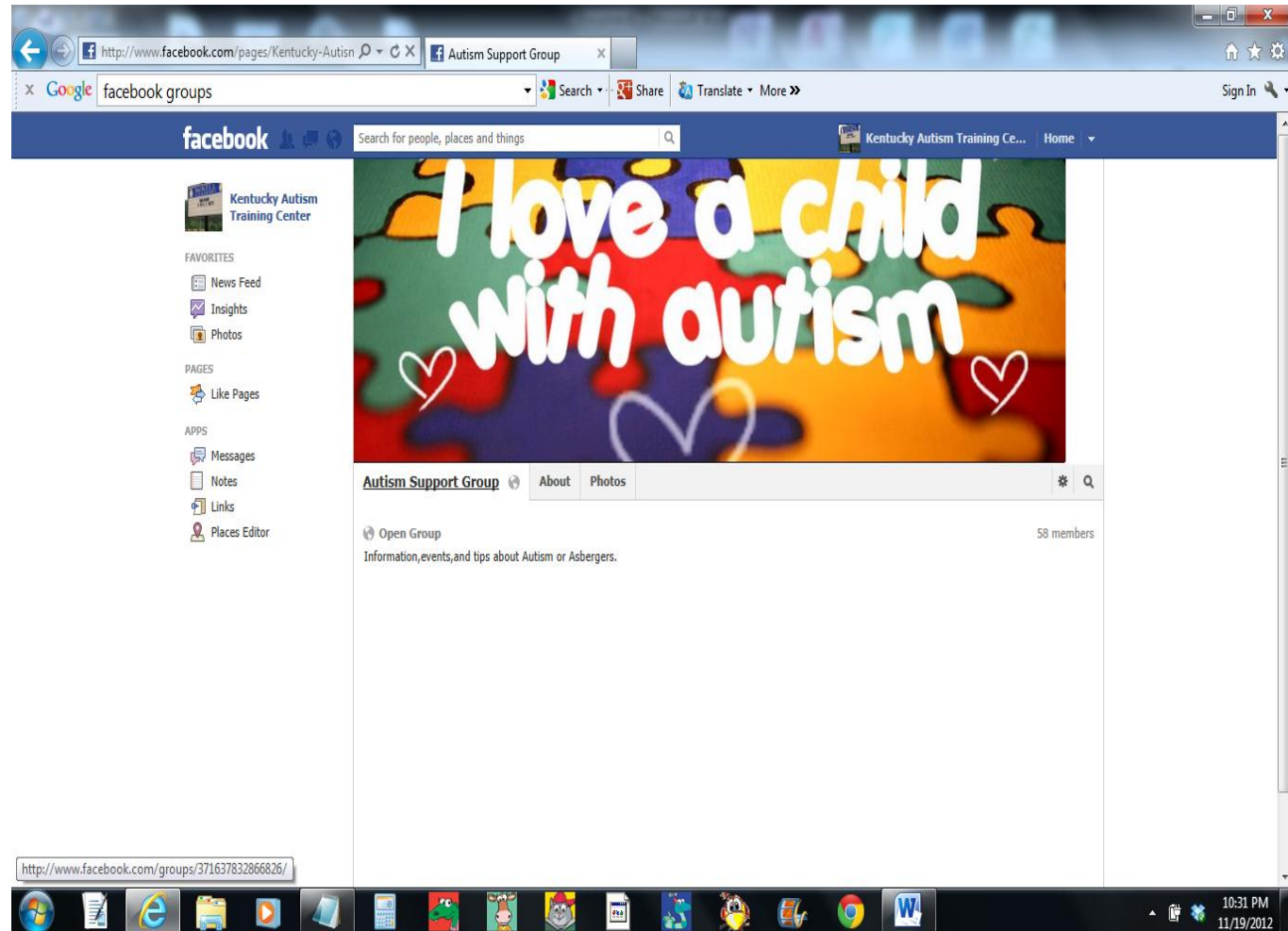


# Start Your Own Online Group

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## PROS

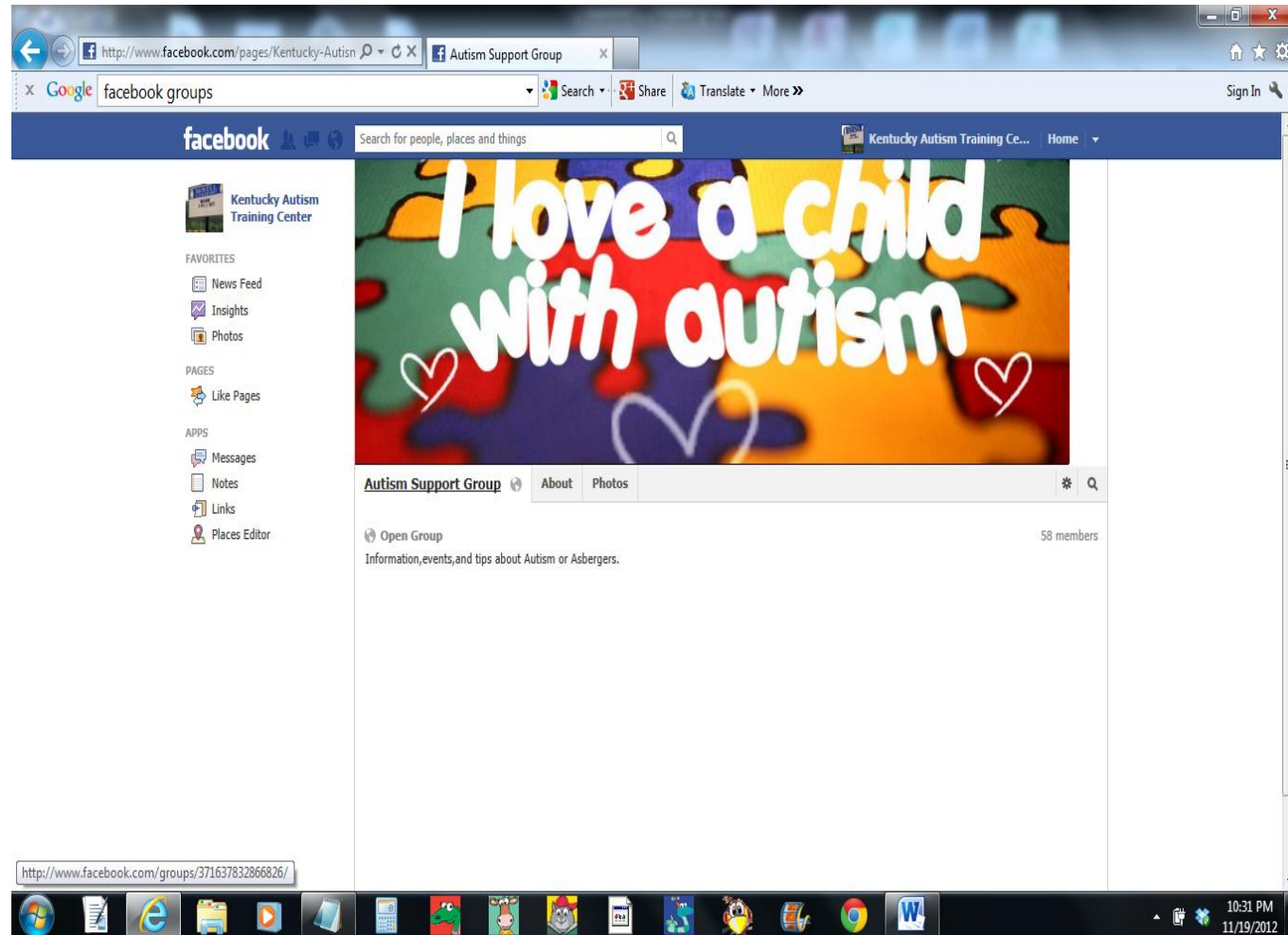
Online community becomes an extension of your current support group



