

AUTISM COLUMBUS



Autism Columbus

Winter 2015

NATIONWIDE CHILDREN'S HOSPITAL

Visual Supports Ease Medical Visits

Clinicians at Vanderbilt Medical Center demonstrate how visual supports can empower young patients with developmental disabilities

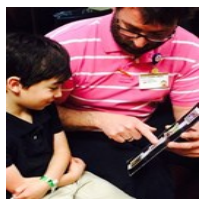
By David Crnabori, education and behavior consultant with the Center for Child Development at the Monroe Carell Jr. Children's Hospital at Vanderbilt University Medical Center, in Nashville. Vanderbilt is one of 14 sites in the Autism Speaks Autism Treatment Network.

"What are you going to do to me?"

"When can I go home?"

When a child with autism arrives for an appointment at our clinic, these are some of the important questions we try to answer visually.

Con't on page 2



The author uses a visual schedule to help a patient who has autism run through his upcoming medical visit. (Left)



A check-up visual schedule (Right)

This visual schedule guides the patient through the tasks he'll complete during his medical visit. (Far Right)

We know that individuals with autism respond well to visual information. Behavioral therapists and special-education teachers have long used visual supports in the classroom. Here at Vanderbilt, we're expanding their use in pediatric healthcare.

I've come to view visual supports as more than another autism intervention. I see them as prosthetic devices. Merriam-Webster defines a prosthesis as "an artificial device to replace or augment a missing or impaired part of the body." I think this definition applies so well to visual supports. We use them to support the neurological and developmental differences shared by many individuals with autism.

Our goal is to provide the best care possible for children with developmental disabilities. This includes providing the necessary supports to turn our clinic into an autism-friendly environment.

From the time our patients check in to the time they leave, we provide visual supports to help address as many of their concerns as possible. Here are some examples of how we do this.

What am I going to do today? In the waiting room, we start the visit with a customized picture schedule with photos of each step of the child's appointment. (See visit schedule, page one.) Our visual schedules are portable so the patient and his or her parents can carry them through the clinic.

What are you going to do to me? In addition to the visual visit schedule, we have visual task lists and instructions for each procedure that will take place. For example, we have a task list for taking vitals such as blood pressure, weight and height. (See vitals schedule, page one.)

We still use another visual support to help communicate the instructions required to complete each task. (See "first-then" schedule for getting weighed, see page 3.)

We encourage our patients to remove pictures from their schedules as they complete each task, a step that helps provide them with a sense of control over the situation.

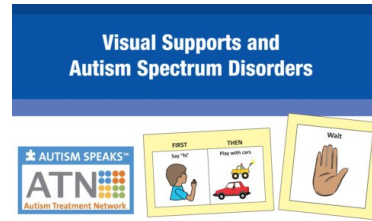
When am I finished? Removing pictures from their schedules provides our patients with a tangible way to track their progress to the end of the visit. Some patients appreciate a little more support in this regard. For them, we'll add a visual timer such as the visual app I have on my smart phone (see page 3). Appointments typically have set times. But if needed, I'll consult with the providers on time estimates and set the timer accordingly.

The last picture on the visual schedule – right after the visit to the treasure chest – shows a child leaving the clinic with the caption "all done."

In addition to easing clinic visits for our young patients, our extensive use of visual supports allows us to demonstrate their usefulness to parents. We send many of our parents home with packets of visual supports, including a copy of the Autism Speaks [ATN/AIR-P Visual Supports Tool Kit](#) which is available at: www.autismspeaks.org



First ... then



What is Family Centered Care?

Family Centered Care (FCC) is very important in the planning and management of treatment for children with Autism Spectrum Disorder. Simply put, Family Centered Care (FCC) is “an approach to the planning, delivery and evaluation of health care and serves as the cornerstone of participation between families and professionals.

Family-Centered Care helps support the family’s relationship with the

child’s health care providers and recognizes the importance of the family’s customs and values in the child’s care.” FCC is comprehensive, accessible, culturally sensitive, compassionate, ongoing and inclusive of family input and has an element of coordination.

