

THE DEVELOPING MIND



The Boone Fetter Clinic: Diagnostic, Clinical and Research Center for Autism and Other Neurodevelopmental and Behavioral Disorders



Welcome

It is sometimes difficult to find a trustworthy source for answers to complex questions about your child's health and development, so we provide this newsletter to bring you up-to-date information from specialists and researchers at Children's Hospital Los Angeles, a proud member of the Autism Speaks Autism Treatment Network. For more information about the Boone Fetter Clinic, or if you have a question about your child's development, please call the Autism Warm Line at 323-361-6102.

In This Edition:

- 2 Autism Advocacy Lesson**
- 3 Safe and Careful Use of Medication**
- 4 Research Highlight: Stuttering**
- 4 Family Support Groups**



To make an appointment, call the Autism Warm Line at 323.361.6102, email BooneFetterClinic@chla.usc.edu or visit CHLA.org/AUTISM.

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Autism Advocacy Lesson



Adapted from the Autism Promotor Manual developed by the Southern California Clinical and Translational Science Institute

When people hear the word "advocacy," what usually comes to mind are activists who help get new laws passed or lead different protests. In reality, we all can engage in some form of advocacy, especially in situations involving our families and loved ones.

Advocacy generally refers to the process of trying to persuade others to support your position or point of view. It is not something to be intimidated by; advocacy is a process of finding your inner voice through knowledge and self-empowerment. For parents, who are likely the primary people responsible for securing their child's future, learning to advocate for their child's needs and well-being is an important part of this responsibility.

The word "fight" is often used when referring to advocacy, but advocacy should not involve a confrontational exchange. Instead, the main goal is to communicate

your concerns and your desired solutions in a way that produces a beneficial outcome, such as receiving the appropriate services for your child's needs. Communication is the most important skill to learn to be an effective advocate. It's true what they say: "You catch more flies with honey than you do with vinegar."

Effective advocacy involves forming partnerships with your child's doctors, teachers and other service providers. To help you set and meet your advocacy goals, follow this step-by-step advocacy plan to get you started.

Eight Steps to Advocacy

Step 1. Identify the goal of your advocacy.
What are you hoping to accomplish?

Step 2. Develop a plan or strategy.
What facts support your position?

Step 3. Consider the perspective of the other party (this may be a doctor, teacher, etc.).
Anticipate and understand their positions and their arguments.

Opportunities to be an advocate for your child:

- Speak to your doctor about treatment options
- Meet with school administrators about an individualized education plan (IEP)
- Speak with insurance providers about your coverage
- Contact social workers about services your child needs
- Write a letter to your local representative about your family's experience

Step 4. Be aware of your emotions.

Your advocacy should be rational. It is important to avoid being governed by emotion and to avoid making your advocacy personal.

Step 5. Identify the best person to speak with about your needs.

Does the person you are addressing have the authority to grant your request or resolve your situation?

Step 6. Present your "case."

Provide examples and documentation of your child's behaviors through your personal notes or video.

Step 7. Consider possible resolutions that might be acceptable to all parties.

Step 8. Follow through.

Be aware that doctors and service coordinators oversee many families, and it's ultimately your responsibility to follow up if, for example, someone has not returned your call.

Contact the Autism Warm Phone Line if you have any questions or concerns about parent advocacy: **323-361-6102**.

Safe and Careful Use of Medication

Families often struggle with challenging autism-related behaviors. For example, anxiety is common among children and teens with autism, but few will express these feelings in words. Instead, we see it in their behaviors, such as increased pacing, rocking, repeating words or phrases, or even temper tantrums. Behavioral therapy can help to identify the underlying emotions or what a child is trying to communicate by his or her behavior, but may not always be enough. Sometimes, medicine also helps.

More than half of children with autism take medication at some point during their childhood, and it can be very helpful for some children in combination with behavioral therapies. But deciding to use medicine to treat children with autism is difficult for most families, and parents want to ensure that the medicine is working as it should and minimize any potential side effects.

The **Autism and Medication: Safe and Careful Use** toolkit was created by Autism Speaks, in its role as the federally funded Autism Intervention Research Network for Physical Health, to help families get the information they need and empower them to use medicines safely, carefully and effectively. The kit includes tools to help monitor effectiveness and practical strategies to treat common side effects.

It can be used any time a child is taking medicine, regardless of when the medicine was first prescribed.

Determining Effectiveness: The kit is designed to help families understand and identify "target symptoms," which are the behaviors that cause a child the most problems. They might include difficulty paying attention, aggression, hyperactivity, sleep problems or tantrums. When families and their health care providers agree on the target symptom or symptoms, it's easier to judge if a medicine is effective. We want to see improvements in at least some of these symptoms. At the same time, it's reasonable to expect that the medicine won't relieve all challenging behaviors. The toolkit also helps families to monitor and track improvement or worsening of target symptoms, and to record their observations.