# Start Your Own Online Group

## PROS

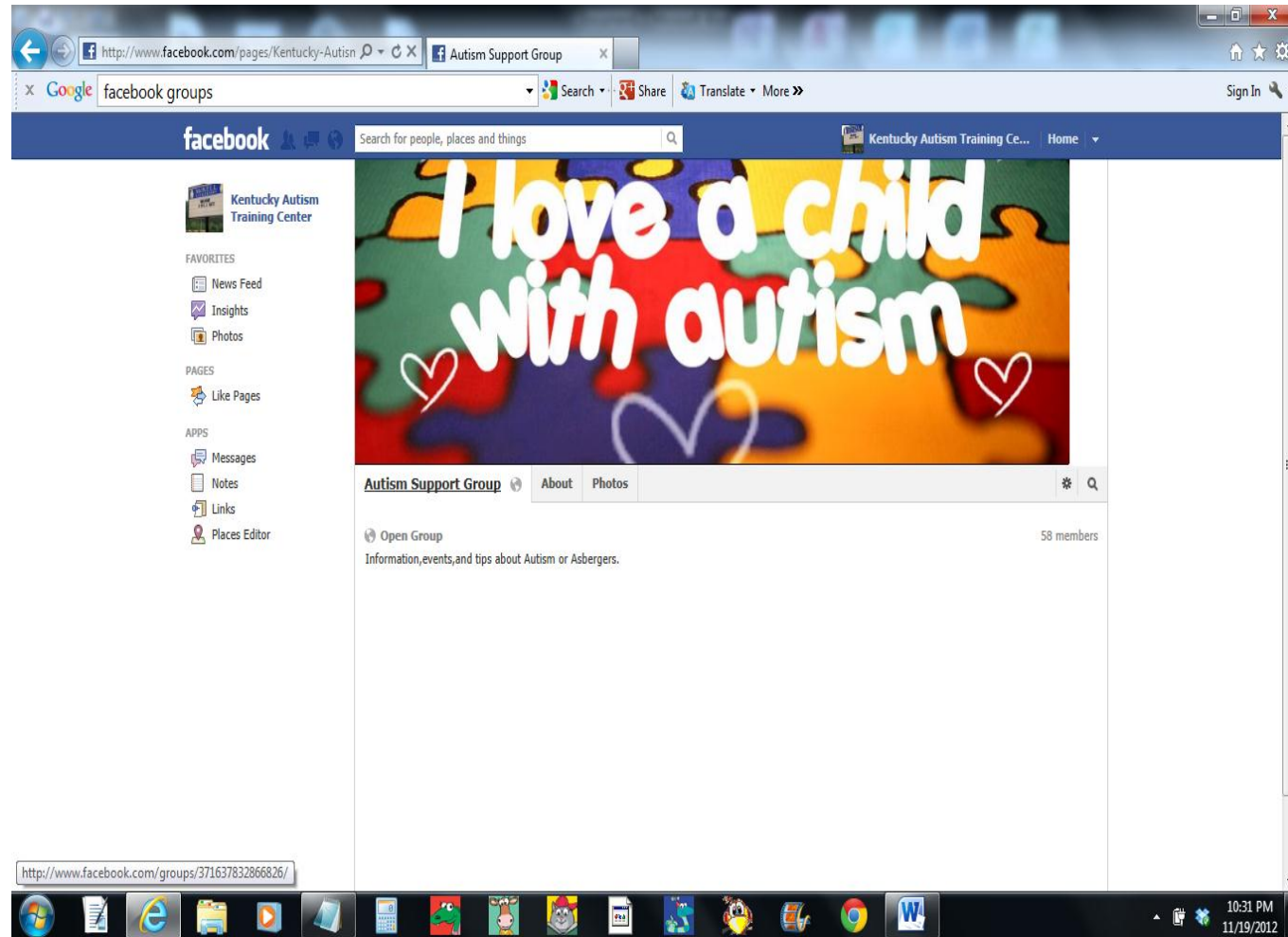
You already know your support group members and the online community gives you an opportunity to get to talk with them more often