The Autism Treatment Network model of care incorporates these core beliefs in the care approach for children with ASD.

It promotes a high standard of coordinated care for the child and family. ATN centers will find an environment that provides the highest level of direct care and clinical expertise and also serves as a resource for families, community physicians, behavioral practitioners, and educational advocates. For more information about the ATN, please go to:

www.nationwidechildrens.org/autism-treatment-center

Access Your Health Information ONLINE!

Nationwide Children’s Hospital offers **MyChart**, which is a new tool to help manage your child's medical information.

MyChart allows access to a summary medical record and allows you to communicate with your NCH health care providers, in turn saving you time and providing you answers.

With MyChart you can:

- View health summary information such as your current health issues, medications, allergies, immunizations, medical, surgical, and family history.
- View released outpatient test results; upcoming appointments and summaries of past appointments.
- Send appointment and

request prescription refills.

- Request non-urgent medical advice and grant access to allow others to view your medical record.

To find out more information about MyChart, go to:

www.nationwidechildrens.org/mychildrens-registration



Sibling Courses 2015

Nationwide Children's Hospital continues to offer our program for siblings of children with autism and with other special needs.

Program Description

Brothers and sisters of children with special needs have feelings that may be hard to express, even to a friend; sadness that a sister has trouble learning, anger when a brother's behavior prevents the family from doing things other families do, or the special pride when their sibling learns a basic but important life skill. At Sibshops, siblings will share these feelings with others who truly understand. Sibshops celebrates the many contributions made by brothers and sisters and engages children through fun and games to explore feelings and share information.

What Happens at Sibshops?

Siblings meet each other in a relaxed, fun setting. Talk with others who "get it" about the good and sometimes not so good part of having a sib with special needs.

Learn how others handle situations commonly ex-

perienced by siblings of children with special needs.

Learn more about their siblings special need. Provide parents and other professionals with the chance to learn more about the concerns of siblings of children with special needs.

Who Can Attend?

7-12 year old brothers and sisters of children with special needs.

How Many Times Can My Child Attend?

Children can attend as many times as they want. The Sibshop program changes with every session to meet the needs of the children enrolled.



For more information go to:

www.nationwidechildrens.org/education-classes

SIBS Weekend

April 2015

SIBS Looking Forward Transition Weekend

April 10-12, 2015

YMCA - Camp Wilson

The SIBS Looking Forward Transition Weekend will be held April 10-12, 2015 at the Camp Wilson YMCA in Bellefontaine, Ohio. This is a unique opportunity for transition age students with disabilities to spend a weekend with one or more of their siblings, while engaging with other students and siblings from around the state.

I encourage you to help us spread the word about this amazing event which, by the way the only one of its kind in the Country. SIBS Looking Forward is now in its fourth year of operation and is managed by Ohio SIBS with generous support from the Ohio Developmental Disabilities Council, the Franklin County Board, and The Ohio State University Nisonger Center. Register at:

<https://files.ctctcdn.com/117fd275201/e3a99638-65eb-462a-aff1-c9b7b79dda53.pdf>

Siblings: Things you should know

By Sapna Shetty, LIMFT

For many families, raising a child with autism or a developmental disability can cause challenges not only for the child with the disability but for their siblings as well. It can affect the social, psychological and emotional development of each child within the family.

A child that has a sibling with a disability may feel isolated and / or left out within the family dynamics due to the amount of time and care that happens to follow that child with the disability. While having a sibling with special needs comes with challenges, it also comes with opportunities along with positive experiences. Siblings have the opportunity to develop many positive qualities such as patience, acceptance and love for differences, maturity and confidence, responsibility along with empathy and kindness to others.