Monitoring and Managing Side Effects: For good reason, most families worry about side effects. The kit provides guidance on questions to ask a health care provider, and an "action plan" for working with your child's doctor or nurse if side effects appear. Since families can manage most mild side effects with guidance, the kit provides clear information on dealing with such common side effects as low appetite, weight gain and sleep problems.

The toolkit is available for free download from the Autism Speaks website. You can find it in the site's alphabetized list of toolkits at www.autismspeaks.org/family-services/tool-kits.

This article was adapted from the Autism Speaks Blog: www.autismspeaks.org/blog

Common target symptoms for children with autism are:

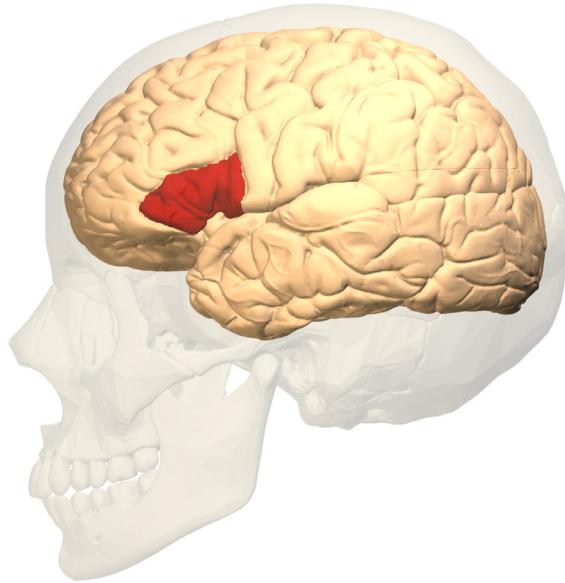
- Hyperactivity (high activity level)
- Short attention span
- Impulsive behaviors (acting without thinking)
- Irritability
- Agitation
- Aggression
- Self-injury
- Tantrums
- Repeating thoughts, interests and behaviors
- Sleep problems
- Anxiety
- Depression
- Mood problems
- Tics

Tips for keeping track of changes in target symptoms:

- Keep it simple. The way you measure target symptoms should be easy enough for you to do it every day.
- Write it down. It is important to record information on paper or a computer. This toolkit includes monitoring sheets you can use.
- Start monitoring target symptoms at least one week BEFORE starting a medicine.
- Continue to keep track of target symptoms for several weeks or months AFTER starting medicine.



Research Highlight: Stuttering



Stuttering is a speech disorder that affects 3 million Americans of all ages, yet it is often overshadowed by other issues people see as more serious. Not only can stuttering significantly impact a person's daily activities, it often causes undue stress and anxiety, which can affect a person's mental and emotional health.

Developmental stuttering, the most common form of stuttering, occurs in young children as they are developing their language skills. Approximately 5-10 percent of all children will stutter during a period of time in their lives; this period may last from a few weeks to several years. The specific causes of stuttering are unknown and there is no cure, but researchers at Children's Hospital Los Angeles have uncovered new information that could lead to more effective treatments for this speech disorder.

A team led by Bradley S. Peterson, MD, director of the Institute for the Developing Mind at CHLA, recently conducted a study of specific brain regions in a group of children and adults. The team compared

and analyzed pictures of the brain from participants who stutter and those who do not. They discovered that among those who stutter, there was reduced blood flow to a particular region of the brain called the Broca's area, which is linked to speech production. According to the researchers, the less blood flow to this part of the brain, the more severe the stuttering.

These findings align with the results from the team's prior study, which found that changes in the areas of the brain that control language, attention and emotion are linked to stuttering. Considering these findings together, the area of the brain responsible for speech plays a major role in the root cause of stuttering.

Treatment strategies for developmental stuttering often involve teaching parents about ways they can help their child speak fluently. With these new research findings, families may soon have access to better, more personalized treatment options, and this information could also shed light on a possible cure for this speech disorder.

Family Support Groups

The East Los Angeles Family Resource Center hosts events and groups to support healthy families.

Support Group for Parents of Young Children With Challenging Behaviors

Second Wednesday of each month, 9:30 – 11 a.m.

Are you struggling to raise a child who has behaviors that are demanding and exhausting? You're not alone. Come join with other parents for a time of sharing resources, support and sometimes solutions! This support group is intended for parents whose children are under 13 years of age. Parking validations and refreshments provided.

Special Moments Playgroup

First Monday of each month, 10 – 11:30 a.m.

Are you a parent looking for a playgroup for your child? Do you have concerns regarding his or her development? Are you looking for support from other parents in caring for your child? This group is open to moms and dads who have children under age 3, and parents with disabilities are especially encouraged to attend. RSVP required. Parking validations and refreshments provided.

Location:

1000 S. Fremont Ave., Suite 5051
Building A5, Lower Level
Alhambra, CA 91803

Contact:

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