# Start Your Own Online Group

## PROS

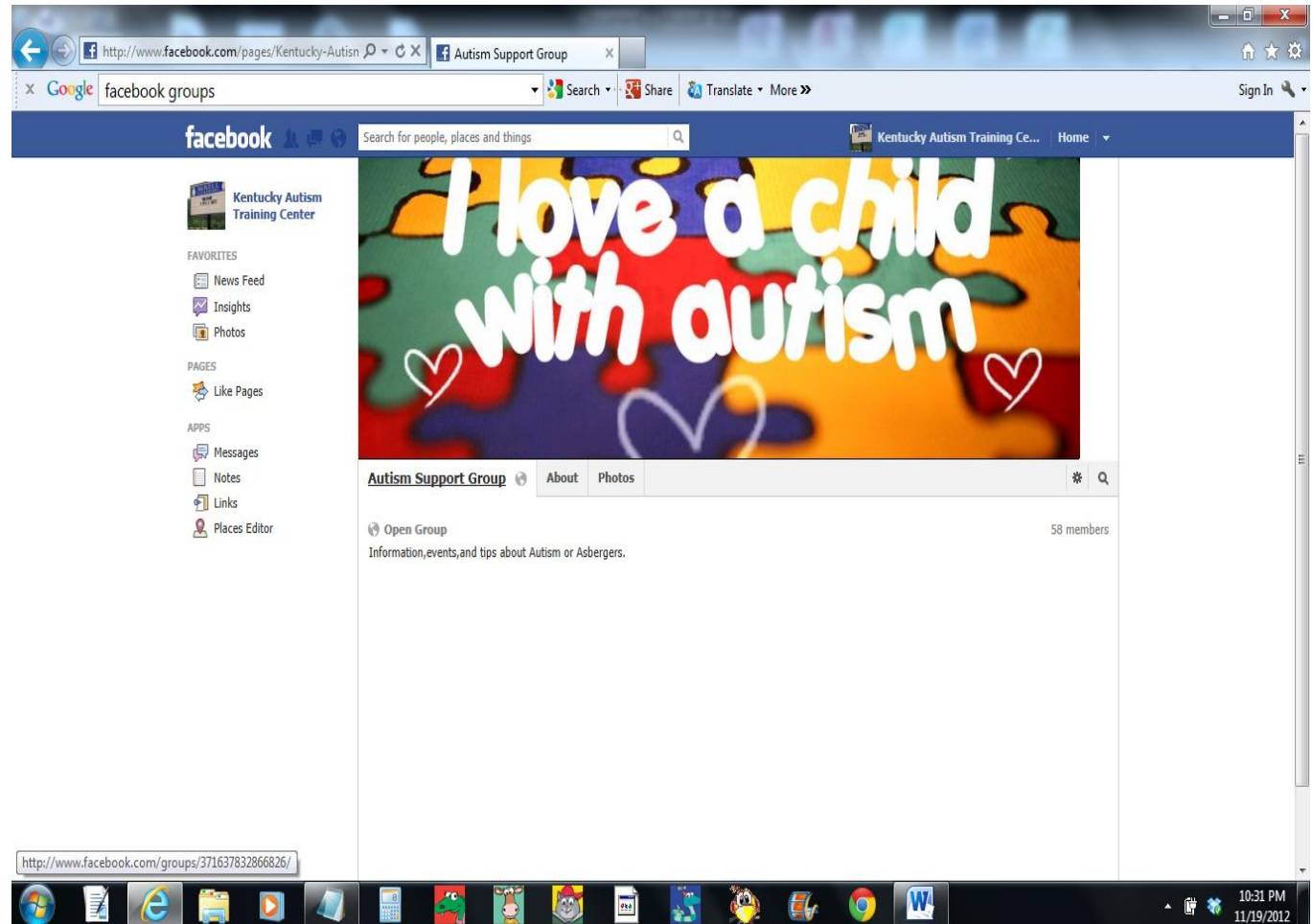
The support group members can create their own set of moderation rules for the online community



# Start Your Own Online Group

## CONS

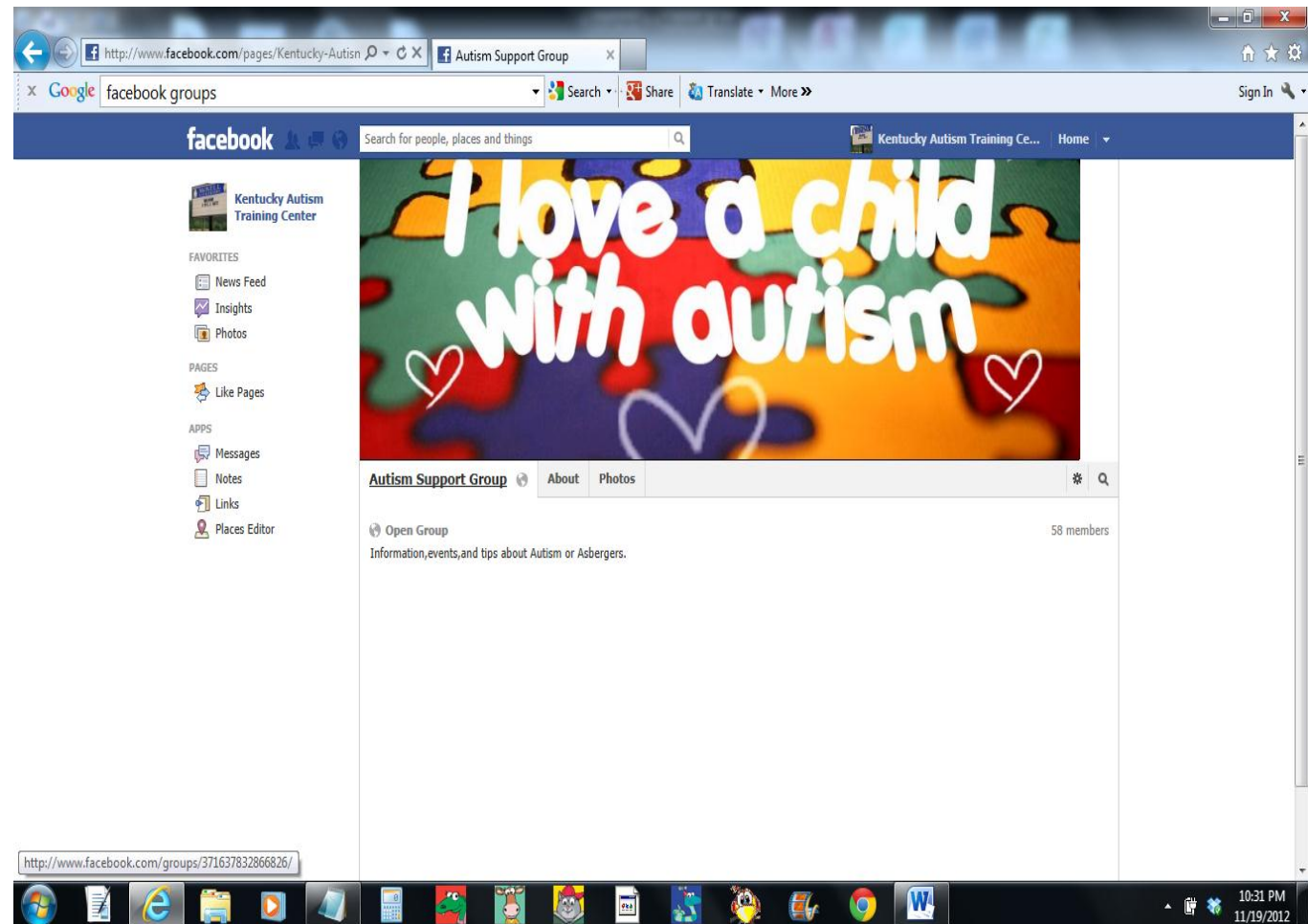
Someone in the support group will need to set up the online community