At times it can also be difficult coping with having a sibling with a special need. It can lead to conflicting emotions. For example, there may be worry and concern about their sibling and yet jealousy for the amount of attention that their sibling is receiving from parents and other family members. There is love for their sibling but embarrassment by their siblings differences when amongst friends or in social settings. There could be excitement in having a sibling to share vacations with but resentment in not being able to go to different places or do different things because of their sibling. There can also be frustration in feeling that they always need to be explaining and taking care of their sibling but also a sense of wanting to protect their sibling from others.

Red flags that may be signs that your child may need additional supports to cope with having a sibling with a disability may include:

- changes in eating or sleeping (too much or too little)
- physical symptoms like headaches and stomach aches
- hopelessness
- perfectionism
- poor concentration
- poor self esteem
- talking of hurting themselves
- difficulty separating from parents
- loss of interest in activities
- frequent crying or worrying
- withdrawal

Although social service agencies have long provided supports for parents and / or other caregivers, only recently have these groups and supports become available to siblings.

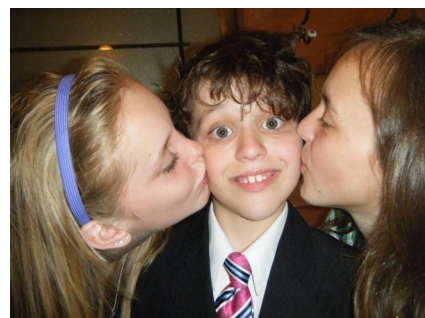
Visit me at one of my next Sibshop Courses:

May 3 - Walking with Flowers

June 21 - Cultural Outreach: Northland Primary Care Center on Morse Road

Sign up at:

www.nationwidechildrens.org/education-classes



Miralax & Laxative Safety:



In response to this week's [news report](#) about an investigation into the safety of Miralax and other laxatives containing polyethylene glycol 3350 (PEG-3350), many of you wrote to us or posted questions in the story's comment section and on the [Autism Speaks Facebook page](#).

In [its news story](#), the New York Times quoted pediatric gastroenterologist and autism specialist Kent Williams as having concerns about PEG 3350's safety when used long term, as is the case with many children who have autism and chronic constipation.

We asked Dr. Williams – who practices in the [Autism Speaks Autism Treatment Network](#) at Nationwide Children's Hospital, in Columbus, Ohio – to provide answers and perspective in response to your concerns:

Our daughter's pediatrician took us straight to daily Miralax for her chronic constipation. I feel like we need to start over, but I don't know where to begin.

Thanks for your question. The safe and effective management of chronic constipation is an important and complex issue for many families with children affected by autism. As GI specialists within the Autism Speaks ATN, we've developed and provided the nation's pediatricians with [guidelines for safe and effective treatment](#) of chronic constipation in children and teens with autism.

The good news is that we have various ways to treat constipation. The best course should reflect the causes and severity of a patient's constipation.

Q&A with GI-Autism Specialist Kent Williams

So the first question is how severe was your daughter's chronic constipation? For mild to moderate constipation, dietary and behavioral changes are often sufficient. Dietary changes include increasing dietary fiber and daily fluids, especially water and juice, to help soften stool and make it easier to pass. Behavioral changes include regular exercise and establishing good daily bowel habits. Working with a behavioral therapist can often help when trying to implement dietary and behavioral changes with children with autism.

However with severe constipation, we generally must go beyond dietary and behavioral changes. Dietary and behavioral treatments are important in these cases. However, a medication is typically needed as well when a child has one or more of the following signs:

1. Having two or less stools per week
2. Having to strain or push hard to have a bowel movement
3. Having hard stools
4. Experiencing pain when passing stool
5. Leaking liquid stool in addition to having constipation.

Until recently, Miralax tended to be our first choice for treating severe constipation. Simply put, it was our most effective option. But now we're seeing concerns raised about its use in young children.

With this information in hand, I hope you'll feel comfortable going back to your child's pediatrician and together review the approach you've been using to manage your child's constipation.

Con't on next page



Miralax was the ONE thing that relieved our son's chronic constipation. Now what? While we welcome the new investigation into safety concerns, I want to emphasize that any blanket rejection of using Miralax and other PEG-3350 laxatives might do more harm than good.