# Start Your Own Online Group

## CONS

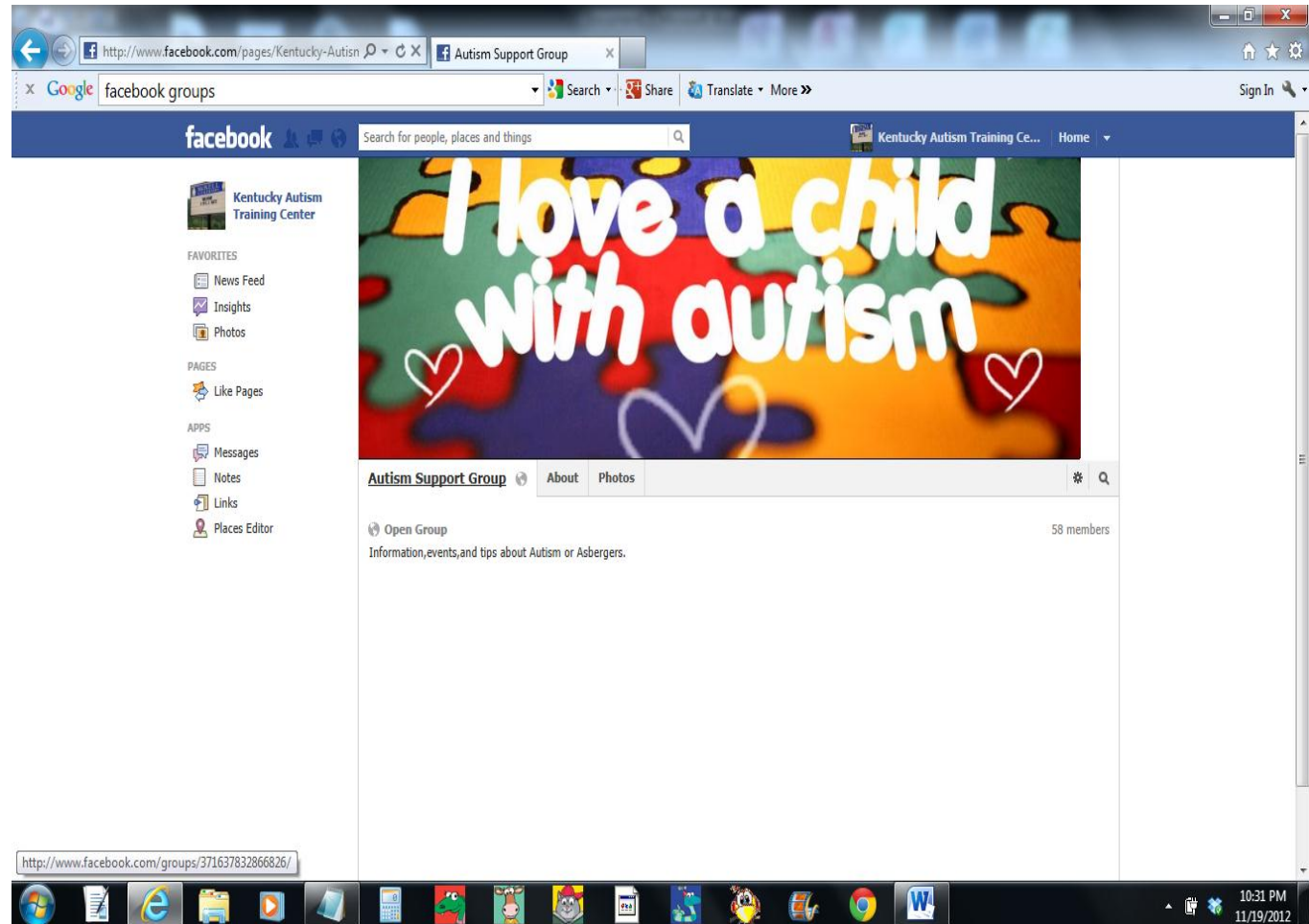
Someone in the support group will need to moderate discussions and make sure nothing inappropriate is being said and to keep the community spam free



# Start Your Own Online Group

## CONS

Someone will need to manage the community and keep the conversation flowing on the network



# Roles, Rules and Privacy

*You need to have them!*





**Community  
Manager**

# Roles

**Moderator**



**Members**



# What's the Difference?

## Community Manager

### Three responsibilities

- Look through all of the posts online to make sure everyone is getting their question answered
- Keep the conversation going by creating content daily
- To reach out to dormant members through email and at support group meetings to encourage them to join the conversation

## Moderator

### Three responsibilities

- To prevent the development of negative information
- To prevent the development of arguments that may conflict with the healthy behaviors the network is trying to promote
- To identify disrespectful posts on the public forum and delete them, warn the member who posted it, and keep records so that people who repeat this behavior can be removed from membership or have limited posting privileges

# Rules

## Best Practices

- Set up rules from the beginning
- Do not make them long or complicated
- Refer to the rules when a site members online behavior is inappropriate to help them understand why an action was taken
- Remember its okay to disagree with opinions but the rules are necessary to protect the integrity of the online community

## Example of rules

We do not permit:

- Sexual or offensive language or content
- Harassment of other users
- Abuse or disruption of our services
- The impersonation of Autism Support Group community manager or moderator
- Advertising of third party services or websites

# Privacy

## Best Practices

- Don't share any information online that you would not feel comfortable sharing with an entire group in person
- Understand how the online community works
- Always check your privacy settings





Let's Have Some Fun!!



# Facebook Groups

# Let's Create a Facebook Group

## Step One

Go to:  
[facebook.com/about/groups](http://facebook.com/about/groups)

Click on Create Group

The screenshot shows the Facebook Groups page in a web browser. The browser's address bar displays the URL <http://www.facebook.com/about/groups/>. The search bar contains the text "facebook groups". The page header includes the Facebook logo and a search bar with the text "Search for people, places and things". The main content area features a "Groups" header with a "Create Group" button. Below this, there are three main sections: "Create a private space", "Share different things with different people", and "Control who sees your group". The "Create a private space" section includes the text: "Have things you only want to share with a small group of people? Just create a group, add friends, and start sharing. Once you have your group, you can post updates, poll the group, chat with everyone at once, and more." The "Share different things with different people" section includes the text: "Groups let you share things with the people who will care about them most. By creating a group for each of the important parts of your life — family, teammates, coworkers — you decide who sees what you share." The "Control who sees your group" section includes the text: "Secret: Only members see the group, who's in it, and what members post." There is also a "Groups for Schools" section with the text: "Join groups for your dorm, classes and". The Windows taskbar at the bottom shows the time as 10:23 PM on 11/19/2012.