I say this because unresolved and severe constipation can have serious consequences. These consequences include severe pain, intestinal blockages and blood loss from rectal bleeding. Years of chronic constipation can lead to loss of intestinal function to the point that part of the colon may need to be surgically removed. In short, untreated chronic constipation can lead to serious and even life-threatening conditions. As with any medication, we should weigh benefit and risk when placing someone on PEG laxatives. This is particularly true of young children. So I urge parents to discuss the following questions with their child's physician:

Does my child need to be on a medication for constipation? Unfortunately severe chronic constipation generally requires more than dietary and behavioral changes. And it's undeniably common among children with autism. In addition, autism-related sensory and behavioral issues can make significant dietary and behavioral changes difficult.

If so, what medication should we use? Medical studies have shown that Miralax and its generic counterparts, when taken appropriately, are our most effective medications for relieving chronic constipation. I say "when taken appropriately" because many children with autism resist taking these laxatives due to oral sensory issues. In other words, they may have strong and emotional resistance to the way these products feel in the mouth. And while we have concerns about the possible safety issues with Miralax, we must keep

in mind that *any medication* has potential side effects. Consider, for instance, these alternatives:

Lactulose. This is my first choice for mild to moderate constipation in children younger than 3 years old. It can likewise be effective in older children, but with age comes the increasing likelihood of painful gas production. This side effect results from lactulose being fermented by the intestinal "flora" (the intestine's normal community of digestive bacteria), which tends to become more active with age. Lactulose may even result in unwanted changes to gut flora.

Mineral oil. Mineral oil is safe and effective for mild to moderate constipation. However many children resist its use. Swallowing mineral oil can be a particular challenge for children with oral sensory issues. Also, it can cause a severe pneumonia if accidentally aspirated into the lungs.

Magnesium laxatives (Milk of Magnesia, magnesium hydroxide, magnesium oxide, magnesium citrate). Again, many children with autism have difficulty with this laxative's taste and consistency. We also worry about the effects of too much magnesium on skeletal and heart muscle. **Colace (docusate sodium).** Colace works by drawing water and fats into the stool. It's considered safe, but isn't as effective as Miralax. It simply doesn't work for many of the children we see in our clinic.

In conclusion, Miralax remains the most-effective medication for many children with autism and severe, chronic constipation. So if you and your pediatrician have worked through other approaches without success, I would still strongly consider using Miralax based upon current safety information. At the same time, however, I strongly recommend that the family and physician work together to find the lowest effective dose. This is true with any stool softener or other type of laxative.

What about the toxic contaminants the FDA found in Miralax?

The FDA reported finding trace amounts of ethylene glycol and diethylene glycol in all eight batches of PEG-3350 laxatives that it tested. These chemicals might be byproducts from the manufacture or breakdown of PEG-3350. We know ethylene glycol and diethylene glycol are toxic in large amounts. However, the FDA allows trace amounts in medicines and even foods because small amounts aren't harmful. Still, their presence raises concerns when a product is used long term.

If PEG-3350 stool softeners are the *only* products that work for your child, I recommend working with your doctor to minimize the potential for side effects by finding the smallest effective dose – in combination with the dietary and behavioral approaches described below.

Those are some scary behavioral side effects the FDA is investigating. Of course, I'm worried...

While abnormal behaviors and tics have been associated with use of PEG laxatives, this association may have more to do with severe chronic constipation itself than with the laxatives. Research has established a clear association between severe constipation and a variety of abnormal behaviors – particularly among children affected by autism. These include aggression, obsessive compulsions and attention deficit and hyperactive behaviors. This association with behavioral symptoms is among the reasons we take the comprehensive treatment of constipation so seriously in our autism clinics.

What about herbal laxatives like senna?

Many herbal supplements and teas can effectively

treat occasional constipation. But there are concerns about using them daily over the long term.

These supplements and teas are made from a variety of herbs such as senna, rhubarb, aloe and frangula. Their laxative properties come primarily from compounds known as anthranoids. In the colon, anthranoids act as irritants, drawing in fluids and causing the colon to contract. They are legitimate alternatives to more-conventional medication. However they, too, are biologically active medicines. As such, they too can produce unwanted side effects. For example there's some evidence – though not conclusive – that chronic use of anthranoid laxatives may increase risk for colon cancer.

If you choose to use herbal laxative teas, I recommend the following guidelines:

- * Use only products from clearly identified and reputable companies with labels listing all ingredients .*
- * Follow the recommended dosing on the product labeling.
- * Don't rely on herbal laxatives for long-term treatment of constipation.

I hope these answers prove helpful in your discussions with your healthcare practitioner. Thanks again for your questions.

Editor's note: Autism Speaks is currently funding cutting edge research into the causes and treatment of autism-related constipation – including investigations into the role of intestinal bacteria and the development of probiotics that may improve autistic symptoms as well as GI distress.





A Day of Arts for All, VSA Ohio honors award winners from each category of this year's Accessible Expressions Ohio exhibition and recognizes all participating artists and their families and providers. Attendees can enjoy refreshments, partake in an official award ceremony, and participate in hands-on activities. Artists and community members also have the opportunity to attend a free professional development workshop on marketing and artistic practice.

This event is free and open to all and takes place at the Westerville Community Center
350 N Cleveland Ave
Westerville, OH 43082.

Schedule of Events (subject to change)

9:00-11:30 FREE Professional Development Workshop for artists, facilitators, and educators and Voting for People's Choice Award winner

12:00-1:30 Official Awards Ceremony

March Events

Center for Autism Spectrum Disorders

Parenting your Child with Autism

March 5 – April 2 | 6:00– 8:30pm

Autism Academy

Managing Difficult Moment

March 18th | 6:30- 8:30p.m.

Autism Society of Central Ohio

Parent Support Meeting

Wednesday, March 11th | 6:30- 8:00pm

For more information on this event and ASCO 2015 Newsletter visit: www.autismcentralohio.org

Columbus Children's Theatre

Fancy Nancy The Musical

Sensory Friendly Performance

Wednesday, March 18th | 10:00—11:00am and 7:30—8:30pm

For more information visit. www.columbuschildrenstheatre.org

OCALI

Using Twitter as Your Personal Learning Network for Universal Design for Learning (UDL) in 30 Minutes

Thursday, March 19th | 3:30—4:00pm

Contact: Ron Rogers— ron_rogers@ocali.org— 614-410-0644

Reading Disabilities Resulting from Organic Dysfunction, Demystified

Tuesday, March 31st | 3:00—4:00pm

Contact: Daniel McNulty— dmcnulty@ciesc.k12.in.us—371-333-7279

April Events

Center for Autism Spectrum Disorders

Autism Academy

IEP & Education: Knowing Your Child's Rights

April 15th | 6:30pm – 8:30p.m.

Contact Community Education at NCH: 614-355-0662

Summer Buddy Camp

Registration begins on April 1st.

June 15th—July 23rd

Mondays—Thursdays 9:00am—12:00pm

For ages 3-12.

For more information contact: Lauren Hengstler at Lauren.Hengstler@nationwidechildrens.org

Group Parenting Program

Triple P (Positive Parent Program)- Stepping Stones

April 16th—June 1st | 5:30pm—8:00pm

For more information contact: Autism Resource Coordinator: 614-355-8315

****Parent training offered as a clinical service to clients of the Center for Autism Spectrum Disorder****

Family Support Group with Caregivers of Individuals with Autism

April 15th | 5:30—6:30 pm

RSVP with Autism Resource Coordinator: autismresourcecoordinator@nationwidechildrens.org

Autism Society of Central Ohio

SIBS Looking Forward Transition Weekend

April 10th—12th

Location: YMCA

For more information view Newsletter 2015 at: www.autismcentralohio.org

2015 Ohio Association for Behavior Analysis Conference

April 10th | 8:30am—4:00pm

April 11th | 9:00am—4:00pm

For more information visit: <http://www.ohaba.org/2015-ohaba-conference.html>

Sensory Friendly Movies Monthly:

Reel Movies for Real Needs

Once per month, Saturdays at 10:30am.