# Let's Create a Facebook Group

## Step Two

Create a Group Name

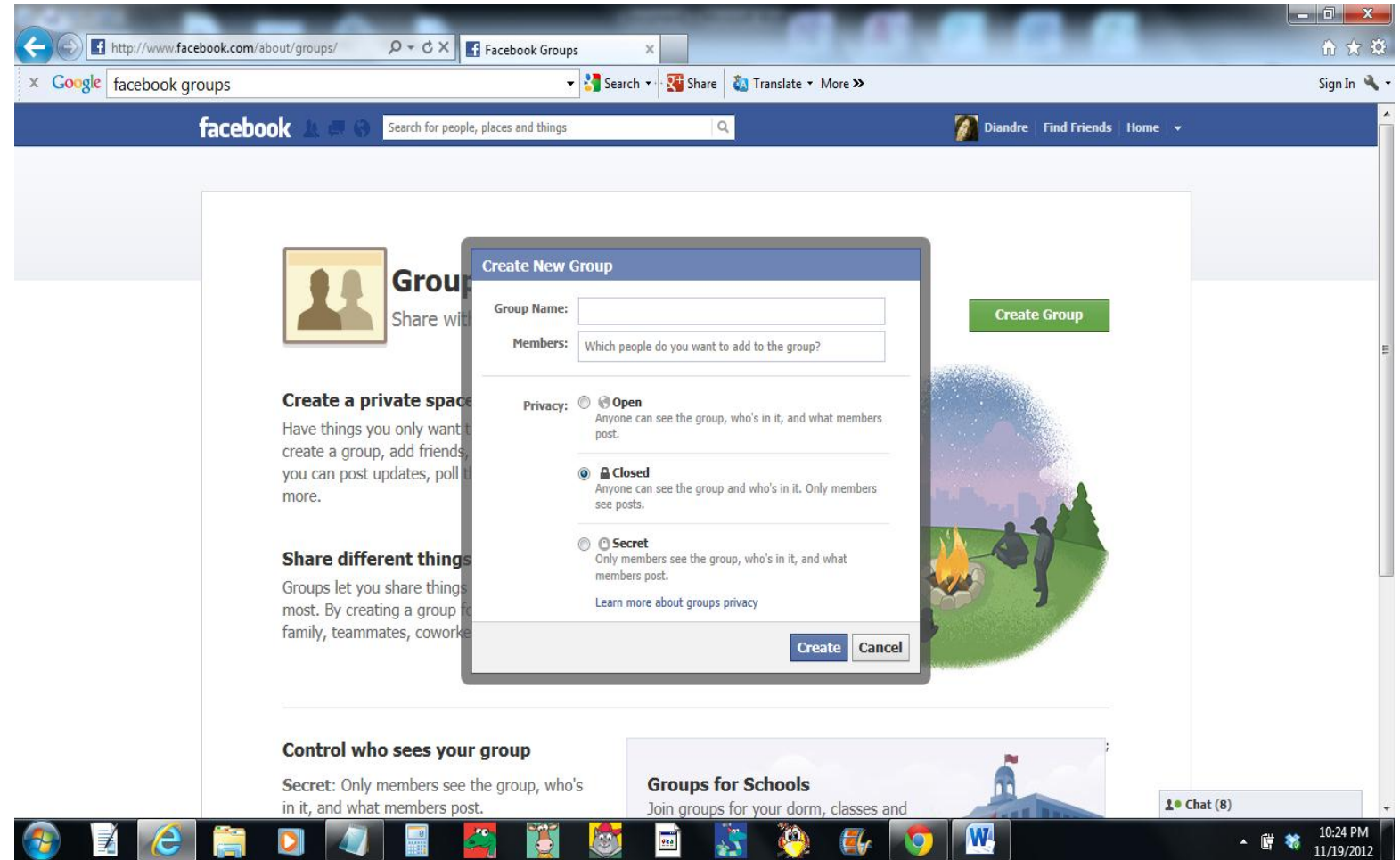
Select members

Select Privacy Settings

(Choose One)

- Open
- Closed
- Secret

Click Create

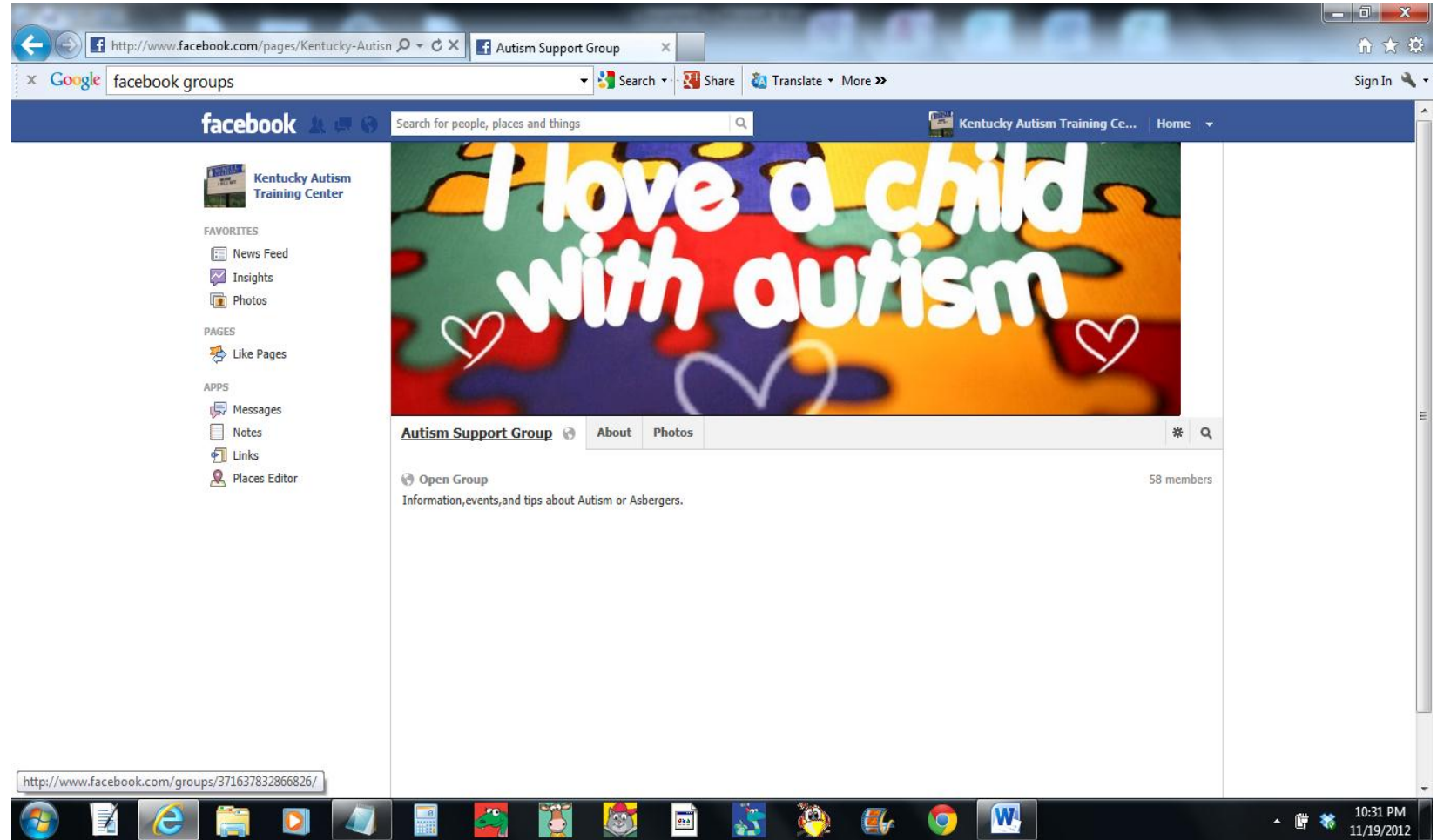




# Let's Create a Facebook Group

## Step Three

Congratulations  
you have a new  
group!