For more information view Newsletter 2015 at: www.autismcentralohio.org

April Events

Autism Awareness Light it Up BLUE

OCALI

Sibs Looking Forward: A Weekend Retreat About Transition

Friday, April 10th | 5:00pm—12:00pm

Contact: Nichele Lyndes—lyndes.3@osu.edu—855-742-7669

Autism Awareness Day Event

Saturday, April 11th | 11:00am—2:00pm

Contact: Scott Short—shortw@marshall.edu

Book Studies Are Not Just for Kids Anymore: Why You Should Participate in a Thoughtful Book Study and Enhance Your PLN

Wednesday, April 15th | 3:30—4:00pm

Contact: Ron Rogers—ron_rogers@ocali.org—614-410-0644

Equality or Equity in Education?

Thursday, April 23rd | 3:30—4:00pm

Contact: Jeff McCormick—jeff_mccormick@ocali.org—614-410-0380

Columbus Children's Theatre

The Emperor's New Clothes

Wednesday, April 15th | 10:00am–11:00am

Saturday, April 18th | 10:00am–11:00am

For more information visit: www.columbuschildrenstheatre.org

May Events

Center for Autism Spectrum Disorders

Family Support Group with Caregivers of Individuals with Autism

May 20th| 5:30pm—6:30pm

Please RSVP with an Autism Resource Coordinator at:

autismresourcecoordinator@nationwidechildrens.org or 614-355-8315

Autism Program Aide Training

May 4, 11, 18| 5:30—8:00pm

For more information contact Community Education at NCH: 614-355-0662

Autism Academy

Autism 101: Knowing the Basics and a Little Bit More

May 20th| 6:30—8:30pm

OCALI

So You've Heard of Multiple Tiered Systems of Support, RTI, PBIS, and UDL

Wednesday, May 13th| 3:30—4:00pm

Contact: Ron Rogers at ron_rogers@ocali.org or 614-410-0644

Dr. Seuss Presents Concepts to Engage Learners!

Thursday, May 21| 3:30pm—4:00pm

Contact: Jeff McCormick at jeff_mccormick@ocali.org or 614-410-0380

For more information about OCALI visit: www.ocali.org

Center for Autism Spectrum Disorder

Group Parent Training Offerings

Parenting Your Child with Autism

June 18th—July 16th| 9:30am—12:00pm

To register contact Community Education at NCH: 614-355-0662

Triple P (Positive Parenting Program) - Stepping Stones

June 10th—July 29th| 9:30am—12:00pm

For more information contact an Autism Resource Coordinator: 614-355-8315

Parent training offered as a clinical service to clients of the Center for Autism Spectrum Disorders

May/June Events

The Ohio State University

Save the Date: Shakespeare and Education Festival at OSU

Thursday, May 14th—Saturday, May 16th

☐ Transformation, Trust, and Love:

Scenes from Shakespeare, performed by Columbus City School K – 12, ☐ Teaching Shakespeare for a Change: Shakespeare Education Conference, ☐ Heartbeat Method Workshops with Kelly Hunter, ☐ In Here Out There: MFA Outreach and Engagement Performance Project, And much more.

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Parenting Your Child with Autism

June 18th—July 16th| 9:30am—12:00pm

To register contact Community Education at NCH: 614-355-0662

Triple P (Positive Parenting Program) - Stepping Stones

June 10th—July 29th| 9:30am—12:00pm

For more information contact an Autism Resource Coordinator: 614-355-8315

(Triple P) Parent training offered as a clinical service to clients of the Center for Autism Spectrum

OCALI

IGNITE: Let's Spread the Word About UDL!