# Secret Facebook Groups for Support Groups

**Group Chats** – Everyone in the group can chat online at the same time

**Shared documents** –If you need to share notes from the support group meetings or flyers for activities

**Private photo sharing**—Only Secret Group members can see photos

**Shared email address** to post messages to the group

**Learn more about these features and adjusting group settings:**

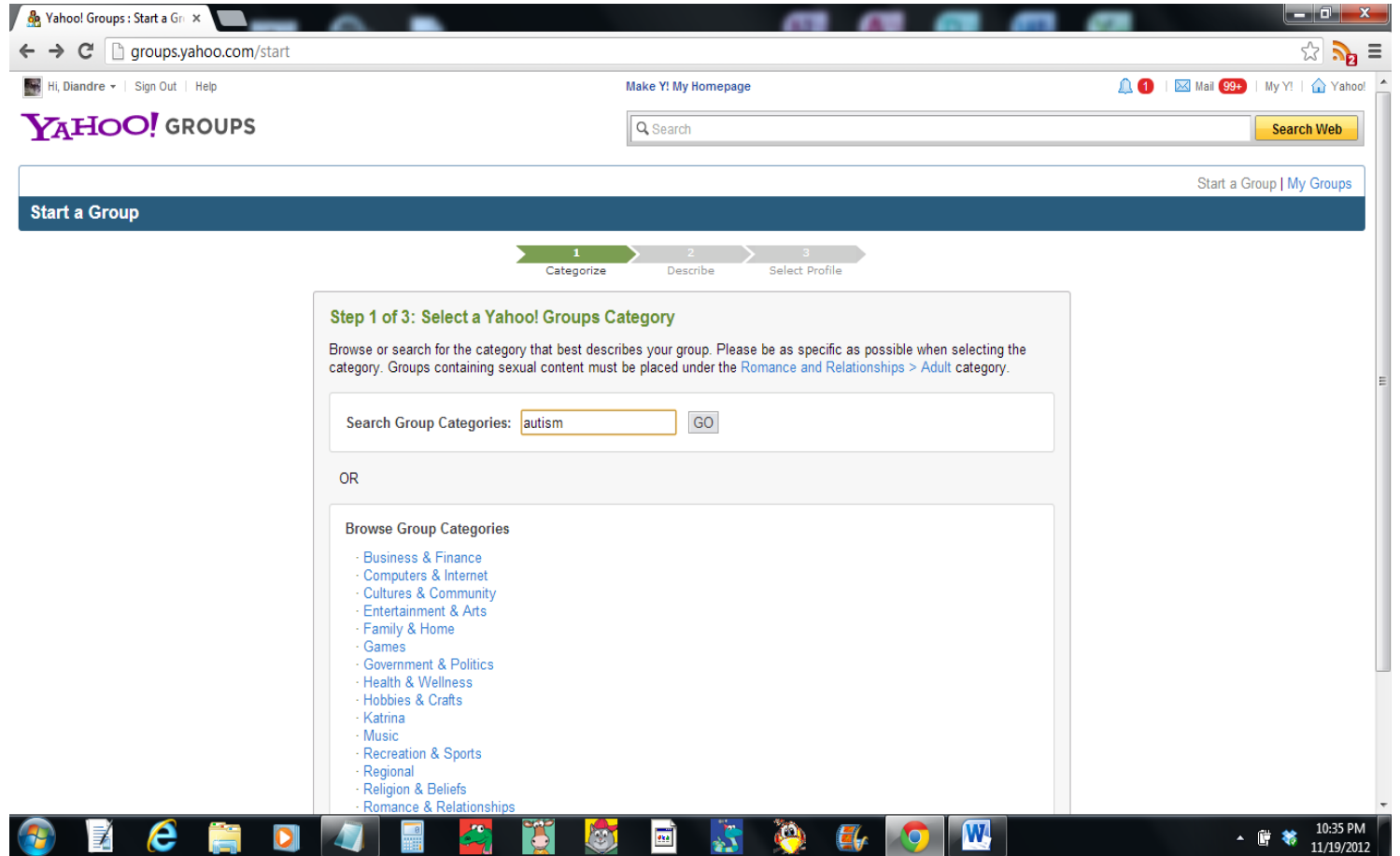
<http://www.socialmediaexaminer.com/how-to-use-secret-facebook-groups-to-enhance-your-business>

# Yahoo Groups

# Let's Create a Yahoo Group

## Step One

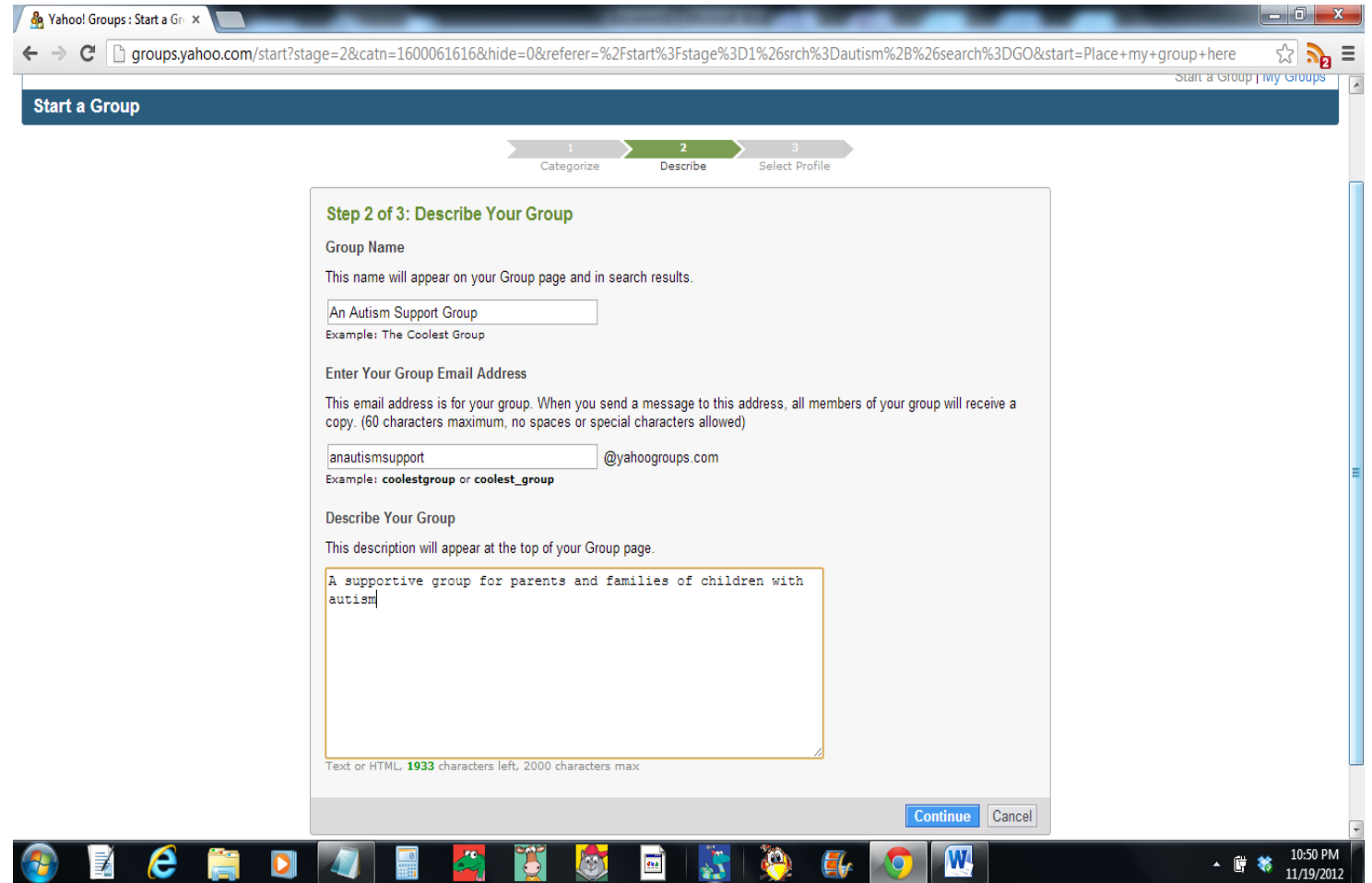
- Go to yahoo.com and create an account
- Go to:  
<http://groups.yahoo.com/start>
- Select a Yahoo Groups category in the Search group categories box enter "autism for a more specific category"
- Click on the suggested link in blue and click place my group here



# Let's Create a Yahoo Group

## Step Two

- Create a Group name
- Select group email address (this works like an email listserv any email sent to this address gets distributed to everyone in the group)
- Describe your group and click continue



The screenshot shows a web browser window with the URL `groups.yahoo.com/start?stage=2&catn=1600061616&hide=0&referer=%2Fstart%3Fstage%3D1%26srch%3Dautism%2B%26search%3DGO&start=Place+my+group+here`. The page title is "Start a Group" and the browser tab is "Yahoo! Groups : Start a Gr...". A progress bar at the top indicates three steps: "1 Categorize", "2 Describe" (highlighted), and "3 Select Profile".

**Step 2 of 3: Describe Your Group**

**Group Name**  
This name will appear on your Group page and in search results.  
  
Example: The Coolest Group

**Enter Your Group Email Address**  
This email address is for your group. When you send a message to this address, all members of your group will receive a copy. (60 characters maximum, no spaces or special characters allowed)  
 @yahoo.com  
Example: coolestgroup or coolest\_group

**Describe Your Group**  
This description will appear at the top of your Group page.  
  
Text or HTML, 1933 characters left, 2000 characters max

Buttons: [Continue](#) [Cancel](#)

The Windows taskbar at the bottom shows the time as 10:50 PM on 11/19/2012 and includes icons for various applications like Internet Explorer, Firefox, and Google Chrome.

# Let's Create a Yahoo Group

## Step Three

- Select your yahoo profile and the email address that responses on the list will go to. The default address is the one that you used when you began to register a group.
- Enter security code and click continue

The screenshot shows a web browser window with the address bar displaying 'groups.yahoo.com/start'. The page title is 'Yahoo! Groups: Start a Group'. A progress bar at the top indicates three steps: '1 Categorize', '2 Describe', and '3 Select Profile', with the third step being active. The main content area is titled 'Step 3 of 3: Select your Yahoo! Profile and Email Address'. It includes an 'Email Address' section with a radio button selected for 'bookserv@yahoo.com'. Below that is a 'Yahoo! Profile' section with a table showing the user's profile information. At the bottom, there is a security code input field containing 'L8z8LwMs', an 'Audio code' button, and a 'Try a new code' button. The 'Continue' and 'Cancel' buttons are at the bottom right of the form.

Start a Group | My Groups

Start a Group

1 Categorize 2 Describe 3 Select Profile

**Step 3 of 3: Select your Yahoo! Profile and Email Address**

Email Address  
If you choose to receive group messages by email, they will be sent to the email address you select below.

bookserv@yahoo.com

Yahoo! Profile  
The profile you select will be used when other members want to learn more about you, or communicate with you via Yahoo! Messenger.

Member	Real Name	Gender	Age
bookserv	(Not Provided)	(Not Provided)	(Not Provided)

[Create new profile](#)

Type the code below

[Need help?](#)

Copyright © 2012 Yahoo! Inc. All rights reserved.  
[Privacy Policy](#) - [Terms of Service](#) - [Copyright Policy](#) - [Guidelines NEW](#) - [Help](#)