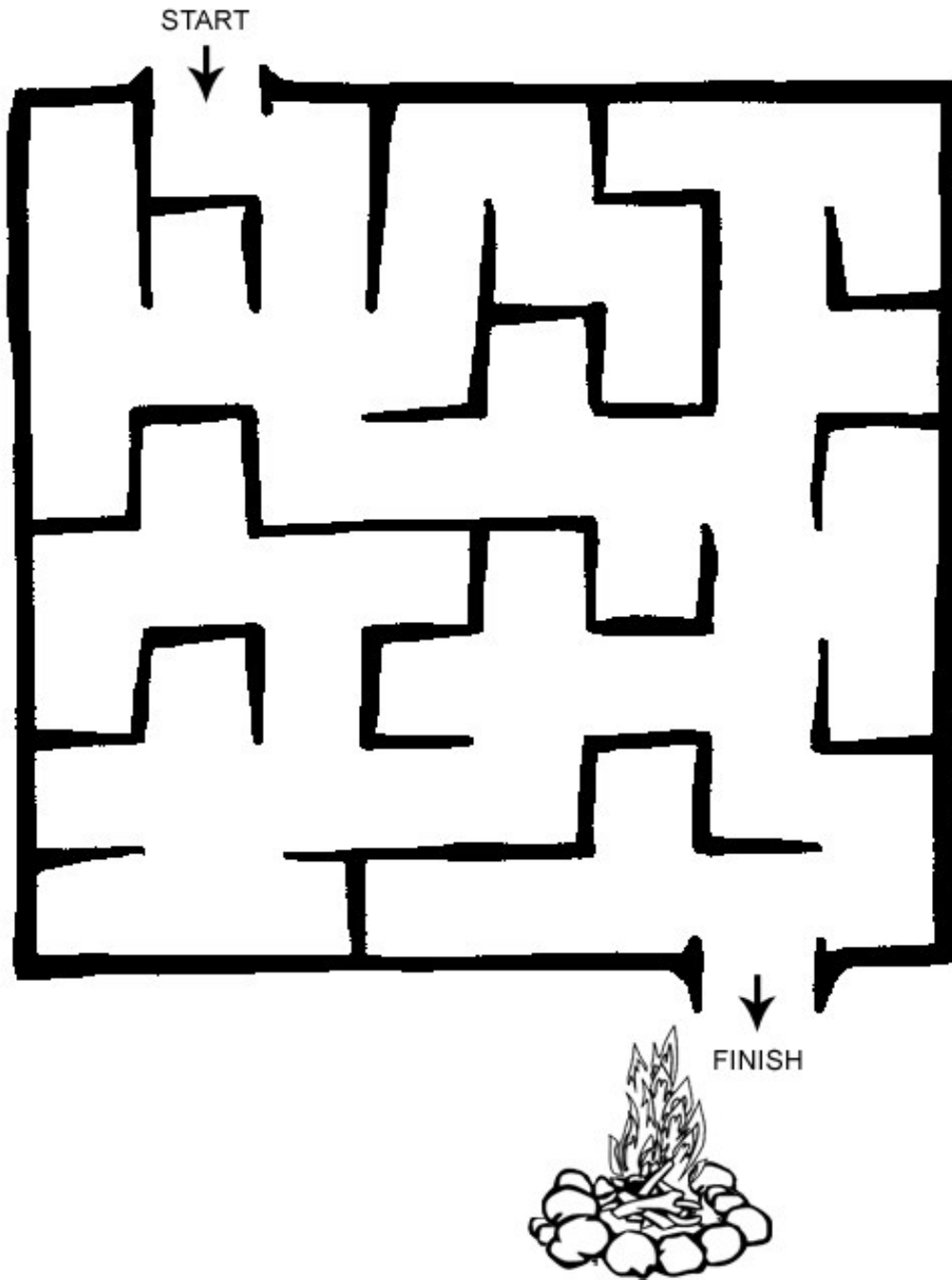
Thursday, June 11, 2015| 3:15– 4:00pm

Contact: Jeff McCormick—jeff_mccormick@ocali.org—614-410-0380

*To list your upcoming events in the
“Autism Columbus” newsletter, send it to
atn@nationwidechildrens.org*

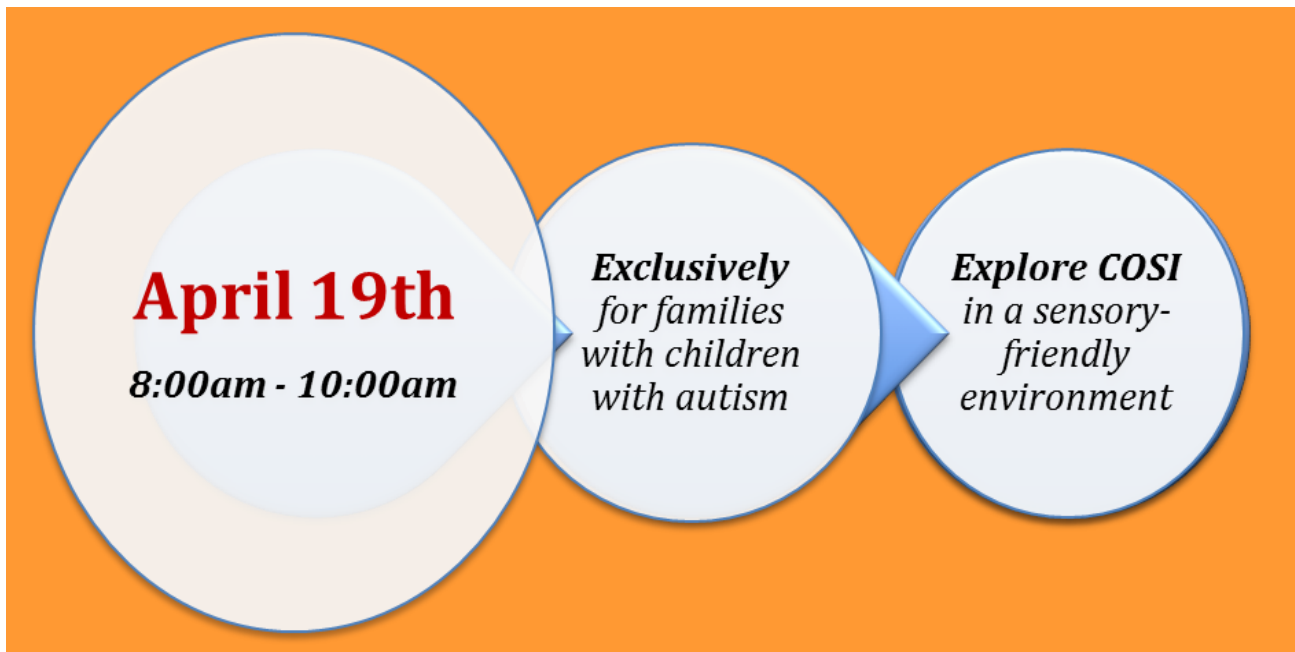
Activity Page

Brrr... let's get out of the cold and over to the fire!





Autism Activities at COSI



\$9 Per Person | Free to COSI Members | PRE-REGISTRATION IS REQUIRED

Pre-registration is required. To maintain the best possible environment for participating children, early admission to COSI is open to the first 250 pre-registered guests only.

A limited amount of need-based family assistance funding is available through the Autism Society of Central Ohio. For assistance please email: www.autismcentralohio.org

Parking is \$5 per car in the lots surrounding COSI (\$4 for COSI Members).

Parking validation is required. Please bring your parking stub into COSI with you.

To register, visit <http://cosiautismevents.eventbrite.com>
PRE-REGISTRATION IS REQUIRED

COSI | 333 West Broad Street | Columbus, OH, 43215 | cosi.org | 614.228.2674