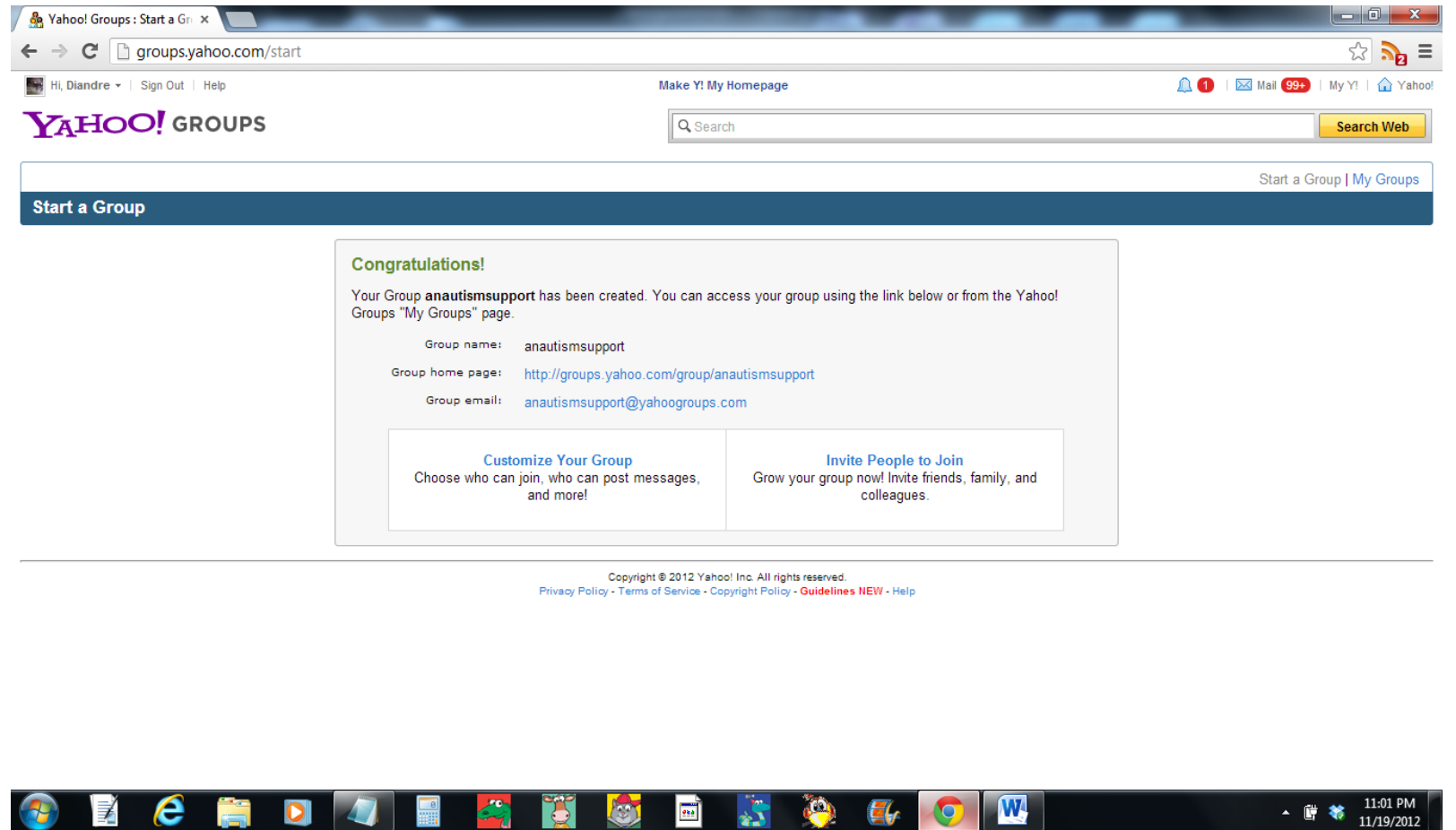
10:58 PM  
11/19/2012

# Let's Create a Yahoo Group

## Step Four

- You will get a homepage for your group and an email account for the group
- You can customize who can join and/or post messages and you can send an email invitation for members to join the group.

**Congratulations you have a new group!**



The screenshot shows a web browser window with the address bar at `groups.yahoo.com/start`. The page header includes the Yahoo! Groups logo and a search bar. A blue banner at the top of the main content area says "Start a Group". The main content area features a "Congratulations!" message: "Your Group **anautismsupport** has been created. You can access your group using the link below or from the Yahoo! Groups 'My Groups' page." Below this message, the following details are listed: "Group name: anautismsupport", "Group home page: <http://groups.yahoo.com/group/anautismsupport>", and "Group email: [anautismsupport@yahoogroups.com](mailto:anautismsupport@yahoogroups.com)". Two buttons are visible: "Customize Your Group" (with the subtext "Choose who can join, who can post messages, and more!") and "Invite People to Join" (with the subtext "Grow your group now! Invite friends, family, and colleagues."). At the bottom of the page, there is a copyright notice: "Copyright © 2012 Yahoo! Inc. All rights reserved." followed by links for "Privacy Policy", "Terms of Service", "Copyright Policy", "Guidelines NEW", and "Help". The Windows taskbar at the bottom shows various application icons and the system clock displaying "11:01 PM 11/19/2012".

# Yahoo Groups

## Allow a shared:

- Calendar
- Files
- Photos
- Polls
- Links
- Email

The screenshot shows a web browser window displaying the Yahoo Groups page for 'anautismsupport'. The browser's address bar shows the URL 'health.groups.yahoo.com/group/anautismsupport/'. The page header includes the group name 'anautismsupport - An Autism Support Group', a 'My Groups' dropdown, a search bar, and a search button. On the left side, there is a navigation menu with links for Home, Messages, Pending, Spam? [Delete], Post, Files, Photos, Links, Database, Polls, Members, Pending, and Calendar. Below this menu are sections for 'Promote' (Invite) and 'Management'. The main content area is titled 'Home' and shows 'Activity within 7 days: (No Activity)'. Below this is a 'Description' section with the text 'A supportive group for parents and families of children with autism' and a note '(No messages for this group)'. On the right side, there is an advertisement for Charmin Ultra Soft and Ultra Strong toilet paper, featuring a bear holding a roll of paper. Below the ad is a 'Group Email Addresses' section listing various email addresses for post messages, subscribing, unsubscribing, and the list owner. At the bottom right, there is a 'SPONSOR RESULTS' section with a link to 'Ticket www.local.com - Find Ticket Here at Local.com!' and a link to 'Local Banking'. The Windows taskbar at the bottom shows various application icons and the system clock indicating 11:05 PM on 11/19/2012.

How to use Yahoo Groups

<http://www.youtube.com/watch?v=buSoEg0Ckx0>



# Engagement

*Keep them coming back!*



Interest

Trust

Value

Respect

# Ideas to Increase Communication

## Fun

- Photos
- Ecards

## Supportive

- Get well soon
- Words of encouragement
- Well wishes (Happy Birthday, Anniversary, Congrats on the new baby, marriage, graduation, promotion etc.)

# Ideas to Increase Communication

## Interesting

- Articles read online that are relevant to the group
- Share information from other autism online communities and email listservs
- Community Events

## Important

### **Offline Activities**

- Support group meetings, notes and date reminders
- Activities such as awareness walks, fundraisers, bake sales, parent's or kids day out

# Most Important Key to Engagement

Give responses  
back to posts



Go out and start or join those online groups today!

QUESTIONS???

Diandre Glover Thomas

[diandre.gloverthomas@louisville.edu](mailto:diandre.gloverthomas@louisville.edu)

(502)852-2467



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